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HOSPITAL BASED COMMUNITY ACTIVITY PROGRAM FOR
INDIVIDUALS WITH SPINAL CORD INJURIES

City University of New York

D.S.W. 1981

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HOSPITAL BASED COMMUNITY ACTIVITY PROGRAM
FOR INDIVIDUALS WITH SPINAL CORD INJURIES

by

DAVID AARON GITELSON

A dissertation submitted to the Graduate
Faculty in Social Work in partial fulfillment
of the requirements for the degree of Doctor
of Social Welfare, The City University of
New York.

1981

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This manuscript has been read and accepted for the Graduate Faculty in Social Work in satisfaction of the dissertation requirement for the degree of Doctor of Social Welfare.

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PREFACE

"They'll Never Know..."

Plush, shaggy rugs; dense, grassy hills
Clothes don't fit right--and the tailoring bills.
Downgrades too steep, uphill so slow
Some of the things--they'll never know.

Doorways too narrow; mirrors too high
Things you can't reach--hard as you try.
A flightful of stairs, tables too low
Drawbacks so frequent--they'll never know.

Inaccessible restrooms, bar-tops too high
"Count me out, fellas," you say with a sigh.
Hot, humid weather, rain, sleet, or snow
More of the things--they'll never know.

Friends soon stop calling, stop passing by
You give them the benefit, but still wonder "why?"
Digestive upsets, "sorry can't go"
Disappointments again--perhaps you should know.

We're not accusing, griping, complaining
Just thought a few things, need some explaining.
If we're suddenly solemn, feeling real low
There are many more things--you'll never know!

Muriel Timlin 3-B

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CHAPTER I

I. Introduction: The Problem

This dissertation reports on the development and implementation of a Hospital Based Community Activity Program for a group of individuals with spinal cord injuries. It was aimed at enhancing their social functioning in their communities, in order to reduce post-hospital social isolation.

Individuals with chronically disabling spinal cord injuries, who have been discharged from rehabilitation centers, may find themselves isolated at home from community avocational resources, or limited in their social contacts with friends and relatives. In her study of one population of paraplegics, Cogswell (1968) noted that:

Compared to pre-trauma life, all of the paraplegics upon returning home had a marked reduction in (a) number of social contacts with others in the community, (b) frequency in entering community settings, and (c) number of roles that they played. All of the paraplegics studied eventually showed some increase in these three activities; however, there is a wide variation in the extent of increase. If one takes resumption of a work role as a final indicator of rehabilitation, only six of 26 followed regularly at this hospital had reached this level at the time of last contact. The others who arrested at lower levels along the way appear to have had common socialization experiences up to this point. (p. 11)

Rossman (1970) and Rusalem (1973) have similarly written of the limited contact chronically ill or homebound individuals may experience with available community resources or with individuals other than immediate family members. In discussing the potential effect of isolation on a homebound individual, Rusalem (1973) has stated:

He finds it more difficult to sustain his own interests and the interest of others in him. Almost inevitably, loneliness and segregation from others replace previous interpersonal involvements and, although he may hunger initially for more contacts with others, recreational studies (Federation of the Handicapped, 1968-1971) indicate that, in time, even this hunger becomes suppressed and the homebound person becomes progressively more withdrawn and depressed. Although the rate with which this occurs varies from person to person, apathy and hopelessness usually dominate the homebound person's outlook, until in time he appears to the casual observer remarkably unmotivated to participate in social as well as in rehabilitation activities. (p. 83)

My experience as a social worker on a Spinal Cord Injury Service at the Veterans Administration Medical Center, Bronx, New York, and the findings of home care and outpatient follow-up studies (Rossman, 1970; Cogswell, 1968; Brown, 1973) confirm the notion that resolving the issue of post-institutional use of time is not completed in the hospital, as might be the treatment of a urinary tract infection, or a decubitus ulcer. The planning of future avocational activity may not necessarily be of primary concern to the hospitalized individual who is able to participate in social activities provided in the hospital, and who, for the moment, may attribute greater

importance to involvement in the development of physical skills.

Several patients who have been discharged from the relatively protective setting of a hospital, where they were surrounded by individuals familiar with, and accepting of the problems associated with physical disability, find it difficult to socially and emotionally reintegrate themselves into their communities. Cogswell (1968) notes:

All paraplegics face problems which evolve from the stigma of disability. In the hospital, medical personnel help paraplegics develop a self-image of independence and personal worth. Although difficulties are encountered, it is easier to establish and maintain this self-image in the sheltered social environment of the hospital than in the world outside. When paraplegics return to their homes and communities, definitions of their disability as a social stigma reach the height of salience. This common problem apparently orders their course of socialization. (p. 12)

Consequently, individuals with severe physical disabilities who have not engaged in the process of identifying and utilizing community avocational resources, or examined their self-perceptions in relation to participating in activities with non-disabled individuals outside the supportive setting of the hospital, may find themselves with little to do at home once discharged. Several outpatients with spinal cord injuries with whom I have worked have expressed:

1. an uncomfortableness (as a result of embarrassing past experiences) with the prospect of venturing into the community to engage in avocational, vocational, or educational pursuits

2. an unfamiliarity with the process of identifying and negotiating those community resources available to someone confined to a wheelchair

3. a negative self-perception resulting from loss of some degree of physical capability

4. a belief that little can be available of interest to an individual who is paralyzed, in relation to pre-injury interests

The establishment of a Hospital Based Community Activity Program, at the Veterans Administration Medical Center, Bronx, New York, evolved from the expressed desire of a group of spinal cord injured outpatients, and inpatients, to identify and examine those social skills necessary to utilize community avocational resources, as well as the potential physical and emotional obstacles to implementation of social activity. Prior to discussing the program, however, it is important to review some of the physical and emotional experiences which participants might bring to such an endeavor.

II. Physical and Emotional Reactions to Disability

Individuals who have suffered a spinal cord injury must adjust physically and emotionally to life in their communities in an altered body state. They must adapt to varying degrees of paralysis of the lower and/or upper extremities; to the possibility of decubitus ulcers (bed sores); to possible loss of sexual functioning and bowel and bladder dysfunction. (Veterans Administration - Department of Medicine and Surgery, 1972; Dunn, 1975).

Simultaneously, they must address potential negative self-perceptions attributed to loss of physical functioning which may result in feelings of shame, inferiority, guilt, frustration and depression (Wright, 1960; White, 1961; Safilios-Rothschild, 1970; Shontz, 1973; Dunn, 1975; Weller and Miller, 1977). They must learn to relate to such "negative social reactions" to disability as "discourteous stares, sympathetic offers of help, remarks of pity or disgust, excessive curiosity, restrictions on his/her behavior, and disapproval." (Mishel, 1978.) They must learn to deal with multiple physical barriers to wheelchair accessibility including stairways, inaccessible bathrooms, narrow doorways, curbs, or non-existent low-cost transportation. (See manuals developed by the Eastern Paralyzed Veterans Association, New York, NY.)

The physical and emotional adjustments required of individuals with spinal cord injuries; the barriers presented by the environment to wheelchair users; and the oftentimes negative, or altered reaction of the non-disabled world towards the disabled individual, greatly challenges their ability to resume active participation in social activities. (See Babcock, 1963, for a discussion of illness and disability as sources of stress.)

Nevertheless, there exists limited evidence to indicate that a primary formal objective in the rehabilitation of individuals with spinal cord injuries is their development of those social skills necessary

to participate in avocational activities in the community. In fact, Dunn (1977) has stated that little empirical knowledge exists regarding "managing the social aspects of disability, relating to the non-disabled environment and making others comfortable with the handicap. . . ." Furthermore, it has been suggested that the teaching of social interpersonal skills in our society has, in general, been unduly neglected (Eisler, 1976). For individuals with severely disabling spinal cord injuries this lack of training may prove a particular hardship.

III. Social Discomfort

Numerous studies and personal observations have focused on the social discomfort experienced between physically disabled and physically "normal" individuals and, consequently, its inhibiting effect on what Kleck (1968) has called accurate communications between the two. In his study of physical stigma and nonverbal cues, Kleck demonstrated the tendency of physically "normal" subjects, while in the presence of an individual with a physical disability, to distort personal opinions in the direction they believed to be more consistent with those held by the disabled individual. Comer and Piliavin (1971), building on the work of Kleck, explored the emotional difficulty the disabled individual himself experiences in interaction with physically well individuals. Quoting Goffman (1963) they write, "We and

he (the stigmatized other) are likely to experience uneasiness; . . ." (p. 19) "during mixed contacts, the stigmatized individual is likely to feel self-conscious and calculating about the impression he is making. . . ." (p. 14)

Dunn (1977), in his study on social discomfort of the patient with a spinal cord injury, found that participants ranked as most difficult those situations involving elimination functions, public embarrassment, and refusing unwanted help. This he attributed to the high degree of importance our culture places on independence, "manliness," and bowel and bladder control. Goffman (1963) has observed the discrediting stigma society attaches to physical deformities, as has Wright (1960) in describing the concept of "spread." "In fact," she states, "physical deviation is frequently seen as the central key to a person's behavior and personality and largely responsible for the important ramifications in the person's life. This spread holds for both the person with the disability himself and those evaluating him" (p. 118). The man who cannot see may also be assumed to be deaf, or unable to make cognitive decisions, or without the ability to function socially in the community, etc.

Thus, the need to provide an opportunity to individuals with severe physical disabilities to learn and to test out social skills which will enable them to engage in avocational activities in their communities

should be apparent. Morgan (1971) has written of "our responsibility to safeguard the patient from becoming victimized by his own limited self image and by the social psychological wounds that can be unwittingly inflicted by the many social systems" (p. 205).

The goal of the Hospital Based Community Activity Program was to enhance the social functioning of those spinal cord injured patients involved in the group, in their communities, and consequently to reduce post-hospital isolation. The purpose of the patient group was to aid participants in identifying and developing those social skills necessary to utilize community social resources (e.g., how does one discover what is available? what is wheelchair accessible? how does one negotiate necessary assistance? etc.), as well as to examine those patient attitudes towards physical disability which interfere with their use of the resources.

The program's goals and purpose were to be accomplished through the group member's:

1. participation in the selection of activities in which they would like to engage (e.g., attending sporting events, museums, etc.)
2. examination of both physical and emotional obstacles to accomplishing tasks, and alternatives (e.g., steps, inaccessible bathrooms, poor self-images, etc.)
3. sorting out tasks which they would assume responsibility for in order to accomplish the activity (e.g., checking on wheelchair accessibility, schedules, etc.)

4. participation in the activity

5. evaluation of their capacity to accomplish the tasks involved in the activity as well as their self-perceptions regarding their involvement

In implementing this program, the following practice principles were to be tested:

1. The particular services provided the individual with a physical disability (within the parameters of the agency's acknowledged function), should not depend solely on the agency's perception of the client's needs (via the worker), but should include for consideration the client's perception of need and alternative solutions; as these will most likely effect the client's ultimate use of the service and perception that they are of benefit to him in his pursuit of a "quality life."

2. The client should have available to him the information and knowledge of community resources that enable him to pursue activity in accordance with his definition of a "quality life," and should be assisted to obtain and utilize the resources when physically and/or emotionally unable to do so independently, as knowledge of, and assistance to make use of resources, will increase the possibility of the client's actual utilization of those resources.

These principles lend themselves to the educational model discussed by Oberman (1978). He states:

The newer behavioral therapy takes into account the client's cognitive process and potential for self-management and allows for a therapist who offers information, makes suggestions, and challenges habitual thinking. It does not involve coercive control that might be imposed on clients who have severe social problems. Instead it consists of voluntary procedures for those clients capable of some autonomy, who seek new skills to improve their lives. Such therapy has a strong affinity with humanistically oriented adult education. (p. 123)

Selection of the group method and task-centered orientation evolved both from theoretical principles of group work and Physical Medicine and Rehabilitation, and from my own practice experience. Segal (1968) notes that:

The individual disabled in later life, though he has had adequate social experiences may be quite unsure of himself and in effect must relearn a role. He must once again learn how to test his abilities at social interaction and learn how to arrive at decisions which effect his participation in the community. (p. 209)

A group, he states, offers participants an opportunity to share concerns, learn and teach problem-solving techniques, question stereotypes and fears, and provides motivation for action.

Task groups compel group members to focus on desired goals as well as the process through which desired goals can best be accomplished.

The process betrays emotional stress which calls for solution in order to achieve the goals. Members must assume responsibility, define norms and confront social roles. A program plan for activities in the community requires preparation for such interaction, particularly discussion on the use of specific facilities, community attitudes, and the image they project onto the general public. (p. 211)

Wright (1960) states that for individuals with similar disabilities, the very process of exchanging reactions to, and interpretations of, various life situations, can ". . . stimulate reappraisal of the disability and events connected with it" (p. 281). Yet, change, she contends, is best generated by discussion ". . . combined with actual trying out new ways of behaving. . . ." (p. 286). Cogswell's (1968) work supports this notion, as does that of Safilios Rothschild (1970), who has noted the importance for individuals with disabilities to interact with both disabled and non-disabled individuals as a means

towards acceptance of one's physical limitations, recognition of remaining capabilities, and the development of mechanisms for dealing with non-disabled individual's reactions to disability (p. 121). Kennard and Shilman (1979) have reported on the unique use of the group method with homebound college students aimed at examining problems of isolation from fellow students, and at sharing of data helpful to solution of common problems. Romano (1976) has pointed toward the safety a group may offer a particular participant. Crosby (1978), discussing a group experience for elderly, socially isolated widows, noted that it provided a vehicle for examining new role definitions and social networks.

Focus on task oriented groups and casework has been highlighted by numerous authors. White's (1961) experiences with severely handicapped patients resulted in her belief that their extreme dependency and anxiety resulted in difficulty in verbalizing the emotional experience. The difficulty, she wrote, was ". . . produced by the struggle to find a new place for his body image and from outer pressure to find a place for the changed self in his pre-illness society." Consequently, she concluded that in addition to traditional interviewing techniques, methods allowing for the patient to test out his strengths and potential must be offered. Reid (1972; 1975) has postulated that systematic interventions with a client, related to specific actions or tasks, serves

as a ". . . first step toward alleviating their problems." His discussion (1975) of task-centered casework has similarly proven helpful when applied to group process. Defined as a ". . . short-term, time limited form of practice designed to help individuals and families with specific psychosocial problems," (p. 3) he outlines a task implementation sequence.

1. Enhancing commitment--practitioner asks client to consider potential benefits of implementing task

2. Planning task implementation--client helped to specify task and to develop plan for carrying it out

3. Analyzing obstacles--worker asks client to consider potential problems in carrying out task

4. Modeling, rehearsal, and guided practice

5. Summarizing--worker restates task and plan for implementation

To these tasks, the Hospital Based Community Activity Program added actual implementation and evaluation of completed tasks and activities.

A community based Geriatric Summer Day Camp program for the mentally and physically frail, aimed at improving participant's social functioning, has been developed and implemented at the City Hospital Center at Elmhurst since the summer of 1966. Among the reported findings of the program (1977) were participant's renewed social abilities (e.g., individual's relating to each other and participating in planning activities); increased sense of self-worth (e.g., better self-care and display of knowledge or skills); and increased reality orientation

(e.g., use of money, awareness of current events, involvement in plans for the future). Most important was the conclusion that providing content in participant's daily experiences, and contacts with community life, stimulated a sense of self-worth. Similarly, the Jewish Home and Hospital, Kingsbridge Center, has reported success in its utilization of a discussion group format for community based elderly, as a vehicle for sharing concerns and solutions to problems of community living. In my own experience at the Veterans Administration Medical Center, Bronx, New York, task focused social activity groups for hospitalized spinal cord injury patients have proven valuable to patients in both identifying physical and emotional obstacles to planning and implementing social activities, and in pooling information and resources necessary to overcoming them.

Finally, the works of Schwartz (1961), Northern (1969), and Lewis (1977) have proven invaluable in the formation of the Hospital Based Community Activity Program. Schwartz has suggested the following propositions:

1. If persons struggling to accomplish similar social tasks in a strange environment can, in a supportive setting, detect and challenge the obstacles which frustrate their efforts (physical and emotional), they will be better able to understand and overcome those obstacles; and that,
2. If persons can exchange data regarding a problem they mutually share, which data may not be available to each individually, they will be better able to cope with the problem.

Northern (1969), in discussing the emergence of a group whose members "accept and are interdependent on others," noted its capacity to sustain work ". . . on problems in personal and social functioning which are related to the goals of the members" (p. 189). In addition, Lewis (1977) has suggested a third proposition. If an individual is offered the opportunity to select tasks of interest to him, in which he wants to engage, and is helped in this process when necessary, the individual will make maximum use of a program resource.

Several key variables evolve out of these propositions:

1. Social Tasks--any social activity in which patients wish to engage in their community as a group
2. Supportive Setting--social work led group aimed at the mutual exchange of ideas, facts, and value concepts resulting in planning, implementing, and evaluating social tasks
3. Obstacles--both physical (wheelchair inaccessibility) and emotional (poor self-perceptions) barriers to the accomplishment of social tasks
4. Data--ideas, facts, and value concepts which are useful in overcoming obstacles
5. Task--personal social activity in which the individual wishes to engage
6. Program Resource--social program offered by a community agency or institution

In summary, the potential problem of social isolation for individuals with severe physical disability has been raised, and the possible effect of disability on the physical and emotional life of the individual explored.

This was followed by a discussion of the relevance of a group and task oriented problem solution approach. In Chapter II, I will describe the program design of the Hospital Based Community Activity Program for a group of individuals with spinal cord injuries.

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CHAPTER II

PROGRAM DESIGN

Once a target population was selected for the Hospital Based Community Activity Program, I planned to meet with the group for a six month period from October 1978 through March 1979. While it was expected that the tasks and activities evolving from the group process would serve as a valuable social outlet for participants, each activity was to be accompanied by a discussion of the effect of identifying, planning and implementing tasks on the self-perception of group members.

Each month of the Hospital Based Community Activity Program was to be organized as follows:

First week--discussion and planning for a
community activity

Second week--community activity, utilizing the
hospital bus, and initial discussion
of activity and agenda for next
meeting. (The hospital bus was not
available to provide transportation
for outpatients to attend in-
hospital meetings.)

Third week--discussion of community activity
and planning for next activity

Fourth week--repeat of schedule for second week

It was anticipated that this schedule would require flexibility, as certain activities might necessitate several weeks of planning, preparation and scheduling. My decision to limit the program to a period of six months was based on the belief, as illustrated by Reid (1972, 1975) that ". . . concentrating systematically on a range of interventions related to specific actions would help clients take critical first steps toward alleviating their problems" (1975, p. 3).

I planned to involve approximately seven to ten outpatients and in-patients in the pilot project. Their age range and level of physical disability was to be determined in the course of the participant selection process (to be discussed below), although they would neither be working full-time nor engaged in a full-time educational program. Since transportation to planned group sessions at the hospital could not be provided to outpatients, participants had to independently arrange to attend meetings. It was expected that some outpatients had relatives or friends who could provide automobile transportation to the hospital; others could drive themselves; while still others were already provided hospital transportation to attend medical or physical therapy clinic appointments. Soon to be discharged patients who wished to participate in the program would not be confronted with this transportation problem.

Participants were to be selected in the following manner:

1. I planned to conduct a review of all patients who were a) discharged from the Spinal Cord Injury Service within the last year; b) known to the Spinal Cord Injury Hospital Based Home Care Program; and c) who had plans to be discharged from the hospital within six months of the implementation of the program to a residence within one hour's drive from the medical setting.

2. A letter describing the program was to be sent to those patients who a) were determined to be physically capable of participating in the program by the outpatient or ward physician and nurse (e.g., free of decubitus ulcers, etc.), and b) lived within one hour's drive from the hospital (see Appendix A for copy of letter).

3. The letter was to be accompanied by a follow-up telephone call from me at which time I would assess the individual's initial interest in the program. In those instances when the individual expressed interest, or ambivalence, I planned to arrange for a home interview to discuss the program in greater detail.

Three major limitations in the selection process were anticipated. I expected that some individuals might not wish to participate, having independently involved themselves in utilizing community resources, while still others would express ambivalence (e.g., "I'll have to leave home;" "What type of activities will we engage in?" "Do I really want to 'expose' myself to the non-disabled members of the community who don't understand?" etc.). I hoped that the planned home visit, to clarify questions regarding the program, and to discuss ambivalent feelings expressed by individuals, would result in the involvement in the project of those who were initially hesitant.

A second limitation was that imposed by the need for patients to provide their own transportation to group

meetings. Numerous patients who had previously expressed interest in participating were unable to do so for this reason. A third limitation was the requirement that those involved in the project be medically approved. Outpatients may find themselves confined to bed at home recuperating from decubitus ulcers, urinary tract infections, etc.

Several staff persons were to be involved in implementing the program, and in assuming responsibility for its functioning. Of primary importance would be:

1. Group Leader--I would be responsible for leading group aimed at the mutual exchange of ideas, facts, and value concepts resulting in planning, implementing, and evaluating social tasks and community activities.
2. Recreation Therapist--would serve as a consultant to the group regarding potential community resources. Would be invited to meetings, by patients, as needed.
3. Nursing Assistants--would accompany group members on scheduled community trips, as required by hospital regulations, to provide nursing assistance when necessary. (Their participation would be arranged through the hospital's Nursing Service.)
4. Volunteers--would accompany group members on scheduled community trips to provide physical assistance to patients when necessary.

The recreation therapist and volunteers were to be instructed, by me, regarding the purpose and goal of the program. They were not to assume to perform a task for the patient(s), but rather to allow the participants to determine their own level of need (e.g., assistance with pushing a wheelchair, emptying a urinary duct, negotiating curbs, etc.).

5. Spinal Cord Injury Outpatient Physician and Ward Physicians--would be responsible for medically approving patients for participation in group meetings and activities, as required by hospital regulations.

Prior to the implementation of the task group, candidates would be interviewed in their homes to discuss the program and to answer any of their questions. If interested in participating, I would administer measurement instruments aimed at assessing:

1. shifts in participant's involvement in community avocational activities from the pre-injury to the post-injury period of the individual's life

2. self-perceived comfort in participating in particular social activities while confined to a wheelchair

3. the individual's post-injury social skills as measured by his problem-solving capacity when confronted by particular social situations. Social skills would be defined as an ability to identify tasks necessary to negotiate use of community resources in spite of a physical disability and confinement to a wheelchair

The measurement instruments would be re-administered at the completion of the program. The data collected on each participant would be analyzed and evaluated as individual case studies to assess:

1. shifts in participant's involvement in community avocational activities prior to and at the conclusion of their involvement in the program

2. shifts in self-perceived comfort in participating in particular social activities while confined to a wheelchair

3. the impact of the task group on the individual's refinement of post-injury social skills

At the conclusion of the program, each participant would also be asked to answer a number of open-ended program evaluation questions. (See Appendix D.)

Measurement Instrument #1--Shifts in Community
Avocational Activity

- A. The patient was shown a set of hand cards--each card identifying a particular social activity (listed below). The patient was asked to note on which of five piles each card within the set should be placed, relating to the period of post-hospitalization. The piles were organized as follows:

<u>Always</u>	<u>Routine</u>	<u>Occasionally</u>	<u>Rarely</u>	<u>Never</u>
(once a week or more)	(every two or three weeks)	(half-dozen to a dozen times all year)	(one to five times a year)	(not at all)

The set of cards included the following:¹

- a. Going to movies
- b. Going to club meetings (social, union, etc.)
- c. Going to church (or religious activities)
- d. Going to classes or lectures
- e. Going to watch sporting events
- f. Participating in sporting events
- g. Going to nightclubs, bars, etc.
- h. Going to concerts, plays, etc.
- i. Going to fairs, museums, exhibits, etc.
- j. Shopping (except for groceries)
- k. Visiting with relatives, neighbors, friends
- l. Playing cards, other indoor games
- m. Working on crafts or hobbies (painting, music, etc.)
- n. Taking pleasure drives
- o. Going on a picnic
- p. Going to the beach
- q. Reading
- r. T.V. viewing
- s. Going out to a restaurant
- t. Going to a party
- u. Going to a service organization meeting
- v. Other (specify)

This question was re-administered at the completion of the program in order to measure pre-participation and post-participation changes.

¹This material was adapted from Converse and Robinson's work in correlations between participation in various types of activities and life satisfaction, which is in press, as reported by John P. Robinson and Phillip R. Shaver in Measures of Social Psychological Attitudes (Appendix B to Measures of Political Attitudes), Survey Research Center, Institute for Social Research, August 1970 (Second Printing), p. 33.

- B. Later, during the interview, I asked the patient to repeat the exercise (utilizing a second set of similar hand cards) indicating the frequency of his involvement in the activities during the year prior to his injury. The patient's recall was tested during the course of the interview by asking him to specify site of activity; name or title of establishment or activity; with whom participated; etc., as appropriate.

This question was not re-administered at the completion of the program as no change in data was expected.

Measurement Instrument #2--Comfort Test

During the initial interview, I asked the patient to respond to the following statements and questions:²

It is not unusual for an individual who led an active avocational life prior to his spinal cord injury to feel somewhat uncomfortable participating in some of the same activities after his injury (i.e., having to ask help from strangers; being stared at; etc.).

Imagine that you are thinking about participating in the following activities (will utilize third set of similar hand cards). Depending on how uncomfortable you think you would feel participating, place the cards into one of the following piles:

<u>Not at All</u>	<u>Somewhat</u>	<u>A Little</u>	<u>Very</u>	<u>Extremely</u>
(would have no second thoughts about engaging in activity)	(would have some doubts whether it was worth the effort but would probably end up doing it)	(do not know what I would do)	(would have some doubts about whether it was worth the effort, and would probably not do it)	(would choose not to engage in activity)

This question was re-administered at the completion of the program in order to measure pre-participation and post-participation changes.

²This material was adapted and modified from Michael Dunn and Steven H. Herman, "Social Skills and Physical Disability" in Behavioral Psychology in Medicine: Assessment and Training Strategies, D.M. Doleys, R.L. Meredith, and R. Ciminero, editors, New York: Plenum, in press.

Measurement Instrument #3--Social Skills Test

The patient was presented a set of social situations and was asked to respond to particular open-ended questions aimed at assessing social skills. The possible responses which I had anticipated were not presented to them but are listed below.

Social Situation #1--(Observer Situation)

You want to attend a community activity (i.e., movie, concert, museum, etc.) in an unfamiliar setting which may or may not be wheelchair accessible (i.e., theatre, public building, etc.). You are not sure if anyone will be going with you, but you want to make plans now.

Questions and Possible Responses:

- A. What things would you think about in making plans?
(Possible Responses)
1. How will I get there? (mode of transportation)
 2. Are there steps leading into the facility?
 3. Which entrance is accessible?
 4. Is the seating wheelchair accessible?
 5. Are there wheelchair accessible bathroom facilities?
 6. Are there wheelchair accessible eating facilities?
 7. If applicable, are there nearby parking facilities?
 8. If applicable, what seats are available?
(i.e., can seats be removed to accommodate a wheelchair?)
 9. Will there be someone to assist if necessary?
 10. If there is a need for additional assistance, who could accompany me on the activity?
 11. Other? (specify)
- B. How would you go about finding answers to your questions?
(Possible Responses)
1. Call facility and ask to speak to knowledgeable person.
 2. Have relatives or friend "check out" facility.
 3. Ask someone who has attended an activity at the facility.
 4. Check with one of various "wheelchair accessibility" community booklets.
 5. Contact a service organization to investigate their knowledge of setting.
 6. Other (specify).

Social Situation #2--(Identifying Resources)

You're getting bored at home but are not sure what you want to do, or what social/recreational activities may be available to you in your immediate community. How would you go about finding out what resources are generally available to you?

(Possible Responses)

1. Contact service organizations to investigate their knowledge of local resources.
2. Subscribe to and scan local community newspapers.
3. Check with other outpatients who live in the community.
4. Contact local religious groups to investigate their knowledge of local resources.
5. Contact known community agencies in the area.
6. Speak to neighbors and local merchants to see what services they are familiar with. Encourage them to keep on the "look out."
7. Obtain "wheelchair accessibility" community booklets.
8. Other (specify).

Social Situation #3--(Participant Situation)

You want to participate in an avocational activity (i.e., sporting event, art course, etc.)

A. What things would you think about in making plans?
(Possible Responses)

1. What activities are available?
2. Where are they available?
3. Can the activity be modified to suit my physical condition?
4. What procedures must I follow to enroll for participation?
5. What are the rules and regulations?
6. Am I medically able to participate?
7. Other? (specify)

B. How would you go about finding answers to your questions?
(Possible Responses)

1. Contact service organizations to investigate their knowledge of resources.
2. Check with other outpatients who live in the community.

3. Inquire of staff at the hospital.
4. Contact known community agencies in the area.
5. Obtain books on wheelchair sports, etc.
6. Other (specify).

Group members would be expected to engage in a similar process in planning and implementing tasks and activities.

This question was re-administered at the completion of the program in order to measure pre-participation and post-participation changes.

Administering Test Questions

The following guidelines were implemented in administering the test questions:

1. Specify participant's right to withdraw from the program without consequences (if possible, would want individual to express reasons for action)
2. Specify maintenance of confidentiality
3. Outline questions to be asked and rationale for questions
4. Question #1--Post-Injury Activity:
 - a. had to modify if participant had not been out of the hospital for one year. In these instances, had patient estimate the number of times he participated in activity since discharge.
 - b. explained that I was interested in learning about how much activity he was engaged in since his injury. I informed him that I would show him cards with activities listed and that I would ask him to place them on one of five piles (see page 24 for description of piles). As I showed each card, I looked for uncertainty in the patient's face. At such times, I re-explained the

five piles. When we completed the deck, I reviewed the patients answers, one pile at a time, offering the opportunity to change responses.

- c. As the questions were administered, I took the opportunity to pause and ask for specifics (e.g., what movie did you go to? with whom? did you enjoy it? etc.), in order to verify data and to establish a more relaxed atmosphere.
5. Question #2--Pre-Injury Activity:
 - a. There was no difficulty in relating to the one year period prior to injury.
 - b. I used the same procedures as in #4 above in explaining the test, although I emphasized that I was interested in pre-injury community activity in order to determine how the injury affected his participation. I also stated that I would utilize the same format as for the previous question.
 6. Question #3--Comfort Inventory:
 - a. I read the explanation of the question to the patient (see page 25), and explained the five possible responses (see page 25). I asked if there were any questions and repeated this process.
 - b. In administering the question, I utilized the same format as in #4 and #5 above.
 7. Question #4--Social Situations:
 - a. Explained questions and rationale (e.g., to determine how you would plan for activities and find out whatever information you would need to know in order to participate).
 - b. Read social situation (see pages 26-28). After each question was asked and answered, I repeated the participant's answers and asked if he wanted to add anything. After all the social situation questions were completed, I repeated questions and answers again giving the participant the opportunity to change, or add to, his responses.

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CHAPTER III

PLAN FOR IMPLEMENTATION OF PROGRAMIntroduction

In developing the Hospital Based Community Activity Program, the following issues were addressed. Who would or would not support its implementation from within the hospital?; from within the hospital's external community? To what degree did those approving its implementation have "power" to influence its outcome? How would implementation of the program affect the allocation of hospital resources? (e.g., use of equipment, staff time, money, etc.).

If, as Patti (1974) suggests, internal advocacy by social workers is

. . . an activity, engaged in by social work practitioners in their roles as professional employees, which is taken for the purpose of changing the formal policies, programs, or procedures of the agencies that employ them, in the interest of increasing the effectiveness of the service provided or removing organizational conditions or practices that are deleterious to the client populations served . . .

then it was important to recognize how any change created by the program might create cohesion, conflict and/or resistance within the organization. For, as numerous

authors have noted, "change" is accompanied by alternatives in rules, resources, and potential power positions. (See Hage and Aiken (1970); Wax (1971); Brager (1967); and Patti (1974).)

Support depended on numerous variables, including the degree to which those who have power to approve new programs felt they would benefit from such innovations, as well as the value base from which agency policy makers establish goals. (Senor (1963), for example, has suggested that benefits may be measured in terms of honors or rewards received, or the desire to be associated with innovative programs; while Parsons (1961) has noted that values guide ". . . the activities of participant individuals.") The importance of assessing the impact of the proposed new program on existing rules, resources, power positions, and "agency values" was therefore critical, and would lay the groundwork for the implementation of the program.

Beginnings

My initial step in implementing the Hospital Based Community Activity Program involved review of the project proposal with the Chief, Social Work Service, my immediate supervisor at the hospital (March 16, 1978). It was essential that he sanction the use of my time in developing and implementing the program. His professional relationships with chiefs of services within the hospital

would also prove invaluable in my negotiating for the participation of inter-disciplinary personnel in the project.

As a result of this meeting, the following steps were formulated. I would:

1. meet with the Chief, Spinal Cord Injury Service to review the project proposal and solicit his support. Since requests for use of the hospital's resources, in particular the bus and the participation of nursing assistants, would initiate from his office, this step was critical. Participation of the physicians on the service in medically clearing inpatients and outpatients for participation in community activities, as required by hospital regulations, would similarly fall within his authority.

2. submit a memorandum to the Hospital Director, along with an abstract of the proposal, requesting use of the bus for excursions into the community with SCI inpatients and outpatients. (See Appendix A for copy of memorandum.)

3. arrange to meet with the Nursing Coordinator of the Spinal Cord Injury Outpatient Clinic. She is responsible for coordinating follow-up medical care to outpatients and had expressed interest in the project during informal discussions. She would also serve as a valuable source of referrals.

4. arrange to meet with the Chief, Recreation Department to discuss the proposal. At the time, he was responsible for scheduling use of the hospital bus, participation of volunteers, and would serve as a consultant to group members regarding community resources.

5. arrange to discuss the project with representatives of two influential veterans service organizations, the Eastern Paralyzed Veterans Association and the Afro-Latin Veterans Association. Their support would prove valuable in influencing patient, staff, and administrator's acceptance of the project.

On April 14, 1978, I arranged to meet with the Chief, Spinal Cord Injury Service, the Assistant Chief, and the Nursing Care Coordinator of the Spinal Cord Injury

Outpatient Clinic. The meeting was held in the office of the Chief. A spinal cord injury ward physician who was present at the time remained for the meeting. I reviewed the abstract of the program proposal, which I had previously provided them, noting the purpose and goals of the project. I solicited comments and reiterated their anticipated roles in its implementation.

Once again, the outpatient nurse expressed interest and support, agreeing to recommend candidates. The Chief offered his verbal support, stating he would consider specific requests for use of the hospital bus and staff. He also agreed to review the medical status of interested outpatients. A positive response by the physicians had been anticipated, since throughout my involvement on the Service they supported programs which might benefit patients, and which received the sanction of highly regarded Service Organizations.

On April 21, 1978, with the support of the Chief, Spinal Cord Injury Service, I met with a representative of the Eastern Paralyzed Veterans Association. The organization, just as the Afro-Latin Veterans Association, represents an external resource actively engaged in representing paralyzed veteran's interests. Both organizations have been officially recognized by Congress to act in this capacity. They have direct access to officials in the Veterans Administration Central Office in Washington, D.C., hospital administrators, the Chief,

Spinal Cord Injury Service, patients and staff on the spinal cord injury wards in order to discuss questions regarding patient care. Most patients belong to one or both organizations.

Relationships between the service organizations and the social work staff assigned to the SCI Service have been historically positive, sharing a mutual concern in clarifying patient's benefits, locating suitable wheelchair accessible housing, and developing programs of benefit to their constituents. Hospital administrators and representatives of the Veterans Administration Central Office have utilized the service organizations in a consultative capacity, recognizing their expertise in the area of spinal cord injuries. The service organizations have acquired considerable power as a result of their expertise, and their active ongoing concern with the quality of care and service provided patients and constituents in the community. Consequently, their support for the program would prove invaluable. (As Weiner (1961) has suggested, consideration should be given to those pressures exerted from an agency's external environment (e.g., political groups, service organizations, etc.) which sanction change.)

At the meeting with a representative of the EPVA (April 21, 1978), I was informed that the project proposal had received the organization's "overwhelming" support. The representative did raise concern regarding

inpatient's need for an activity program. I assured him that inpatients expecting to be discharged within six months would be considered for the program, while attempts to provide similar programs for long stay inpatients would continue. I emphasized my interest in addressing the needs of those patients for whom the difficulties of utilizing community social resources became apparent post-hospitalization. (Cogswell, 1968; Dunn, 1977; and Romano, 1976.)

While the EPVA's representative offered to submit a letter of the organization's support to whomever I felt appropriate, I indicated my desire to discuss the project first with those involved. I did ask for, and received, permission to indicate to hospital staff and administrators that the service organization supported the program, recognizing the weight this would carry as a result of the EPVA's status within the hospital system. Similar support was received from the representative of the Afro-Latin Veterans Association.

Having gained the support of my immediate professional supervisor, the Chief, Social Work Service; the Chief, Spinal Cord Injury Service; and influential service organizations, I submitted a memorandum (April 25, 1978) to the Hospital Director, requesting use of the bus for spinal cord injured outpatients. (See Appendix A for copy of memorandum.) Accompanying the memorandum was an abstract of the project proposal. This memorandum was

to generate a series of unanticipated requests from his office, expanding the number of issues with which I would have to be concerned.

On May 24, 1978, I received a memorandum requesting a cost estimate of the program. (Brager (1967) and Patti (1974) have noted the significance of these issues in any new program.) In addition, the Hospital Director requested clarification, through the V.A. New York Regional Office, of our institution's liability for outpatients involved in community activities which utilized the hospital bus. (See Appendix A for copy of memorandum.)

On August 3, 1978, I contacted the District Counsel, New York Regional Office, by telephone, regarding the Director's request. The District Counsel suggested I clarify the social work role as outlined in the Veterans Administration's Department of Medicine and Surgery Manual (1975). He indicated that should the program fall within the parameters of social work responsibility, the Hospital Director could authorize use of the bus.

A review of the manual revealed, in part:

Within the VA health care system, social work services will be particularly directed to the needs of persons confronted with crises, life threatening illnesses, traumatic losses, and chronic diseases or disabilities, including those social and environmental problems which represent barriers to hospital discharge and the patient's successful return to community living. (1.03 Functions, paragraph b, underlining mine.)

Social Work Service will utilize services offered by volunteer groups, individuals, and organizations, through the VAVS (Voluntary Service) and other sources, in order to augment professional care, to enhance community understanding of the needs of veterans, and to aid in developing resources to fill gaps in established community services. (1.03 Functions, paragraph e, underlining mine.)

Social workers will participate in the initial assessment of the patient placing special emphasis on the social aspects of the problem and will formulate a social treatment component of the overall treatment plan. Social treatment may consist of individual, group, and family therapies, psychotherapy, financial and vocational planning, and developing and utilizing community resources. The social worker will also formulate a discharge and follow-up plan specifying the social treatment required and how it will be provided. Services are provided where needed and for the duration of such need. (2.01 In Relation to Health Care, paragraph a, underlining mine.)

I forwarded this information to the Office of the District Counsel, indicating my involvement in the Hospital Based Community Activity Program appeared consistent with the function and responsibilities of the Social Work Service. (See Appendix A for copy of letter dated 8/9/78.) The Manual supported implementation of the program as a means of augmenting the service mandate of the hospital. Consequently, I submitted a memorandum to the Hospital Director in response to his request, dated May 24, 1978, for estimated hospital costs and the liability status of the hospital. (See Appendix A for copy of memorandum dated 8/9/78.) I noted:

I am anticipating involving outpatients who are presently being transported to the hospital for outpatient programs, or are able to provide their own transportation to the hospital. Consequently,

the cost of the program will be limited to the use of the hospital bus and driver on a bi-weekly basis, for four months, to transport patients, a social worker, and volunteers to local community vocational activities.

In addition, I attached a copy of the letter I had sent to the Regional Office District Counsel requesting clarification of the liability status of the hospital. (See Appendix A for a copy of letter dated 8/9/78.) I concluded the memorandum noting the support for the program expressed by the Chief, Social Work Service and the Eastern Paralyzed Veterans Association.

On August 22, 1979, I received a formal response from the District Counsel. (See Appendix A for copy of response dated 8/22/78.) It indicated that the Veterans Administration Department of Medicine and Surgery Manual states that:

Social Services will be directed toward a) helping patients and families cope with the crisis of illness, b) maximizing social and interpersonal functioning of patients, c) promoting vocational and social rehabilitation, d) facilitating the patient's return to community at the highest level of potential, e) working with dying patients and bereaved families, f) developing special approaches such as mutual assistance groups to provide solutions to unique social problems, g) organizing community resources to augment services, and h) delivering information and referral services. (M-2, Part XII, Par. 2.01b(3).)

Furthermore, Social Work Service is directed ". . . to participate in planning and development of ambulatory care which encompasses all non-bed care and treatment settings, including clinics and even veterans homes."

(Response from District Counsel dated 8/22/78. Refers

to VA Department of Medicine and Surgery Manual, M-2, Part XII, Par. 2.01e.)

The response concluded with the statement:

According to the extent that your planned Community Activities Program for outpatient spinal cord injury patients serves to further the functions assigned to the Social Work Services in M-2, Part XII, Pars. 1.01, 1.03, and 2.01, there is no legal objection to it. It is, of course, for the hospital to determine the appropriateness and adequacy of the program. But it is clear that such services may be rendered to outpatients as well as in-hospital patients.

This highlighted the importance of obtaining the Hospital Director's sanction for the program.

On September 11, 1978, I forwarded the response of the District Counsel to the Hospital Director. As this administrative process proceeded, I discussed the program with spinal cord injury staff at staff meetings (9/13/78; 10/4/78) and with the members of the Spinal Cord Injury Hospital Based Home Care Team (8/23/78), all of whom expressed interest. Members of the home care team, in particular, have recognized the social isolation experienced by some patients who have been discharged from the hospital.

At the same time, I met informally with staff members who had voiced particular interest, to solicit their suggestions and comments regarding the format of the proposal. During a meeting with an occupational therapist and a registered nurse on October 16, 1978, I raised issues regarding the number of patients to be involved in the program; my expectation that participants

not be provided with transportation by the hospital for the specific purpose of attending the meetings; and my question regarding implementing the program during the fall and winter months, when weather might negatively influence candidate's desire, or ability to participate. The nurse noted that some individuals with physical disabilities might feel that too large a group would expose them to stares and excessive curiosity. (Mishel, 1978.) The therapist indicated that expecting outpatients to provide their own transportation lent itself to the focus of the program, as they would have to confront this issue when engaging independently in community activities. (This raised the question of developing programs to meet the needs of the homebound individual, or the individual without available transportation. See Rusalem, 1973.) Regarding the timing of the program, the therapist indicated it could prove advantageous to implement it during the fall and winter months, a time of year when individuals might tend to find themselves homebound. The findings of the program, however, would highlight certain discrepancies in these observations, to be discussed in Chapter VI.

A final decision regarding the program appeared to be set for October 17, 1978. I was invited to discuss the program at the Joint Conference Council of the hospital, headed by the Hospital Director. Attending the meeting were the Hospital Director, Assistant Hospital

Director, Chief of Staff, Special Assistant to the Director, Management Analyst, and three Administrative Residents. The Hospital Director and Chief of Staff led the discussion, raising the following questions:

Hospital Director: "Why not provide the service as an in-hospital training program?"

Reply: For many inpatients, planning post-hospital activities is not as primary a concern as focusing on physical rehabilitation (Romano, 1976). I did inform the Council that inpatients who planned to be discharged within six months would be eligible participants.

Hospital Director and Chief of Staff: "In bringing outpatients back to the hospital for meetings weren't we encouraging an unnecessary contra-therapeutic dependence on the institution?"

Reply: The program was scheduled for a four-month trial period, after which it would be evaluated for its effectiveness. There are outpatients who have not been utilizing community avocational resources to the degree they desire, and who, while hospitalized, did not anticipate the difficulties they would encounter post-hospitalization. I also informed them that while the need for such a program had been established, no program in the community offering such services had been identified. The members of the Joint Conference Council nodded in appreciation of this latter point.

Hospital Director: "What would the program cost the hospital?"

Reply: I informed the group members I would serve as the primary staff member in implementing the program, and would utilize staff members in a consultative capacity.

Hospital Director: Indicated that hospital policy required that a nursing assistant be assigned to all community trips, as well as volunteers. Consequently, he noted, these staff members would be away from in-hospital duties during planned activities.

Reply: While recognizing that budgetary concerns were important, I emphasized the potential benefit of the program to patients.

Chief of Staff: Asked about my anticipated time schedule, which I outlined.

Chief of Staff: Asked about the percentage of outpatients who might qualify as participants, and the number I anticipated recruiting.

Reply: I indicated that I could not offer a percentage based on all outpatients, but that the need for the program evolved from my work on the SCI Service and on the SCI Hospital Based Home Care Program. I noted my intention to recruit up to seven SCI inpatients and outpatients--hoping to keep the group small enough so that participants would not feel scrutinized by the public as "a large wheelchair group from some institution."

At the conclusion of the meeting, the Council came to the following consensus:

1. Allow for the implementation of the program on a trial basis for a four-month period
2. Schedule a meeting with the Council for the end of February to report on:
 - a. findings of program
 - b. use of staff in a consultative capacity
 - c. cost benefit of program

(See Appendix A for copy of minutes of Joint Conference Council Meeting.)

As the program was about to be implemented, one final unanticipated issue arose. Although hospital regulations required that a nursing assistant accompany patients on all off-station trips, I had inadvertently overlooked sharing my proposal with the Chief, Nursing Service. On October 25, 1978, I met with the Assistant

Chief, Social Work Service, who, in the absence of the Chief, had received a telephone call from the Chief, Nursing Service, concerned that she had not been informed of the pilot project. In relating directly to the Chief, SCI Service, who initiates requests for the participation of nursing assistants, I had overlooked the importance of direct contact with the Nursing Department, responsible for approving requests.

When I telephoned the Chief of Nursing to apologize for the oversight, I was referred to the Assistant Chief with whom I met on October 26, 1978. She expressed interest in the program and a desire to cooperate in its implementation.

Summary

In implementing the Hospital Based Community Activity Program, it proved essential to consider who within the institution, and within the hospital's external community, would or would not support the project, and their "power" position within the institution. Clearly, implementation required the legal sanction of the District Counsel regarding use of the hospital bus; as well as the Hospital Director, whose support would set the tone for the Chiefs of the various services. In addition, close working relationships and support had to be established with those staff members who would be directly involved in the program, and who, by virtue of their authority,

maintained an ability to schedule and control daily use of hospital resources (e.g., bus, staff, etc.). Finally, a third level of support proved valuable--that derived from a working relationship with external resources as represented by important service organizations. Their sanction of the program further legitimized its implementation.

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CHAPTER IV

GROUP PROCESS

I. Patient Recruitment

Recruitment for the activity group occurred in two phases. In the first, a review of outpatients presently on the Hospital Based Home Care Program, or formerly served by the program, resulted in eleven potential candidates. Those outpatients who resided beyond one hour's drive from the hospital, or who did not have any means to travel to the hospital for meetings, were eliminated from consideration. Six additional outpatients stated that they were satisfied with their current level of involvement in community avocational activities, while another three expressed interest but had no regular means of transportation to the medical setting. Of the eleven potential candidates, all were interviewed and agreed to participate in the pre-program questionnaire process. (See Chapters V and VI for discussion and analysis of findings.)

During the implementation period of the program, the second phase of recruitment occurred. Three hospitalized patients were recruited as a result of the

sporadic participation of several outpatients who had initially expressed interest. Since the original proposal allowed for the inclusion of patients who might be returning to the community within six months, this process presented no difficulties. One of the three inpatients, however, was medically advised to limit his "sitting" time in his wheelchair shortly after he returned home, and could not participate.

Of the eleven patients who were initially interviewed, six were interviewed in their homes and five were interviewed in the hospital during clinic visits. All expressed some interest in attending meetings and activities. These interviews took place between August 12 and October 19, 1978. (One of the eleven patients was interviewed shortly after the initial group meeting held on October 5, 1978 at the hospital.) The two in-hospital patients, who were recruited for the program once it had already been implemented, were interviewed on January 2 and 3, 1979. (See Chapter II for discussion of recruitment interview and explanation of test questions.)

II. Group Meetings and Community Activities

During the five-month period between October 5, 1978 and March 3, 1979, ten group sessions were held. Although the initial program design called for bi-monthly group planning meetings to be attended by a designated number of participants, this process was abandoned early

in the program's implementation. A shift to a more flexible meeting schedule, with greater utilization of telephone contacts with outpatients, was necessitated due to unanticipated problems confronted by outpatients. As will be noted below, in a review of the group process, problems included poor weather conditions, illnesses, varying interest in particular activities, and problems with individual transportation. Systems problems also presented themselves, in particular, difficulty in scheduling use of the hospital bus and staff.

Of the fourteen patients who were ultimately recruited for the group, nine participated in actual group sessions and/or community activities as follows:

<u>Number of Participants</u>	<u>In-Hospital Group Meetings*</u>	<u>Community Trips</u>
1	10	4
2	6	3
1	3	1
2	1	1
1	3	0
1	2	0
<u>1</u>	1	0
9		

*These figures do not include involvement via the telephone.

Five outpatients who had been recruited for the group did not participate for the following reasons:

Two--confined to bed due to decubitus ulcers or recuperating from medical procedures

One--confined to apartment due to non-functioning elevator or realistic anticipation that there might be a problem

One--confined to home as meetings fell on bowel care day

One--changed mind regarding participation

No measurement instruments were employed to determine emotional resistance of participants to participate in the program once it was implemented. However, numerous physical and social situations, verified by home care staff during home visits, did account for poor attendance at hospital based meetings and community activities.

Among those most frequently encountered were:

1. physical difficulties as a result of decubitus ulcers and difficulties with catheters (affected two patients)

2. scheduled bowel care or medical examinations (two patients)

3. broken elevators (one patient)

4. visit from friends or relatives (one patient)

5. lack of transportation or automobile in need of repair (three patients)

6. inclement weather (five patients; did not affect those provided hospital transportation or in-patients)

7. illness (two patients)

8. outpatients in the process of training a new home aide which necessitated their being home (two patients)

Of these, physical difficulties, lack of transportation, and inclement weather conditions accounted for the greatest number of missed group sessions and absence from community activities. (See Chapter V for a discussion of resistance.)

As a consequence of the problems encountered, greater use

was made of the telephone as an instrument for communicating ideas and plans between group members. (See Crosby (1978) for discussion of social networks.)

III. Group Sessions

The in-hospital group sessions focused on four major work areas. The first was the identification of physical and emotional barriers to participating in avocational activities in the community. The second was agreeing on community activities of interest to the participants. The third area consisted of identifying problems the participants anticipated in implementing the specific activities and problem solving procedures. Finally, the participants were asked to evaluate their reactions to the activities and the planning process.

A. Identifying Physical and Emotional Barriers to Participation in Avocational Activities in the Community

While a review of the post-injury level of participation in community activities demonstrates a decrease in activity, as compared with pre-injury levels (see Chapters V and VI for data and analysis), those patients who participated in the program, regardless of frequency, identified numerous physical and emotional obstacles. Throughout the course of the project, the following list of concerns were expressed:

1. Asking for Help

- a. having to ask for help when physical barriers prevent easy access into facilities (e.g., steps)
- b. having to relate to non-disabled individuals who may not know how to help, but who assume to know (e.g., helping to negotiate a curb without utilizing proper wheelchair techniques)
- c. having to relate to non-disabled individuals who, while assuming a helping posture, do not listen to instructions from the disabled individual

2. Dealing with Crowds

- a. having to relate to people who "run into you" (e.g., one participant stated, "since you're shorter in a wheelchair you're sometimes 'invisible' on lines")
- b. having to deal with the possibility of not being able to see over others at crowded events and exhibits

3. Dealing with the Public

- a. having to deal with "people who act as if you've lost the ability to think" (e.g., someone asking a companion a question that they'd normally ask you) (See also Comer; and Kleck (1969).)

4. Dealing with Accessibility Issues

- a. having to negotiate inaccessible bathrooms, steps, posts at shopping centers, etc. (elaborated on below in planning for community resources)

5. Concern with Medical Problems

- a. having potential problems with catheters and/or bowel accidents while on trips

6. Previous Individual Experiences

- a. concern over participating in activities in inclement weather (e.g., waiting in cold or rain for help)

- b. concern over the feeling of isolation from others while participating in certain community activities (e.g., one participant, in relating to a trip to an ice skating event, stated, "I had to sit in the aisle because of the wheelchair--away from everyone")
- c. frustration over not being able to participate, in the same way, in certain pre-injury activities with friends (e.g., sports)

7. Group Experiences

- a. problems with attending meetings and/or activities (e.g., inclement weather, limited modes of transportation)
- b. problems with seating arrangements at various community resources (e.g., fire codes limit the number of wheelchair users at certain facilities)
- c. problems with having to schedule certain activities months in advance, due to limited wheelchair seating, without prior knowledge of weather conditions and/or medical conditions, etc. (See also, Timlin (1972).)

B. Community Activities

The group had little difficulty in developing lists of activities of interest to most participants.

C. Anticipated Problems and Problem Solving Process

At the initial meeting (October 5, 1978), participants raised concerns over the wheelchair accessibility of community avocational resources. In planning specific future activities group members were to collectively enumerate their concerns. Among the questions addressed were:

1. Are there steps which need to be negotiated in entering the community facility?

issue for group--If there are steps, is there an alternative entrance? Or is assistance available?

2. Are there wheelchair accessible bathroom facilities?

issue for group--If there are no accessible facilities, is there an alternative? (One group member suggested that those who utilized a catheter could bring a container with them to collect urine.)

3. Are there parking facilities for the hospital bus within a reasonable distance from the community facility?

issue for group--Whether involved in a group or individual activity, can parking facilities be made available which take into account distance from event, weather conditions, space requirements for maneuvering wheelchair out of vehicle, etc.?

4. What are the schedules of events?

issue for group--Will there be time to arrange for volunteers, if necessary, and transportation? Will the time of the event interfere with personal care (e.g., bowel care)? If necessary, can personal care schedule be altered?

5. What are the costs involved in participating in an activity?

issue for group--Will all group members be able to afford costs of activity? Are there group rates for activity? If individual is participating in activity on his own, can he afford additional costs related to confinement to a wheelchair? (e.g., potential need to rent a van)

6. What is the location of the event?

issue for group--How will group members arrange to get to the hospital, and to be picked up after the event? What is each group member's sitting tolerance? How does sitting tolerance relate to length of time necessary to travel to and from the event?

7. How many wheelchairs are permitted in community facility at one time?

issue for group--Are there fire codes or limitations in the architectural structure of the facility, which limit the number of individuals in wheelchairs permitted at one time?

8. Where is the wheelchair seating in the community facility?

issue for group--Will participants be able to sit together? Is the wheelchair accessible seating such that participants will be made to feel conspicuous? (e.g., seated in aisles) Is it the policy of the facility that the wheelchair confined individual must transfer to a regular seat, and that his wheelchair is stored in another area of the facility? If the wheelchair is stored elsewhere, what provisions are made to return the chair in the event of an emergency?

Problem Solving Process

Group members, both collectively and individually, employed various techniques for collecting data necessary for implementing activities. Included among them were:

a. group "brainstorming" resulting in questions regarding specific activities (participants drew upon their own experiences in this process), and problem solving techniques (one suggestion to bring along a change of clothes in the event of a problem with a catheter; a suggestion to carry a container to collect urine if the bathroom facilities were inaccessible; the suggestion to check on special showings of exhibits if there was a concern for large crowds which would make viewing difficult).

b. direct telephone contact with facilities, by participants, at group meetings, or from their homes, aimed at collecting data

c. use of consultants with community experience (e.g., Recreation Therapist)

d. use of newspaper clippings provided by individual participants

IV. Participant's Evaluation of Activities and Planning Process

(See Chapter VI, Analysis of Data, for discussion of this subject.)

V. Activities

The first actual activity, a trip to a jai-a lai competition, was arranged directly by telephone by group members. In checking on the facility, the participants utilized the list of questions they had developed during group sessions regarding time of activity, location, wheelchair accessibility, parking facilities, etc. A second and third trip to the Museum of Natural History and the Planetarium, were similarly planned by the participants who utilized the "group's" questions.

Much learning, however, accompanied the planning of trips that were not successfully implemented. While technical problems (e.g., hospital bus unavailable due to needed repairs) accounted for the cancellation of several trips, weather considerations and the need for earlier planning were also significant factors. Discussions of outdoor trips to a local zoo and an aquarium were not implemented as group members were concerned about potential inclement weather (cold weather and snow). The possibility of long waits boarding and exiting from the bus, and waiting on lines, served as a deterrent.

The necessity to plan certain trips well in advance also became apparent, as when a desired excursion to an ice skating show had to be cancelled when the limited wheelchair accessible seating, in a rather large arena, had been sold out. This experience resulted in the planning of a trip to the circus several months in advance.

In implementing both the trip to the jai-a lai activity, and the circus, the participants experienced cooperation in accommodating to physical obstacles (e.g., use of parking facilities close to entrances; use of wheelchair accessible entrances not ordinarily available to the public). Pre-planning trips (e.g., calling in advance with questions) proved invaluable in assessing the feasibility of each activity, and in overcoming various obstacles.

CHAPTER V

FINDINGS

1. Introduction

Two sets of data were collected during the course of the program. The first set consisted of the pre-participation questionnaire administered to 13 inpatients and outpatients, as noted in Chapter IV. These data consisted of a pre-injury and post-injury inventory of avocational activities, and a comfort inventory. It is presented as a measurement of the effect of the physical disability on the avocational lives of those involved.

The primary data of the study were collected from six of the 13 individuals who actually participated in the program, and in both the pre-participation and post-participation questionnaires. These data serve as an indicator of the effect of participation in the program on the participant's acquisition of social skills.

All data are presented in the form of case histories. As a consequence of the multiple-barriers to participation (see Chapter IV) it was difficult to identify a group of individuals similar in age, diagnosis,

family composition, social-economic status, and/or length of time post-disability. Had it been possible to overcome these obstacles, the philosophy of the SCI Service would have, nevertheless, mandated its being made available to all spinal cord injured patients who might benefit through participation. It also proved difficult to compare case histories due to the multiple variables which influenced each individual's level of participation in avocational activities over the five month period.

(See Campbell, 1957.)

2. Data on the Effect of Disability on the Individual's Participation in Avocational Activity

As noted in Chapter II, each of the 11 outpatients were asked to indicate how frequently he participated in a set of avocational activities during the year prior to the spinal cord injury, and during the period since his discharge from the hospital. One of the two inpatients who participated in the program responded to the post-discharge question on the basis of the year he spent in the community between his first and current admissions to a hospital. The second inpatient responded to his level of activity since hospitalization, as he had not yet been discharged from the rehabilitation unit.

In analyzing the data, the set of avocational activities were divided into the following two categories:

1. "Active" Activities--activity taking place in the community (e.g., going to a museum), or in a home where unfamiliar individuals will be present (e.g., going to a party)

- a. going to movies
- b. going to club meetings (social, union, etc.)
- c. going to church (or religious activities)
- d. going to classes or lectures
- e. going to watch sporting events
- f. participating in sporting events
- g. going to nightclubs, bars, etc.
- h. going to concerts, plays, etc.
- i. going to fairs, museums, exhibits, etc.
- j. shopping (except for groceries)
- k. going on a picnic
- l. going to the beach
- m. going to a restaurant
- n. going to a party
- o. going to a service organization meeting
- p. other (specify)

2. "Passive" Activities--activity confined to home; home of friend; car (e.g., pleasure drive)

- a. visiting with relatives, neighbors, friends
- b. playing cards, other indoor games
- c. working on crafts or hobbies (painting, music, etc.)
- d. taking pleasure drives
- e. reading
- f. TV viewing
- g. other (specify)

The findings of the effect of the spinal cord injury on the individual's avocational activity follow.

Case 1

Date interviewed: August 12, 1978

Period since discharge: two months

Diagnosis: quadriplegic

Family composition: married

A. Mr. 1 indicated that in the year prior to his injury he participated in 17 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 17 activities, 12 were classified as "active" and five as "passive." Another four activities were rated in the "never" to "rarely" (one to five times a year) categories. Of these four activities, three were classified as "active" and one as "passive." (See Appendix B for scoring sheets.)

B. During the two months post-hospitalization, Mr. 1, although not confined to bed, reported a notable shift in activity level. At the time the avocational questionnaire was administered he reported participating in three activities ranging in frequency from "occasionally" (one to six times since discharge) to "always" (once a week or more). Of these three activities, all were rated in the "passive" category. Mr. 1 reported that his participation in the remaining 18 activities ranged from "never" to "rarely" (one to five times since discharge). Of these 18 activities, 15 were rated "active" and three "passive."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activity he did choose to engage in was rated in the "passive" category (activity confined to home; home of friend; car (e.g., pleasure drive)).

D. An unanswered question remains--has enough time passed since discharge from the hospital to assess his actual level of involvement in community avocational activities? A follow-up review one year post-discharge would better allow for an assessment of Mr. 1's utilization of community resources. What can be assessed is his initial decrease in activity (17 to three in the "occasionally" to "always" category), and in the types of activity (12 "active"/five "passive" to three "passive" in the "occasionally" to "always" categories).

E. Although Mr. 1 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities he reported that he was "not at all" (would have no second

thoughts about engaging in activity) to "somewhat" (would have some doubts whether it was worth the effort but would probably end up doing it) in 18 of the activities, while "extremely" (would choose not to engage in activity) through "a little" (do not know what I would do) in only three. (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 2

Date interviewed: August 12, 1978

Period since discharge: 32 months

Diagnosis: paraplegic

Family composition: married

A. Mr. 2 indicated that in the year prior to his injury he participated in 15 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 15 activities, nine were classified as "active" and six as "passive." Another seven activities were rated in the "never" to "rarely" (one to five times a year) categories. Of these seven activities, all were classified as "active." (See Appendix B for scoring sheets.)

B. During the 32 months post-hospitalization, Mr. 2 reported a notable shift in activity level. At the time the avocational questionnaire was administered, he reported that he participated in four activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these four activities all were rated in the "passive" category. Mr. 2 reported that his participation in the remaining 18 activities (one additional in the "other" category--hosting parties) ranged from "never" to "rarely" (one to five times a year). Of these 18 activities, 17 were rated "active" and one "passive."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activity he did choose to engage in were rated in the "passive" category (activity confined to home; home of friend; car (e.g., pleasure drive)).

D. Although Mr. 2 indicated a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities, he reported that he was "not at all" (would have no second thoughts about engaging in activity) in 17 of the activities, while "a little" (do not know what I would do) in only five. (See page 76 for additional comments.)

Case 3

Date interviewed: September 21, 1978

Period since discharge: 36 months

Diagnosis: quadriplegic

Family situation: widowed

A. Mr. 3 indicated that in the year prior to his injury he participated in 21 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 21 activities, 16 were classified as "active" and five as "passive." One activity was rated in the "rarely" category (one to five times a year). This activity was classified as "active." (See Appendix B for scoring sheets.)

B. During the 36 months post-hospitalization, Mr. 3 reported a notable shift in activity level. At the time the avocational questionnaire was administered, he reported participating in five activities ranging in frequency from "occasionally" (one to six times since discharge) to "always" (once a week or more). Of these five activities, all were rated in the "passive" category. Mr. 3 reported that his participation in the remaining 16 activities ranged from "never" to "rarely" (one to five times since discharge). Of those 16 activities, 15 were rated "active" and one "passive."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activity he did choose to engage in were rated in the "passive" category (activity confined to home; home of friend).

D. Although Mr. 3 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities he reported that he would "not at all" (would have no second thoughts about engaging in activity) in all 21. (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 4
Date interviewed: September 26, 1978
Period since discharge: three months
Diagnosis: paraplegic
Family situation: single

A. Mr. 4 indicated that in the year prior to his injury he participated in 13 activities ranging in frequency from "routine" (every two or three weeks) to "always" (once a week or more). Of these 13 activities, nine were classified as "active" and four as "passive." Another nine activities were rated in the "never" to "rarely" (one to five times a year) categories. Seven of these activities were classified as "active" and two as "passive." (See Appendix B for scoring sheets.)

B. During the three months post-hospitalization Mr. 4 reported a shift in activity level--although it was not as notable as for others who participated. At the time the avocational questionnaire was administered, he reported participating in eight activities ranging in frequency from "occasionally" (six to 12 times since discharge) to "always" (once a week or more). Of these eight activities, six were rated as "active" and two as "passive." Mr. 4 reported that his participation in the remaining 13 activities ranged from "never" to "rarely" (one to five times since discharge). Of these 13 activities, nine were rated "active" and four "passive."

C. While there is a downward shift in avocational activity, it is not as notable as for others who participated in the program. A more extensive review would allow for an assessment of the availability of transportation on an individual's use of community avocational resources as Mr. 4 is an independent driver and owns his own automobile.

D. Although Mr. 4 indicates a shift in activity level, when asked to respond to his perceived level of comfort in participating in the set of avocational activities he reported that he would "not at all" (would have no second thoughts about engaging in activity) in 21. Only when it came to going to dances, a pre-injury activity, did he report an "extremely" level of discomfort (would choose not to engage in activity). (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 5

Date interviewed: September 26, 1978

Period since discharge: eight months

Diagnosis: quadriplegic

Family situation: single, living with family

A. Mr. 5 indicated that in the year prior to his injury he participated in 19 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 19 activities, 13 were classified as "active" and six as "passive." Two activities were rated in the "rarely" category (one to five times a year). These activities were classified as "active." (See Appendix B for scoring sheets.)

B. During the eight months post-hospitalization, Mr. 5 reported a notable shift in activity level. At the time the avocational questionnaire was administered, he reported participating in eight activities ranging in frequency from "routine" (every two or three weeks) to "always" (once a week or more). Of these eight activities, three were rated "active" and five "passive." Mr. 5 reported that his participation in the remaining 13 activities ranged from "never" to "rarely" (one to five times since discharge). Of these 13 activities, 12 were rated "active" and one "passive."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. Of the eight activities he chose to engage in, only three were rated as "active" (activity taking place in the community, e.g., going to a museum, or a home with unfamiliar individuals, e.g., going to a party).

D. Although Mr. 5 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities, he reported that he would "not at all" (would have no second thoughts about engaging in activity) in 20. In regards to one activity--shopping--he reported a comfort level of "somewhat" (would have some doubts whether it was worth the effort but would probably end up doing it). (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 6

Date interviewed: September 28, 1978

Period since discharge: 29 months

Diagnosis: quadriplegic

Family situation: single, living with family

A. Mr. 6 indicated that in the year prior to his injury he participated in 12 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 12 activities, eight were classified as "active" and four as "passive." Another nine activities were rated in the "never" to "rarely" (one to five times a year) categories. Seven of these activities were classified as "active" and two as "passive." (See Appendix B for scoring sheets.)

B. During the 29 months post-hospitalization, Mr. 6 reported a shift in activity level. At the time the avocational questionnaire was administered, he reported participating in seven activities ranging in frequency from "occasionally" (six to 12 times in the year since discharge) to "always" (once a week or more). Of these seven activities, one was rated as "active" and six as "passive." Mr. 6 reported that his participation in the remaining 14 activities ranged from "never" to "rarely" (one to five times since discharge). Of these, all were rated as "active."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activity he did choose to engage in were rated in the "passive" category (activity confined to home; home of friend, car (e.g., pleasure drive)), with the exception of one--going out to a restaurant. This represents a decrease in participation in "active" avocational activities.

D. Although Mr. 6 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities, he reported that he would "not at all" (would have no second thoughts about engaging in activity) in eight activities; "somewhat" (would have some doubts whether it was worth the effort but would probably end up doing it) in four activities; and "a little" (do not know what I would do) in six. In only three activities did he report a discomfort level of "extremely" (would choose not to engage in activity). (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 7

Date interviewed: September 29, 1978

Period since discharge: 34 months

Diagnosis: paraplegic

Family situation: single

A. Mr. 7 indicated that in the year prior to his injury he participated in 13 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 13 activities, eight were classified as "active" and five as "passive." Another eight activities were rated in the "never" to "rarely" (one to five times a year) categories. Seven of these activities were classified as "active" and one as "passive." (See Appendix B for scoring sheets.)

B. During the 34 months post-hospitalization, Mr. 7 reported a shift in activity level. At the time the avocational questionnaire was administered, he reported participating in seven activities ranging in frequency from "occasionally" (six to 12 times in the year since discharge) to "always" (once a week or more). Of these seven activities, one was rated as "active" and six as "passive." Mr. 7 reported that his participation in the remaining 14 activities ranged from "never" to "rarely" (one to five times in the first year since discharge). Of these, all were rated as "active."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activity he did choose to engage in were rated in the "passive" category (activity confined to home; home of friend; car, e.g., pleasure drive), with the exception of one--shopping. This represents a decrease in participation in "active" avocational activities.

D. Although Mr. 7 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities, he reported that he would "not at all" (would have no second thoughts about engaging in activity) in all 21. (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 8

Date interviewed: October 3, 1978

Period since discharge: 67 months

Diagnosis: quadriplegic

Family situation: single, living with family

A. Mr. 8 indicated that in the year prior to his injury he participated in 13 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 13 activities, seven were classified as "active" and six as "passive." Another eight activities were rated in the "never" to "rarely" (one to five times a year) categories. All eight were classified as "active." (See Appendix B for scoring sheets.)

B. During the 67 months post-hospitalization, Mr. 8 reported a notable shift in activity level. At the time the avocational questionnaire was administered, he reported participating in six activities ranging in frequency from "occasionally" (six to 12 times in the first year since discharge) to "always" (once a week or more). Of these six activities, two were rated as "active" and four as "passive." Mr. 8 reported that his participation in the remaining 16 activities ranged from "never" to "rarely" (one to five times in the first year since discharge). Of these, 14 were rated as "active" and two as "passive."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activity he did choose to engage in were rated in the "passive" category (activity confined to home; home of friend; car, e.g., pleasure drive), with the exception of two--shopping and going to the movies. This represents a decrease in participation in "active" avocational activities.

D. Although Mr. 8 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities, he reported that he would "not at all" (would have no second thoughts about engaging in activity) in six activities and would "somewhat" (would have some doubts whether it was worth the effort but would probably end up doing it) in an additional eight. In seven activities he reported he would fall into the categories ranging from "extremely" (would choose not to engage in activity) to "a little" (do not know what I would do). (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 9

Date interviewed: October 4, 1978

Period since discharge: 3½ months

Diagnosis: paraplegic

Family situation: single

A. Mr. 9 indicated that in the year prior to his injury he participated in 18 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 18 activities, 14 were classified as "active" and four as "passive." Another three activities were rated in the "never" to "rarely" (one to five times a year) categories. Of these, one was classified as "active" and two as "passive." (See Appendix B for scoring sheets.)

B. During the 3½ months post-hospitalization, Mr. 9 reported a notable shift in activity level. At the time the avocational questionnaire was administered, he reported participating in eight activities ranging in frequency from "occasionally" (six to 12 times in the first year since discharge) to "always" (once a week or more). Of these eight activities, two were rated as "active" and six as "passive." Mr. 9 reported that his participation in the remaining 13 activities ranged from "never" to "rarely" (one to five times in the first year since discharge). Of these, all 13 were rated as "active."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activities he did choose to engage in were rated in the "passive" category (activity confined to home; home of friend; car, e.g., pleasure drive), with the exception of two--shopping and going to church. This represents a decrease in participation in "active" avocational activities.

D. Although Mr. 9 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities he reported that he would "not at all" (would have no second thoughts about engaging in activity) in all 21 activities. (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 10
Date interviewed: October 4, 1978
Period since discharge: 2½ months
Diagnosis: Quadriplegic
Family situation: single

A. Mr. 10 indicated that in the year prior to his injury he participated in 19 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 19 activities, 13 were classified as "active" and six as "passive." Another two activities were rated in the "rarely" category (one to five times a year). Of these, both were classified as "active." (See Appendix B for scoring sheets.)

B. During the 2½ months post-hospitalization Mr. 10 reported a notable shift in activity level. At the time the avocational questionnaire was administered, he reported participating in five activities ranging in frequency from "occasionally" (six to 12 times in the first year since discharge) to "always" (once a week or more). Of these five activities, one was rated as "active" and four as "passive." Mr. 10 reported that his participation in the remaining 16 activities ranged from "never" to "rarely" (one to five times in the first year since discharge). Of these, 14 were rated as "active" and two as "passive."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activities he did choose to engage in were rated in the "passive" category (activity confined to home; home of friend; car, e.g., pleasure drive), with the exception of one--going to church. This represents a decrease in participation in "active" avocational activities.

D. Although Mr. 10 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities, he reported he would "not at all" (would have no second thoughts about engaging in activity) in 15 activities, and "somewhat" (would have some doubts whether it is worth the effort but would probably end up doing it) in five. In only one activity did he report he would fall into the category "a little" (do not know what I would do)--going to the beach. (See page 76 for a discussion of these data in comparison with others engaged in survey.)

Case 11

Date interviewed: October 19, 1978

Period since discharge: two months

Diagnosis: Quadriplegic

Family situation: single, living with aide

A. Mr. 11 indicated that in the year prior to his injury he participated in 19 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 19 activities, 13 were classified as "active" and six as "passive." Another three activities were rated in the "rarely" category (one to five times a year). Of these, all three were classified as "active." (See Appendix B for scoring sheets.)

B. During the two months post-hospitalization, Mr. 11 reported a notable shift in activity level. At the time the avocational questionnaire was administered, he reported participating in seven activities ranging in frequency from "occasionally" (six to 12 times since discharge) to "always" (once a week or more). Of those seven activities, one was rated as "active" and six as "passive." Mr. 11 reported that his participation in the remaining 15 activities ranged from "never" to "rarely" (one to five times since discharge). Of these, 14 were rated as "active" and one as "passive."

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activities he did choose to engage in were rated in the "passive" category (activity confined to home; home of friend) with the exception of going to a party. This represents a decrease in participation in "active" avocational activities.

D. While Mr. 11 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities he reported he would "not at all" (would have no second thoughts about engaging in activity) in 12 activities and "somewhat" (would have some doubts whether it was worth the effort but would probably end up doing it) in five. In five activities he reported he would fall into the category "a little" (do not know what I would do)--shopping and going to a party; "very" (would have some doubt whether it was worth the effort, and would probably not do it)--participating in sporting events and going to nightclubs, bars, etc.; and "extremely" (would choose not to engage in activity)--going to the beach. (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 12

Date interviewed: January 2, 1979
Period since discharge: hospitalized
Diagnosis: Quadriplegic
Family situation: single

A. Mr. 12 indicated that in the year prior to his injury he participated in 14 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 14 activities, ten were classified as "active" and four as "passive." Another seven activities were rated in the "never" to "rarely" (one to five times a year) categories. Of these, five were rated as "active" and two as "passive." (See Appendix B for scoring sheets.)

B. During the three months during hospitalization, Mr. 12 reported a notable shift in activity level. At the time the avocational questionnaire was administered he reported participating in three activities ranging in frequency from "occasionally" (six to 12 times during period) to "always" (once a week or more). Of these three activities, all were rated as "passive." Mr. 12 reported that his participation in the remaining 18 activities ranged from "never" to "rarely" (one to five times during period). Of these, 15 were rated as "active" and three as "passive." (Of these 15 activities, 14 fell in the "never" category; one in "rarely"--a trip planned by the group.)

C. This shift in avocational activity level represents a decrease in participation in those activities which the outpatient reported as important to him pre-injury. The activities he did choose to engage in were rated in the "passive" category (activity confined to hospital).

D. While Mr. 12 indicates a decrease in activity, when asked to respond to his perceived level of comfort in participating in the set of avocational activities, he reported he would "not at all" (would have no second thoughts about engaging in activity) in 20 activities and "somewhat" (would have some doubts whether it was worth the effort but would probably end up doing it) in one--going to the beach. (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

Case 13
Date interviewed: January 3, 1979
Period since discharge: 11 months
Diagnosis: paraplegic
Family situation: single

A. Mr. 13 indicated that in the year prior to his injury he participated in nine activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these nine activities, five were classified as "active" and four as "passive." Another 12 activities were rated in the "never" to "rarely" (one to five times a year) categories. Of these, ten were rated as "active" and two as "passive." (See Appendix B for scoring sheets.)

B. During the 11 months post-hospitalization (first hospitalization), Mr. 13 reported a small upward shift in activity level. At the time the avocational questionnaire was administered, he reported participating in 11 activities ranging in frequency from "occasionally" (six to 12 times a year) to "always" (once a week or more). Of these 11 activities, six were rated as "active" and five as "passive." Only one activity, however, fell in the "always" category (once a week or more)--a decrease from six. Mr. 13 reported that his participation in the remaining ten activities ranged from "never" to "rarely" (one to five times since discharge). Of these, nine were rated as "active" and one as "passive."

C. While Mr. 13 indicates a shift in activity (although smaller than others who participated when post-injury activity is compared to pre-injury activity), when asked to respond to his perceived level of comfort in participating in the set of avocational activities, he reported he would "not at all" (would have no second thoughts about engaging in activity) in 19 activities and "somewhat" (would have some doubts whether it was worth the effort but would probably end up doing it) in two--going to the beach and taking pleasure drives. (See page 76 for a discussion of these data in comparison with others engaged in the survey.)

The Comfort Inventory

The aim of administering the comfort questionnaire was not to assess those underlying emotional factors present when an outpatient perceived difficulty in participating in particular avocational activities. In the course of administering the questionnaire, however, several patients did volunteer impressions. Included were discomfort at:

1. being stared at by members of the community
2. feeling conspicuous at particular events which they felt they would not participate in, or could not participate in in the same physical manner as during their "pre-injury life," (e.g., dances, going to the beach)
3. feeling they might drop items while shopping, or at a nightclub
4. feeling in the way of others (e.g., sitting in the aisle at particular events)
5. having to explain to non-physically disabled individuals what assistance might be necessary; or having to explain what happened to them (e.g., parties)
6. not being able to maneuver in the wheelchair in a particular facility (e.g., small restaurant)
7. having to be concerned about such issues as parking, crowds, accessibility of facilities

However, individuals who have suffered spinal cord injuries, including those who participated in the program, do involve themselves in the avocational activities represented in the questionnaire. Additional research aimed at assessing underlying emotional factors in the individual's choice to participate, or not participate, in particular activities, would prove valuable.

3. Data on the Effect of Participation in the Program on the Participant's Acquisition of Relevant Social Skills

As noted in Chapter II, each of the participants in the program was asked to indicate how frequently he participated in the set of avocational activities during the eight month period following the implementation of the program (October 1978 through May 1979). These data were compared to their level of activity during the period between their injury and their participation in the program.

In addition, the participants were asked to respond to a Social Skills Test (see Chapter II). The data acquired from this test were compared to their pre-participation responses. (All 13 patients recruited for the program were administered the Social Skills Test. Only the results of those who eventually participated, whose pre-participation data could be compared to their post-participation responses, were utilized in this research.) The participants were also asked to evaluate the program. (See Appendix D for Evaluation Questionnaire.)

An analysis of the effect of participation in the program on the participant's acquisition of relevant social skills follows. (The case numbers correspond to the number assigned the individual in Part 2 of this chapter--Data on the Effect of Disability on the Individual's Participation in Avocational Activities.)

Case 4 (See page 66 for data regarding the effect of the physical disability on Mr. 4's participation in avocational activity.)

Date interviewed: May 1, 1979

A. During the post-program period, October 1978 through May 1979, Mr. 4 indicated that he participated in six activities ranging in frequency from "occasionally" (six to 12 times during the period) to "always" (once a week or more). (See Appendix C for scoring sheets.) Of these six activities, three were rated "active" and three "passive." This level of activity did not notably differ from his post-injury/pre-participation level of avocational pursuits. (In addition to previous activities he added "taking pleasure drives" and did not engage in "going to watch sporting events;" "going to movies;" and "going on picnics." (See page 66 for a discussion of Mr. 4's pre-injury avocational activity level.)

B. During the period October 1978 through May 1979, Mr. 4 stated that he participated in 15 activities ranging in frequency from "never" to "rarely" (one to five times during the period). Of these 15 activities, 12 were rated as "active" and three as "passive."

C. Although Mr. 4 did not notably increase his post-program level of participation in avocational activities, as compared with his post-injury/pre-participation levels, he reported no shift in perceived level of discomfort when contemplating participating in the set of avocational activities. Mr. 4 reported that he was "not at all" uncomfortable (would have no second thoughts about engaging in activity) in all 21 activities.

D. It is noteworthy that while Mr. 4 did own his own automobile it was in need of repairs on numerous occasions, and was therefore inoperable. This directly affected his use of community avocational resources as he regularly attended program activities when it was functioning.

E. When post-program participation responses to a Social Skills Test were compared with pre-participation responses, Mr. 4 did demonstrate an increased level of verbal sophistication in formulating questions and solutions regarding participation in community avocational activities. The pre-program participation, and post-program participation responses to Situations 1 through 3 of the Social Skills Test follow:

Situation 1 (See page 26
situation.)

for explanation of

Question A

Pre-program Participation Responses

1. Are there steps into the facility?

Additional Responses Post-program Participation

1. Is the facility accessible? Are there steps?
2. Are the bathrooms accessible?
3. Are there parking facilities which are accessible and near the activity?
4. Is there a need to get tickets in advance?

Question B

1. Go to place to see.

1. Call box office.
2. Speak to someone who may have been there.

Situation 2 (See page 27

for explanation of situation.)

1. Look at community affairs section in city-wide newspaper.

1. Look in local newspaper.
2. Call VA to ask staff.
3. Call other patients or outpatients.
4. Get on mailing lists of community resources.

Situation 3 (See page 27

for explanation of situations.)

Question A

1. Accessibility of facility (can I get into setting?)

1. How often are you expected to go?
2. Is there parking?
3. Are the facilities accessible? e.g., steps/bathrooms
4. Are there fire regulations which limit the number of wheelchair users in the facility?

Situation 3 (Continued)Question B

1. Call facility.
 2. Go to facility to see.
1. Read service organization bulletins.
 2. Ask patients who have participated in activity.
 3. Call service organizations.
 4. Ask individuals who are familiar with activity (e.g., VA staff).

Case 13 (See page 75 for data regarding the effect of the physical disability on Mr. 13's participation in avocational activities.)
Date interviewed: May 4, 1979

A. During the post-program period, October 1978 through May 1979, Mr. 13 indicated that he participated in six activities ranging in frequency from "occasionally" (six to 12 times during the period) to "always" (once a week or more). (See Appendix C for scoring sheets.) Of these six activities, two were rated "active" and four "passive." This represents a decrease in activity level from his post-injury/pre-participation level of avocational pursuits. (See page 75 for a discussion of Mr. 13's pre-injury avocational activity level.)

B. During the period October 1978 through May 1979, Mr. 13 stated that he participated in 15 activities ranging in frequency from "never" to "rarely" (one to five times during the period). Of these 15 activities, 13 were rated as "active" and two as "passive."

C. Although Mr. 13 did not increase his post-program level of participation in avocational activities, as compared with his post-injury/pre-participation levels, he reported a slight shift upward in perceived level of comfort when contemplating participation in the set of avocational activities. Mr. 13 reported that he was "not at all" (would have no second thoughts about engaging in activity) in all 21 activities. Pre-participation Mr. 13 reported a "somewhat" rating (would have some doubts whether it was worth the effort but would probably end up doing it) for "going to the beach" and "taking pleasure drives." It is noteworthy that Mr. 13 did not have access to an accessible transportation system, while in the community. While hospitalized, however, he did participate in group activities.

D. When post-program participation responses to a Social Skills Test were compared with pre-participation responses, Mr. 13 did demonstrate an increased level of verbal sophistication in formulating questions and solutions regarding participation in community avocational activities. The pre-program participation, and post-program participation responses to Situations 1 through 3 of the Social Skills Test follow:

Situation 1 (See page 26 for explanation of situation.)

Question A

Pre-program Participation Responses

1. Is the facility wheelchair accessible?
e.g., steps/ramps
2. Are doorways wide enough?
3. Are bathroom facilities accessible?

Additional Responses Post-program Participation

1. What are the costs involved in participating in the activity?
2. What time is the activity? How long does it last? (Need to plan on time necessary to prepare for activity.)

Question B

1. Call facility.
2. Contact friends who might have been there.
3. Contact other rehabilitation facilities which might have information.

1. Call service organizations.
2. Contact VA social workers.
3. Check local newspapers.

Situation 2 (See page 27 for explanation of situation.)

1. Ask social worker.

1. Call service organizations.
2. Call friends.
3. Contact VA staff.
4. Check local newspapers.

Situation 3 (See page 27 for explanation of situation.)

Question A

1. Can I do it?
2. Is transportation available?
3. Costs of participating
4. Do any friends want to accompany him?

1. Same as pre-program responses.

Situation 3 (Continued)Question B

1. Phone facility
1. Call service organizations.
 2. Call friends who have participated in activity.
 3. Contact staff at VA.

Case 11 (See page 73 for data regarding the effect of the physical disability on Mr. 11's participation in avocational activities.)

Date interviewed: May 10, 1979

A. During the post-program period, October 1978 through May 1979, Mr. 11 indicated that he participated in seven activities ranging in frequency from "occasionally" (six to 12 times during the period) to "always" (once a week or more). (See Appendix C for scoring sheet.) Of these seven activities, three were rated as "active" and four as "passive." This level of activity did not notably differ from his post-injury/pre-group participation level in avocational pursuits (shopping; going to club meetings in his apartment complex; and going to service organization meetings, replaced listening to radio; going to a service organization party; and playing cards and other indoor games). (See page 73 for a discussion of Mr. 11's pre-injury avocational activity level.)

B. During the period October 1978 through May 1979, Mr. 11 stated that he participated in 14 activities ranging in frequency from "never" to "rarely" (one to five times during the period). Of these 14 activities, 12 were rated "active" and two "passive."

C. Although Mr. 11 did not notably increase his post-program level of participation in avocational activities, as compared with his post-injury/pre-participation level, he reported a decrease in perceived discomfort level when contemplating participating in the set of activities (maintaining participating in sporting events within the "very" (would have some doubt whether it was worth the effort, and would probably not do it) to "extremely" (would choose not to engage in activity) categories, while dropping from this category "going to nightclubs, bars, etc., and "going to the beach).

D. It is noteworthy that Mr. 11, who was living independently while participating in the program, did not have an accessible transportation system available to him for use in avocational activities. This limitation did influence his involvement in community avocational activities, and in the program, as he was frequently unable to get to the hospital. Increased activity in club meetings was, in part, facilitated by the abundance of activity available to him in his apartment complex.

E. When post-program responses to a Social Skills Test were compared with pre-participation responses, however, Mr. 11 demonstrated a small increase in his level of verbal sophistication in formulating questions

and solutions regarding participating in community avocational activities. The pre-program and post-program participation responses to situations 1 through 3 of the Social Skills Test follow:

Situation 1 (See page 26 for explanation of situation.)

Question A

Pre-program Participation Responses

1. Is the facility accessible? (e.g., ramps)
2. Will there be an aide to accompany me?
3. Is there available transportation?
4. How much time is involved?
5. What are the costs?

Additional Responses Post-program participation

1. Is the facility accessible? (e.g., stairs)
2. Is there seating (facility removes seat) or do you sit in aisle?
3. Is the activity dependent on weather? (What alternatives are available?)

Question B

1. Call facility.
2. Call friends, or potential aides with whom to go.
3. Ask people who have already gone.
4. Accumulate literature on activities.

1. Same as pre-participation

Situation 2 (See page 27 for explanation of situation.)

1. Check local community paper.
2. Check with local organizations and join them.
3. Check with people who live in community.
4. Listen to radio shows related to community activities.

1. Check local apartment complex newsletter.
2. Join community groups that sponsor activities.
3. Speak with individuals in similar situation at hospital and in apartment complex.
4. Call organizations for the physically disabled.

Situation 3 (See page 27 for explanation of situation.)

Question A

Pre-program Participation Responses

1. Time of activity?
2. Travel time?
3. Availability of transportation?
4. Would participants represent peer group?
5. Cost factor?
6. What possibilities would there be for developing friendships?

Additional Responses Post-program Participation

1. What can I get to that does not necessitate transportation?
2. Who could I invite to apartment to participate jointly in a hobby?

Question B

1. Call facility.
2. Speak to people who had already participated.
3. Check local publications.

1. Call veterans organizations.

Case 6 (See page 68 for data regarding the effect of the physical disability on Mr. 6's participation in avocational activities.)

Date interviewed: May 16, 1979

A. During the post-program period, October 1978 through May 1979, Mr. 6 indicated that he participated in six activities ranging in frequency from "occasionally" (six to 12 times during the period) to "always" (once a week or more). (See Appendix C for scoring sheets.) Of these six activities, two were classified as "active" and four as "passive." This level of activity did not notably differ from his post-injury/pre-group participation level in avocational pursuits ("shopping" and "crafts" replaced "taking pleasure drives;" "visiting with neighbors, relatives and friends;" and "going to the library"). (See page 68 for a discussion of Mr. 6's pre-injury avocational activity level.)

B. During the period October 1978 through May 1979, Mr. 6 stated that he participated in 15 activities ranging in frequency from "never" to "rarely" (one to five times during the period). Of these 15 activities, 13 were classified as "active" and two as "passive."

C. Although Mr. 6 did not notably increase his post-program level of participation in avocational activities, as compared with post-injury/pre-program participation level he continued to report no significant shift in perceived level of discomfort when contemplating participating in the set of avocational activities. (Mr. 6 reported that he was "not at all" uncomfortable (would have no second thoughts about engaging in activity) in six activities; "somewhat" (would have some doubts whether it was worth the effort but would probably end up doing it) in three; "very" (would have some doubt about whether it was worth the effort, and would probably not do it); and "extremely" (would choose not to engage in activity) in one.)

D. It is noteworthy that Mr. 6, who resided with his parents, was dependent on them to provide transportation. When transportation was provided by the hospital, he did participate in three of the four activities. He reported that he was ill for a fourth and suggested numerous trips for the group to consider.

E. When post-program participation responses to a Social Skills Test were compared with pre-participation responses, Mr. 6 did demonstrate a small increase in level of verbal sophistication in formulating questions and solutions regarding participation in community

avocational activities. The pre-program participation responses and post-program responses to Situations 1 through 3 of the Social Skills Test follow:

Situation 1 (See page 26 for explanation of situation.)

Question A

Pre-program Participation Responses

1. Are there steps?
2. Who would I go with?
3. Is there available transportation?
4. Is there available parking?
5. How much travel time is required?

Additional Responses Post-program Participation

1. Are doors wide enough?

Question B

1. Call facility.
2. Ask friends who have been there and are knowledgeable regarding accessibility
3. Ask family.

1. Same as pre-participation responses.

Situation 2 (See page 27 for explanation of situation.)

1. Read paper.
2. Check with service organization.

1. Same as pre-program responses.

Situation 3 (See page 27 for explanation of situation.)

Question A

1. Is there available transportation?
2. Is the facility accessible?
3. Who would go with me?

1. How comfortable would it be to participate? (due to wheelchair, would I be separated physically from others?)

Question B

1. Call facility.
2. Ask friends.

1. Call relatives regarding transportation.

Case 3 (See page 65 for data regarding the effect of the physical disability on Mr. 3's participation in avocational activities.)

Date interviewed: June 26, 1979

A. During the post-program period, October 1978 through May 1979, Mr. 3 indicated that he participated in four activities ranging in frequency from "occasionally" (six to 12 times during the period) to "always" (once a week or more). (See Appendix C for scoring sheets.) Of these four activities, all were classified as "passive." This level of activity did not notably differ from his post-injury/pre-group participation level in avocational pursuits, when in addition to the four activities he reported that he had participated in working on "crafts or hobbies." (See page 65 for a discussion of Mr. 3's pre-injury avocational activity level.)

B. During the period October 1978 through May 1979, Mr. 3 stated that he participated in 17 activities ranging in frequency from "never" to "rarely" (one to five times during the period). Of these 17 activities, 15 were classified as "active" and two as "passive."

C. Although Mr. 3 did not notably increase his post-program level of participation in avocational activities, as compared with his post-injury/pre-participation level, he reported no shift in perceived level of discomfort when contemplating participating in the set of avocational activities. (Mr. 3 reported that he was "not at all" uncomfortable (would have no second thoughts about engaging in activity) in all 21 activities.)

D. It is noteworthy that Mr. 3, who was living independently while participating in the program, did not have an affordable accessible transportation system available to him. This limitation did influence his involvement in community avocational activities, as he did participate in all program activities when hospital transportation was provided. Similarly, he had previously involved himself in a non-Veterans Administration summer activity program which provided transportation.

E. When post-program participation responses to a Social Skills Test were compared with his pre-participation responses, Mr. 3 did demonstrate an increased level of verbal sophistication in formulating questions and solutions regarding participation in community avocational activities. The pre-program

participation responses, and the post-program responses to situations 1 through 3 of the Social Skills Test follow:

Situation 1 (See page 26 for explanation of situation.)

Question A

Pre-program Participation Responses

1. Are the bathrooms accessible?

Additional Responses Post-program Participation

1. Is there help to get into facility, if necessary?
2. Are the facilities accessible? e.g., ramps/elevators
3. Is there available transportation?
4. Are there eating facilities?
5. Is medical assistance available, if necessary?

Question B

1. Ask someone who had been there.
2. Contact the facility.

1. Obtain brochures and publications regarding activities.
2. Contact senior citizens groups.

Situation 2 (See page 27 for explanation of situation.)

1. Call library.
2. Watch TV and listen to radio for daily information.
3. Check in newspaper.

1. Contact senior citizens groups.
2. Contact social organizations in local community.
3. Contact other disabled individuals in area.
4. Contact veterans organizations.
5. Contact organizations servicing the physically disabled.

Situation 3 (See page 27 for explanation of situation.)

Question A

Pre-program Participation Responses

1. Am I interested?
2. What time factors would be involved?
3. What would be the cost of participating?

Additional Responses Post-program Participation

1. Is activity accessible? (e.g., steps/bathroom)
2. Are medical attendants available, if necessary?
3. Is transportation available?
4. What activities are available?

Question B

1. Look in newspapers.
2. Listen for discussion of activity on TV and radio.
3. Obtain books on subject.
4. Ask others who may have participated in activity.

1. Contact local colleges.
2. Contact public schools for evening activities.
3. Contact city information bureau.
4. Contact museums.

Case 10 (See page 72 for data regarding the effect of the physical disability on Mr. 10's participation in avocational activities.)

Date interviewed: June 26, 1979

A. During the post-program period, October 1978 through May 1979, Mr. 10 indicated that he participated in eight activities ranging in frequency from "occasionally" (six to 12 times during the period) to "always" (once a week or more). (See Appendix C for scoring sheets.) Of these eight activities, three were rated as "active" and five as "passive." This level of activity did not notably differ from his post-injury/pre-group participation level in avocational pursuits. (In addition to pre-participation activities he added "playing cards, indoor games, etc.;" "going shopping;" and "going to restaurants".) (See page 72 for a discussion of Mr. 10's pre-injury avocational activity level.)

B. During the period from October 1978 through May 1979, Mr. 10 stated that he participated in 13 activities ranging in frequency from "never" to "rarely" (one to five times during eight month period). Of these 13 activities, 12 were rated as "active" and one as "passive."

C. Although Mr. 10 did not notably increase his post-program level of participation in avocational activities, as compared with his post-injury/pre-group participation level, he reported no shift in perceived level of discomfort when contemplating participating in the set of avocational activities.

D. It is noteworthy that Mr. 10 did experience medical difficulties during this period which periodically confined him to bed.

E. Mr. 10 did demonstrate an increased level of verbal sophistication in formulating questions and solutions regarding participation in community avocational activities. The pre-program participation responses, and the post-program responses to situations 1 through 3 of the Social Skills Test follow:

Situation 1 (See page 26 for explanation of situation.)

Question A

Pre-program Participation Responses

1. What is the distance, and travel time to facility?
2. Is facility accessible? (e.g., bathrooms, stairs)
3. Are there eating facilities which are accessible? (or lodging facilities)
4. What time of day does the activity occur?
5. Will weather conditions affect activity?
6. How is the facility equipped to deal with emergency situations?

Additional Responses Post-program Participation

1. Are there emergency exits?
2. Are there architectural barriers outside facility? (e.g., streets, curbs)
3. Are there parking facilities?

Question B

1. Phone facility.
2. Contact individuals familiar with facility and wheelchair accessibility (e.g., staff at VA).
3. Obtain available literature regarding activity.

1. Contact other SCI individuals who may be familiar with activity.

Situation 2 (See page 27 for explanation of situation.)

1. Call veteran's groups
2. Call friends.
3. Call neighbors.
4. Check in newspapers.
5. Collect resource file.

1. Ask individuals at local church.
2. Contact Chamber of Commerce.

Situation 3 (See page 27 for explanation of situation.)

Question A

Pre-program Participation Responses

1. What will I have to wear?
2. What help will I need?
3. How will I have to schedule day?
(accounting for personal care)
4. What transportation is available?
5. Length of activity?
6. Will weather conditions affect activity?

Question B

1. Call facility.
2. Ask individuals who are familiar with activity (e.g., staff at VA; neighbors)

Additional Responses Post-program Participation

1. How can I set up my home to prepare for my return from activity?
(e.g., if I get home late, set up bedroom and/or bathroom facilities in order to provide personal care)

1. Check in local newspapers.

Chapter References

Campbell, D. "Factors Relevant to the Validity of Experiments in Social Settings," Psychological Bulletin, Vol. 54, No. 4, 1957.

CHAPTER VI

ANALYSIS OF DATA

While the small number of participants involved in this pilot demonstration preclude generalizations to the population from which the sample was drawn, the data collected do provide useful cues for program design and implementation. In this chapter, two elements of the program will be considered. Patterns of participation in avocational activities; and reflections of the program based on participant's knowledge of accessibility skills and activity preferences, will be discussed in Section I. Section II will present conclusions and suggestions for future efforts to replicate or improve on this pilot effort, and will consider the strengths and limitations of the practice principles that provided the justification for the program design that was followed.

Section I

A. Patterns of Participation in Avocational Activities

As indicated in Table 1, 12 of the 13 participants, prior to their involvement in the Hospital Based Community Activity Program, decreased their level of

participation in those "active" activities (activity taking place in the community, e.g., going to a museum--or in a home where unfamiliar individuals will be present--going to a party) in which they engaged "occasionally" (six to 12 times a year) to "always" (once a week or more) prior to their injuries.

Table 1. "Active" Activities
("Occasionally" (six to 12 times per year) to "Always" (once a week or more))

<u>Partici-</u> <u>pant</u>	<u>Pre-injury</u> <u>Activities</u> <u>(occasionally</u> <u>-always)</u>	<u>Post-hospitalization</u> <u>Pre-group Activities</u> <u>(occasionally-</u> <u>always)</u>	<u>Percent</u> <u>increase</u> <u>or</u> <u>decrease</u>
1	12	0 (2 month period)	100%-
2	9	0 (32 month period)	100%-
3	16	0 (36 month period)	100%-
4	9	6 (3 month period)	33%-
5	13	3 (8 month period)	77%-
6	8	1 (29 month period)	87.5%-
7	8	1 (34 month period)	87.5%-
8	7	2 (67 month period)	71%-
9	14	2 (3½ month period)	76%-
10	13	1 (2½ month period)	92%-
11	13	1 (2 month period)	92%-
12	10	0 (3 month period)	100%-
13	5	6 (11 month period)	16%+

In addition, there appeared to be no association between the length of time post-hospitalization/pre-group participation, and the percentage of decrease in involvement in "active" activities. (See Table 1.)

However, when post-hospitalization/pre-group participation in "passive" activities (confined to home;

home of friend; car (e.g., pleasure drive)) were considered, participants demonstrated a smaller percentage of decreased involvement in six instances, when compared with their decreased involvement in "active" activities (participants 1, 2, 5, 8, 10, and 12); an increase in activities in four instances (participants 6, 7, 9, and 13); and no change in two instances (participants 3 and 11). In only one instance was there a greater percentage of decrease in activity level in "passive" activities, as compared with "active" activities (participant 4). (See Table 2.)

Table 2. "Passive" Activities
("Occasionally" (six to 12 times per year) to
"Always" (once a week or more))

Partici- pant	Pre-Injury Activities (occasionally -always)	Post-hospitalization Pre-group Activities (occasionally- always)	Percent increase or decrease
1	5	3 (2 month period)	40%-
2	6	4 (32 month period)	33%-
3	5	5 (36 month period)	0%
4	4	2 (3 month period)	50%-
5	6	5 (8 month period)	17%-
6	4	6 (29 month period)	33%+
7	5	6 (34 month period)	17%+
8	6	4 (67 month period)	33%-
9	4	6 (3½ month period)	33%+
10	6	4 (2½ month period)	33%-
11	6	6 (2 month period)	0%
12	4	3 (3 month period)	25%-
13	4	5 (11 month period)	20%+

Again, no major differences in the percentage of decreased or increased involvement was apparent when length of time

post-hospitalization/pre-group participation for each participant was considered. (See Table 2.)

Summary of Tables 1 and 2

It is apparent that considering this particular population of individuals with spinal cord injuries, participation in "passive" activities (activity confined to home; home of friend; car) post-hospitalization/pre-group participation was more prevalent than involvement in "active" activities (activity taking place in the community or in a home where unfamiliar individuals will be present), when measured on the occasional to always scale.

As would be expected from these findings, as participant's post-hospitalization/pre-group participation in routinized "active" avocational activities ("occasionally" (six to 12 times per year) to "always" (once a week or more) decreased, when compared with pre-injury avocational activity, their participation in the "active" and "passive" activities on a non-routinized "rarely" (one to five times a year) to "never" basis increased in all but five instances. (See Tables 3 and 4. Asterisks indicate decrease in activity.)

Table 3. "Active" Activities
 ("Rarely" (one to five times a year) to "Never")

<u>Participant</u>	<u>Pre-injury (Rarely- Never)</u>	<u>Post-hospitalization Pre-group (Rarely-Never)</u>
1	3	15 (2 months)
2	7	17 (32 months)
3	1	15 (36 months)
4	7	9 (3 months)
5	2	12 (8 months)
6	7	14 (29 months)
7	7	14 (34 months)
8	8	14 (67 months)
9	1	13 (3½ months)
10	2	14 (2½ months)
11	3	14 (2 months)
12	5	15 (3 months)
13	10	9 (11 months)*

Table 4. "Passive" Activities
 ("Rarely" (one to five times a year) to "Never")

<u>Participant</u>	<u>Pre-injury (Rarely- Never)</u>	<u>Post-hospitalization Pre-group (Rarely-Never)</u>
1	1	3 (2 months)
2	0	1 (32 months)
3	0	1 (36 months)
4	2	4 (3 months)
5	0	1 (8 months)
6	2	0 (29 months)*
7	1	0 (34 months)*
8	0	2 (67 months)
9	2	0 (3½ months)*
10	0	2 (2½ months)
11	0	1 (2 months)
12	2	3 (3 months)
13	2	1 (11 months)*

Summary

It is apparent that prior to the implementation of the program, participants demonstrated a decrease in participation in routinized "active" activities after suffering their physical disability.

B. Reflections on the Program Based on Participant's Knowledge of Accessibility Skills and Activity Preferences

Data collected during the course of developing and implementing the program indicates an increase in participant's social/accessibility skills, but no meaningful increase in the actual utilization of community resources.

Social Skills Knowledge

The following data is presented as case studies as it would prove difficult to cross-tabulate the six participant's responses. (The number assigned the participants corresponds to those assigned them as participants in the pre-program questionnaires. See Chapter V.)

In response to the Social Situations Questionnaire, participants demonstrated increased social/accessibility skills in all of the three social situations with which they were presented. Pre-program participation and post-program participation responses to Situation 1 (see page 26 --Observer Situation) were:

Question A ("What would you think of in making plans?")

<u>Case #</u>	<u>Pre-program participation responses</u>	<u>Additional post-program participation responses</u>
4	<ol style="list-style-type: none"> 1. Are there steps into the facility? 	<ol style="list-style-type: none"> 1. Are there steps within the facility? 2. Are the bathrooms accessible? 3. Are there parking facilities which are accessible and near the activity? 4. Is there a need to get tickets in advance?
13	<ol style="list-style-type: none"> 1. Are there steps into the facility? ramps? 2. Are the doorways wide enough for wheelchair? 3. Are the bathrooms accessible? 	<ol style="list-style-type: none"> 1. What are costs involved in the activity? 2. What time is the activity? How long does it last? (Need to plan on time necessary for preparing for activity) 3. Are there accessible parking facilities?
11	<ol style="list-style-type: none"> 1. Is the facility accessible? ramps? 2. Will there be an aide to accompany me? 3. Is there available transportation? 4. How much time is involved? 5. What are the costs involved? 	<ol style="list-style-type: none"> 1. Is there seating (facilities removes seats) or do you sit in aisle? 2. Is the activity affected by weather conditions? (What alternatives are available?)
6	<ol style="list-style-type: none"> 1. Are there steps? 2. Who would I go with? 3. Is there available transportation? 4. Is there available parking? 5. How much travel time is required? 	<ol style="list-style-type: none"> 1. Are doors in facility wide enough to accommodate a wheelchair?

- 3
1. Are the bathrooms accessible?
1. Is there help to get into the facility if necessary?
 2. Are the facilities accessible? (e.g., ramps, elevators)
 3. Is there available transportation?
 4. Are there accessible eating facilities?
 5. Is medical assistance available if necessary?
- 10
1. What is the distance to facility? Travel time?
 2. Is the facility accessible? (bathrooms, stairs)
 3. Are there accessible eating and/or lodging facilities?
 4. What time of day does the activity take place?
 5. Will weather conditions affect activity?
 6. How is the facility equipped to deal with emergency situations?
1. Are there emergency exits?
 2. Are there architectural barriers outside facility? (e.g., streets, curbs)
 3. Are there parking facilities?

Concerns raised by participants after their participation in the program included accessibility issues (steps, bathrooms, seating, parking, doors, dining, and curbs); questions regarding emergency exits and emergency medical facilities; questions regarding costs; time considerations which might affect sitting tolerance (travel time? length of activity?); questions regarding the scheduling of physical care (bowel care based on time of activity); questions regarding the availability of assistance, and the need to plan in advance ("If there is limited accessible seating do I need to get tickets in advance?" "Will weather conditions affect my attendance?").

Question B ("How would you go about finding answers to your questions?")

<u>Case #</u>	<u>Pre-program participation responses</u>	<u>Additional post-program participation responses</u>
4	<ol style="list-style-type: none"> 1. Go to place to see for self. 	<ol style="list-style-type: none"> 1. Call box office. 2. Speak to someone who may have been there.
13	<ol style="list-style-type: none"> 1. Call facility. 2. Contact friends who might have been there. 3. Contact other rehabilitation facilities which might have information. 	<ol style="list-style-type: none"> 1. Call service organizations. 2. Contact VA social workers. 3. Check local newspapers.
11	<ol style="list-style-type: none"> 1. Call facility. 2. Call friends, or potential aides with whom to go. 3. Ask people who have already gone. 4. Accumulate literature on activities. 	<ol style="list-style-type: none"> 1. Same as pre-participation responses.
6	<ol style="list-style-type: none"> 1. Call facility. 2. Ask friends who have been there and are knowledgeable regarding accessibility. 3. Ask family. 	<ol style="list-style-type: none"> 1. Same as pre-participation responses.
3	<ol style="list-style-type: none"> 1. Ask someone who had been there. 2. Contact the facility. 	<ol style="list-style-type: none"> 1. Obtain brochures and publications regarding activities. 2. Contact senior citizens groups.
10	<ol style="list-style-type: none"> 1. Telephone facility. 2. Contact individuals familiar with facility and wheelchair accessibility (e.g., staff at VA). 3. Obtain available literature regarding activity. 	<ol style="list-style-type: none"> 1. Contact other spinal cord injured individuals who may be familiar with activity.

Techniques suggested by participants post-program included outreach to individuals who might be able to assist (friends, service organizations, VA social workers, senior citizens groups, and other physically disabled individuals); as well as the collection of appropriate written material (e.g., brochures and newspaper articles).

Pre-program and post-program responses to Situation 2 (see page 27 --Identifying Resources) were:

Question ("How would you go about finding out what resources are generally available to you?")

<u>Case #</u>	<u>Pre-program participation responses</u>	<u>Additional post-program participation responses</u>
4	1. Look at community affairs section in city-wide newspaper.	1. Look in local newspaper. 2. Call VA to ask staff. 3. Call other patients or outpatients. 4. Get on mailing lists of community resources.
13	1. Ask social worker.	1. Call service organizations. 2. Call friends. 3. Contact staff at VA. 4. Check local newspapers.
11	1. Check local community newspaper. 2. Check with local organizations and join them.	1. Check local apartment complex newsletter. 2. Join community groups that sponsor activities. 3. Speak with people in a similar situation at the hospital and in the apartment complex.

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| 6 | <ol style="list-style-type: none"> 1. Read newspaper. 2. Check with service organizations. | <ol style="list-style-type: none"> 1. Same as pre-program responses. |
| 3 | <ol style="list-style-type: none"> 1. Call library. 2. Watch television and listen to the radio for daily information. 3. Check in newspaper. | <ol style="list-style-type: none"> 1. Contact senior citizens groups. 2. Contact social organizations in local community. 3. Contact other disabled individuals in the area. 4. Contact veterans organizations servicing the physically disabled. |
| 10 | <ol style="list-style-type: none"> 1. Call veterans groups. 2. Call friends. 3. Call neighbors. 4. Check in newspapers. 5. Collect resource file. | <ol style="list-style-type: none"> 1. Ask individuals at local church. 2. Contact Chamber of Commerce. |

Suggestions by participants post-program included outreach to potentially knowledgeable individuals (VA staff, other patients, service organizations, friends, senior citizens groups, social organizations in the community, church groups, Chamber of Commerce); as well as suggestions to get on mailing lists and to check local newspapers.

Pre-program and post-program responses to Situation 3 (see page 27 --Participant Situation) were:

Question A ("What things would you think about in making plans?")

<u>Case #</u>	<u>Pre-program participation responses</u>	<u>Additional post-program participation responses</u>
4	<ol style="list-style-type: none"> 1. Accessibility of facility? (Can I get into setting?) 	<ol style="list-style-type: none"> 1. How often are you expected to go? 2. Is there parking? 3. Are the facilities accessible? (e.g., steps, bathrooms) 4. Are there fire regulations which limit the number of wheelchair users in the facility at one time?
13	<ol style="list-style-type: none"> 1. Can I physically engage in activity? 2. Is transportation available? 3. Costs of participating? 4. Do any friends want to accompany me? 	<ol style="list-style-type: none"> 1. Same as pre-program responses.
11	<ol style="list-style-type: none"> 1. Time of activity? 2. Travel time? 3. Availability of transportation? 4. Would participants represent peer group? 5. Costs? 6. What possibilities would there be for developing friendships? 	<ol style="list-style-type: none"> 1. What can I get to that does not require transportation? 2. Who could I invite to apartment to participate jointly in a hobby?
6	<ol style="list-style-type: none"> 1. Is there available transportation? 2. Is the facility accessible? 3. Who would go with me? 	<ol style="list-style-type: none"> 1. How comfortable would it be to participate? (Due to wheelchair, would I be separated physically from others?)

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| 3 | <ol style="list-style-type: none"> 1. Am I interested in the activity? 2. What time factors would be involved? 3. What would be the costs of participating? | <ol style="list-style-type: none"> 1. Is the facility accessible? (e.g., steps, bathroom) 2. Are medical attendants available if necessary? 3. Is transportation available? 4. What activities are available? |
| 10 | <ol style="list-style-type: none"> 1. What will I have to wear? 2. What help will I need? 3. How will I have to schedule day? (accounting for personal care) 4. What transportation is available? 5. Length of time involved in activity? 6. Will weather conditions effect participation in activity? | <ol style="list-style-type: none"> 1. How can I set up my home to prepare for my return from activity (e.g., If I get home late, set up bedroom and/or bathroom facilities to allow for implementing daily routine (bowel care, catheter care on required days)). |

Post-participation responses to this situation varied greatly from participant to participant, and represented the particular concerns of each.

Question B ("How would you go about finding answers to your questions?")

<u>Case #</u>	<u>Pre-program participation responses</u>	<u>Additional post-program participation responses</u>
4	<ol style="list-style-type: none"> 1. Call facility. 2. Go to facility to see for self. 	<ol style="list-style-type: none"> 1. Read service organization bulletin. 2. Ask patients who have participated in activity. 3. Call service organizations. 4. Ask individuals who are familiar with activity (e.g., VA staff).
13	<ol style="list-style-type: none"> 1. Telephone facility. 	<ol style="list-style-type: none"> 1. Call service organizations. 2. Call friends who have participated in activity. 3. Contact staff at VA.
11	<ol style="list-style-type: none"> 1. Call facility. 2. Speak to people who had already participated. 3. Check local publications. 	<ol style="list-style-type: none"> 1. Call veterans organizations.
6	<ol style="list-style-type: none"> 1. Call facility. 2. Ask friends. 	<ol style="list-style-type: none"> 1. Call relatives regarding transportation.
3	<ol style="list-style-type: none"> 1. Look in newspapers. 2. Listen for discussion of activity on TV and radio. 3. Obtain books on subject. 4. Ask others who may have participated in activity. 	<ol style="list-style-type: none"> 1. Contact local colleges. 2. Contact public schools for evening activities. 3. Contact city information bureau. 4. Contact museums.

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| 10 | <ol style="list-style-type: none"> 1. Call facility. 2. Ask individuals who are familiar with activity (e.g., staff at VA, neighbors). | <ol style="list-style-type: none"> 1. Check in local newspapers. 2. Check with other spinal cord injured individuals who may be familiar with activity. |
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Again, responses varied with participants, but included outreach to VA staff, service organizations, and fellow patients and outpatients.

Activity Preferences

Although all participants demonstrated a verbal increase in social skills knowledge (see pages 101-111), there is no indication that they increased their level of participation in community activities during the eight month post-program period. (See Table 5.)

Table 5. Pre-group and Post-group Participation in Community Activities

<u>Participant</u>	<u>Post-hospitalization/ Pre-group Participation (occas.-always) Active Activities</u>	<u>Post-participation in Group (8 months) Active Activities</u>	<u>Post-hospitalization Pre-group Participation (occas.-always) Passive Activities</u>	<u>Post-participation in Group (8 months) Passive Activ.</u>
#4	6	3	2	3
#13	6	2	5	4
#11	1	3	6	4
#6	1	2	6	4
#3	0	0	5	4
#10	1	3	4	5

In reviewing the difficulties participants expressed in utilizing community resources, it became apparent that multiple variables influenced their level of activity. Among those factors most frequently identified were the absence of accessible transportation, inclement weather, and physical concerns (decubitus ulcers, urinary tract infections, pre-scheduled bowel care). Table 6 illustrates the affect of these, and several other variables, on participant's involvement in the hospital based community activity program.

Table 6. Variables Affecting Participant's Involvement in Program

<u>Problem</u>	<u>Patients Affected by Problem During the Course of the Program</u>
1. Physical difficulty (decubitus ulcer/urinary tract infection)	2
2. Scheduled bowel care or clinic visit	2
3. Broken elevator preventing exit	1
4. Other activity (visit from friend)	1
5. Absence of accessible transportation	3*
6. Inclement weather	5
7. Illness	2
8. Need to train new homemaker	2

*Two additional participants would not have been able to participate for this reason. One, however, was an in-patient; the other was provided transportation by the VA in order to attend a therapy clinic.

Clearly, innovative methods for providing services, which take into account these variables, will have to be developed. (See discussion of conclusions and suggestions for future efforts to replicate or improve program, pages 125-131.)

Section II

A. Conclusions and Suggestions for Future Efforts to Replicate or Improve Program

1. Program Development

Much has been learned from the planning and implementing phases of the hospital based community activity program. From the beginning, it became apparent how important it was to involve a broad range of interdisciplinary staff in the planning process, in order to obtain suggestions (of colleagues); solicit support and involvement of staff (Chiefs of Services, Recreation Department, Nursing Service); receive official sanction (Chiefs of the Spinal Cord Injury and Social Work Services, and the Hospital Director); and access to resources (staff time, bus, etc.). The importance of monitoring this process throughout the evolution of the program, in order to identify and correct inadvertent omissions, was critical--as was evident in my failure to involve the Chief, Nursing Service in the initial planning phase. This omission could have resulted in

the failure to arrange for the required participation of nursing personnel on community trips due to inadequate time for scheduling coverage, and/or the assignment of staff to other programs.

2. Assessment of Program

In assessing the program, it became clear that I overemphasized quantitative rather than qualitative measures of program "success," in my assessment of the process. Throughout the implementation period, I focused on the number of activities a participant involved himself in pre- and post-injury; the number of meetings he attended; and the number of group activities in which he participated. Future programs should place greater emphasis on developing measurement instruments aimed at assessing the client's perception of the program as a vehicle for interacting with others in a similar situation; for engaging in social exchanges in person and/or by telephone, regardless of the activity; and for acquiring new knowledge or skills, or refining those already acquired, in a program designed to allow for intermittent participation due to the physical obstacles noted previously, varying levels of motivation over time, or interest in particular activities.

At the same time, while regular participation was limited to a few potential candidates, and while

frustration with scheduling transportation and obtaining tickets to desired events was quite high at times, members did attend meetings when physically possible; expressed their concerns (pages 52-54); shared in the problem solving process (pages 54-56); and made every effort to notify me in advance when they could not attend. When asked at the conclusion of the program why they felt it was important for the hospital to run such a program, the responses were:

1. Sometimes you feel stuck at home.
2. You have transportation to go places.
(hospital bus)
3. Others in your life may be busy with other things.
4. You can learn from the reactions of others; from others' mistakes and successes.
5. Provides socialization.
6. Provides better expectations for future.
7. Provides necessary resources--transportation, aide, volunteers.
8. Good to get out--might not go otherwise.
9. Provides an opportunity to be with others who are facing similar experiences.
10. Can accomplish more when several people are trying to solve problems.

Two of the more important variables expressed by participants over and over again at meetings, to account for their involvement, were 1) the program provided an opportunity to get away from home and to be with other

individuals; and 2) the program provided resources to overcome obstacles to use of community activities (e.g., transportation, aides, volunteers).

An additional area which warrants further study is the development of network systems of communication to supplement face-to-face contacts. When it became apparent that group members could not attend all meetings, or activities, they willingly agreed to exchange telephone numbers to allow for the transmission of group decisions and the sharing of information regarding activities. This process evolved towards the conclusion of the program. It could have, if implemented early in the process, become an effective system for data sharing, and allowed for participants to develop their own networks of problem solving and interacting. One specific modification to the program would have proven a valuable tool for solidifying group interaction, while maintaining the involvement of the group member unable to attend a particular meeting --the utilization of a conference-call telephone system. Such a system would have allowed all group members, and a homebound participant, to engage in simultaneous conversations. This system would also have permitted a totally homebound individual to engage in the social interaction and problem solving process.

Additional areas for consideration would include further development of pre-discharge activity groups,

focused on social skills training and the development of community network systems. White (1961) has asked:

If the objective is to restore the patient to a community where he can feel accepting of himself and accepted by his society, might not the most effective approach be to test him out in a society (the rehabilitation center) where he is understood and accepted? (p. 54, parentheses mine)

Then, in reporting on the effect of a task-oriented activity program for handicapped patients, she states:

These repeated successful experiences give him new strength and stimulate him to attempt others. As he begins to see potentials for a new kind of independence, the patient becomes more relaxed and shows progress and growth in his daily living activities, physically and emotionally. His acceptance of self and of others is demonstrated in his increased interest in other patients and a different kind of interest in staff and people in general. . . . (pp. 55-56).

Consideration should also be made for involving former patients in the process to serve as role models, and to be available to share their experiences in overcoming potential physical and emotional barriers to utilizing community resources.

Three significant findings did emerge regarding the organization of the program. As indicated above, multiple variables influenced the individual's ability to participate in planning sessions and community activities. Table 7 represents the level of participation.

Table 7. Level of Participation

<u>Number of Participants</u>	<u>Number of In-hospital Meetings Attended</u>	<u>Number of Community Trips Participated In</u>
1	10	4
2	6	3
1	3	1
2	1	1
1	3	0
1	2	0
1	1	0
<u>9*</u> Total		

*Three patients who did not participate in community activities were not administered the post-participation questionnaire.

These results would further indicate a need to reassess the meeting format, and to consider a more innovative communication system between individuals who wish to participate. It would also prove valuable to assess the impact of even limited participation in planning sessions, and community trips, on the participant's social skills and perception of a "quality life."

A second program finding was the high level of frustration expressed over delays in implementing trips due to problems obtaining the bus, or tickets to events. While it became apparent that long range planning of certain activities was necessary, group members noted a desire to be involved in the interim. Consequently, they suggested that they participate in in-hospital activities and trips planned by the Recreation Department.

A third finding of the group process was that

participants expressed no particular concern that the composition of the group be based on similarities in age, level of disability, or length of time post-hospitalization. The primary desire of each participant was to participate in activities of personal interest. It must be recognized, however, that the limited number of participants in this program, as well as candidates who had access to transportation, did not allow for a more substantial inquiry into this area.

Finally, since it became clear that the social interaction and involvement in community activities was valuable as a means of developing and refining social skills (see Chapters V and VI), as well as a valuable human interactive experience (see participant's responses, page 116), future programs should explore possibilities of obtaining grants specifically aimed at providing transportation to interested individuals who might otherwise be unable to participate. This would allow for group meetings to be held in settings other than a hospital (e.g., community center, participant's home, etc.), and could provide additional out-of-hospital experience for inpatients.

B. Strengths and Limitations of Practice Principles

It should be noted that my assessment of the two practice principles is based on a review of what did or did not occur regarding participant's behavior in the

course of implementing the program. Since I operated from the principles, and did not utilize control groups, the evidence presented supports their applicability rather than serves to prove them.

Practice Principle 1 states:

The particular services provided the individual with a physical disability (within the parameters of the agency's acknowledged function), should not depend solely on the agency's perception of the client's needs (via the worker), but should include for consideration the client's perception of need and alternative solutions; as these will most likely affect the client's ultimate use of the service and perception that they are of benefit to him in his pursuit of a "quality life."

The findings of the study support this practice principle in two distinct ways. First, the group participants planned and implemented four trips into the community which they themselves had not engaged in since their physical injury occurred (during or post-hospitalization), but which they identified as being of particular individual interest (trips to jai-a lai, circus, museum, planetarium). In addition, they expressed interest in attending the Ice Capades and the theater. All suggestions for community activities were generated by group members without my assistance. In fact, I had not envisioned the trips to jai-a lai, the circus, Ice Capades, the planetarium, and the theater during the period of developing the program.

Secondly, in support of the practice principle, was my pre-implementation misperception that group members would not be interested in participating in activities

with large groups of hospitalized patients (. . . might feel that too large a group would expose themselves to stares and excessive curiosity). In fact, a post-participation questionnaire (see Appendix D) revealed the following: Participants felt that inpatients might learn from the post-hospitalization experiences of outpatients; that they still had common concerns to talk about; that it was a good idea to keep in touch with paraplegic friends who would "understand what you're going through;" that going on trips with inpatients was a good way to meet new people; and that a larger group would allow for greater input in making plans for community excursions. (Again, one must be reminded that the small number of individuals who were administered this questionnaire limits its generalizability.)

One additional misperception, that participants "would want to plan all trips by themselves," was also addressed by several participants in the post-participation evaluation questionnaire. Members reacted positively to the question: "how would you feel about the Recreation Department staff planning the trips for you?" Some felt that the recreation staff would be aware of activities they had not thought of, and that they might have easier access to tickets, transportation and volunteers. However, all participants who addressed this question during group meetings and/or in responding to the questionnaire, expressed a desire to be involved in the process, either

through helping to plan the activity or by making suggestions, so that their particular interests would be considered. In fact, all participants in the group expressed the desire to receive notification of programs run by the Recreation Department staff, and thought that it might be valuable for interested outpatients to be placed on a mailing list.

In summary, inclusion of the client in the process of identifying desired services resulted in their identifying numerous activities which I (the agent of the agency) had not envisioned, and in their clarifying several pre-program misperceptions.

Practice Principle 2 states:

The client should have available to him the information and knowledge of community resources that enable him to pursue activity in accordance with his definition of a "quality life," and should be assisted to obtain and utilize the resources when physically and/or emotionally unable to do so independently, as knowledge of, and assistance to make use of resources, will increase the possibility of the client's actual utilization of those resources.

Data collected during the course of developing and implementing the program indicate an increase in participant's social/accessibility skills (see Reflections on the program based on participant's knowledge of accessibility skills. . . , pp. 101-111), but no meaningful increase in the actual utilization of community resources (see Activity Preferences, pp. 111-114).

It was apparent that a primary physical obstacle to the participant's independent utilization of community

resources was the unavailability of low-cost, wheelchair-accessible transportation to and from activities, and of the assistance of a volunteer, or attendant, in the absence of a friend or family member. A program such as the Hospital Based Community Activity Program makes these services available. Consequently, it should be viewed, in and of itself, as a valuable resource for the severely physically disabled individual, in addition to a "training" program for independent functioning.

CHAPTER VII

CONCLUSIONS

In implementing the Hospital Based Community Activity Program, it became apparent that individuals with spinal cord injuries may find themselves homebound, post-hospitalization, as a result of a) limited community resources (accessible transportation, availability of attendant care, etc.); b) physical barriers (inaccessible facilities, etc.); c) emotional concerns attributed to the loss of physical functioning (feelings of shame, inferiority, guilt, frustration, etc.), or the reactions of the "non-disabled" public (stares, pity, disapproval, etc.); and d) an unfamiliarity with the process of identifying and negotiating those community resources available to an individual confined to a wheelchair (Chapter I).

The Hospital Based Community Activity Program was designed to enhance the social functioning of individuals with spinal cord injuries, within their communities. Its purpose was to aid participants in identifying and refining those social skills necessary to utilize community social resources (Chapter II).

The Program

The process of developing and implementing the program suggested ways in which obstacles confronted by participants could be avoided. For example, blocks to communication, which limited participation, could be overcome if routinely, when developing such a program, emphasis was placed on the organization of a formal communication network linking all those involved. The use of in-person meetings and telephone exchanges could provide such a network, offering opportunities for all to raise questions and concerns regarding the use of community resources, and to share in the responses and clarifications that fellow participants can provide. This emphasis should be given higher priority than that of frequency and consistency of attendance at meetings and/or trial trips. The project demonstrated that participants were able to use each other effectively, in direct and telephone contact, to solve problems related to overcoming obstacles, whether they attended meetings or went on trips.

This communication network would probably have benefited from a telephone party-line system linking individual homes and the hospital. It would have permitted outpatients who could not attend all, or any meetings or trips, to participate in the verbal interaction of the group. Individuals who could attend meetings, as well as those who were homebound, could

have had input into the group's problem solving process, while refining social avocational skills. Homebound individuals could also have utilized the program to share experiences, as well as to develop new friendships while maintaining old acquaintances. Exploration of a mechanism for establishing such a communication system should be part of the initial planning when considering such a program with the hospital's administration and/or service organizations.

Similar programs should also consider requests to members of service organizations to participate in group sessions as resource persons. The sharing of their experiences post-hospitalization could prove valuable in overcoming obstacles, and in serving as role models for individuals returning to their communities for the first time. Their experiences in adjusting to the new demands of community living might prove particularly valuable, as the study demonstrated that although participants did indicate some positive shift in their comfort in participating in certain activities, their level of participation, overall, decreased. Members of service organizations could share their own management of such potentially trying situations as participating in sporting events, sitting in the aisle of a theater, grocery shopping, etc. While problems in these areas did not affect all participants equally, and an individualized approach to each participant's needs is indicated, the

model that service organization members would provide could be helpful to all.

The pilot project did, however, demonstrate the desire and ability of a group of individuals with spinal cord injuries to meet to share emotional and physical concerns, as well as to collectively formulate problem solving techniques. Group members identified questions regarding use of community social resources; established mechanisms for obtaining answers; and implemented activities. (See Chapter IV.) As a result, individual's verbal social skills improved after participating in the program, although their post-program participation in community activities did not. (See Chapter V.) This latter lack of change may be attributed in part to the unavailability of low-cost, wheelchair-accessible transportation to and from activities, and to the unavailability of attendants to assist the individual in the absence of a friend or family member, since group members readily participated when these resources were provided through the program.

The System

In retrospect, several systems issues appear in a new perspective. The initial expectation, as conveyed to the administrators of the medical center, that the program might serve to reduce patient's dependency on the institution, was unfounded. While participants refined

their social avocational skills, the lack of community resources (e.g., transportation system, aides, etc.), influenced their level of community involvement, regardless of their knowledge of techniques for minimizing the effects of physical obstacles. The importance of the Hospital Based Community Activity Program, for participants, was not only the training that occurred, but also the resources provided by the hospital.

It now appears more appropriate to regard such a program as an ongoing therapeutic service providing a formalized outpatient network system to discharged patients. In addition, such a program could be viewed as a positive resource for hospitalized patients, aimed at reducing the anxiety attached to leaving the protective setting of the institution.

A Hospital Based Community Activity Program can serve another valuable function, in addition to providing an arena for the individual with a physical disability, and his family, to engage together in community activities. It can also offer the family and the patient, who requires an aide, time apart from each other, with the security that the program will provide necessary resources during group activities.

Finally, this project confirmed the notion that in establishing any new program within an agency, it is essential that the worker continually review the effect of its implementation on the system as a whole. Monitoring

for oversights in negotiating for the use of agency resources--including time, staff, and budget--is essential. The development stage does not occur at a fixed point in time, prior to implementation, but is constantly evolving throughout the life of a program, as available resources and/or interests of agency decision makers change.

In conclusion, the entire process raised a critical question which warrants the attention of anyone involved in the rehabilitation process of individuals with physical disabilities. Do we, in fact, sufficiently address the issue of social skills learning while the individual is involved in the hospital phase of rehabilitation? Unique as the post-hospital experience is in its challenges to any individual, can not the process of exploring potential physical and emotional obstacles to use of community avocational resources begin in the institution? While the small number of participants involved in this pilot demonstration precludes generalizations to other individuals with spinal cord injuries, the pilot effort suggests possibilities for developing useful programs for individuals discharged from rehabilitation centers, as well as for those who are still undergoing in-hospital treatment. Certainly, the strength and determination of those who participated in this program is confirmation that the challenges presented by a spinal cord injury are met daily by countless individuals.

APPENDIX A

VETERANS ADMINISTRATION
HOSPITAL
130 West Kingsbridge Road
Bronx, New York 10468

August 7, 1978

In reply
refer to: 526/128

Dear

I am starting a group for spinal cord injured outpatients who are interested in participating in social activities in the community, but who have not been able to, for one reason or another.

This group will offer those who participate an opportunity to meet with others to plan activities and to work together to overcome any obstacles that might arise in the course of participating in them.

I would like to visit you to explain the program in more detail. I will call in a few days to set up a time that is convenient for you, and to answer any questions you might have regarding the program.

I look forward to seeing you.

Sincerely,

David Gitelson,
Social Worker,
Spinal Cord Injury Service

DG/ad

United States Government

MEMORANDUM

Date: May 24, 1978

To: Spinal Cord Injury Program Coordinator
From: Chairman, Joint Conference Council
Subject: Use of Hospital Bus for Hospital Based
Community Activity Program

To further consider your proposal the following additional information is needed:

1. estimated program costs
2. hospital liability status

The Office of the District Counsel may be of help to you in determining the latter.

Lloyd V. Sturm

VETERANS ADMINISTRATION
HOSPITAL
130 West Kingsbridge Road
Bronx, New York 10468

August 9, 1978

In reply
refer to: 526/122

Mr. Stephen Kraut
Office of the District Counsel
VA Regional Office
252 Seventh Avenue
New York, New York 10001

1. At the request of our Hospital Director, I am seeking clarification of our liability status if the hospital bus is utilized for a spinal cord injury community activity program for outpatients.
2. During our telephone conversation of August 3, 1978 you informed me that our Hospital Director could authorize use of the bus if the program conformed to the role of the social worker as outlined in the Department of Medicine and Surgery Manual. The DM&S Manual, M-2, Part XII, Revised, dated November 7, 1975 entitled "Professional Services, Social Work Service," Chapter 1, "Social Work Service Functions," paragraph 1.03 and Chapter 2, "Program Responsibilities and Operations," paragraph 2.01 seems to indicate that such a program is consistent with the function and responsibilities of Social Work Service.
3. I look forward to your response, since we are ready to initiate this program as soon as possible.

Very truly yours,

David Gitelson
Social Work Program
Coordinator

Hospital Director (00)

August 9, 1978

David Gitelson, Social Work
Program Coordinator

Use of Hospital Bus for SCI Outpatients

1. In your memo regarding use of the hospital bus for a Hospital Based Community Activity Program for SCI Outpatients dated May 24, 1978, from the Joint Conference Council, you requested information regarding estimated program costs and hospital liability status.
2. I am anticipating involving outpatients who are presently being transported to the hospital for outpatient programs, or are able to provide their own transportation to the hospital. Consequently, the cost of the program will be limited to the use of the hospital bus and driver on a bi-weekly basis, for four months, to transport patients, a social worker, and volunteers to local community vocational activities.
3. Attached is a copy of a letter I have sent to Mr. Stephen Kraut, of the Office of the District Counsel, requesting clarification of our liability status if the hospital bus is utilized for the outpatient program. I will inform you of his response as soon as it is received.
4. To date, the program has received the support of the Chief SCI Service, Chief Social Work Service, and the Eastern Paralyzed Veterans Association.

DAVID GITELSON

Enclosure 1

Hospital Director (00)

526/122

David Gitelson, Social Work
Program Coordinator

Use of Hospital Bus for Spinal Cord Injured
Outpatients

1. The memorandum regarding use of the hospital bus for a Hospital Based Community Activity Program for SCI outpatients dated May 24, 1978, from the Joint Conference Council, requested information regarding hospital liability status. It was suggested that the District Counsel might be of help in clarifying this matter.
2. Attached is a copy of a letter we received from Mr. S.M. Camm, District Counsel, in response to my letter of inquiry dated August 9, 1978.
3. The District Counsel's response states that the hospital's bus may be utilized for outpatients if the program serves to further the functions assigned to the Social Work Services in M-2, Part XII, Pars. 1.0., 1.03, and 2.01. Since the proposed program has received the support of the Chief Spinal Cord Injury Service, Chief Social Work Service, and the Eastern Paralyzed Veterans Association, I request permission to utilize the hospital bus for the Hospital Based Community Activity Program which I have previously submitted to your office for consideration.

DAVID GITELSON

Enclosure: 1

VETERANS ADMINISTRATION
OFFICE OF DISTRICT COUNSEL
252 Seventh Avenue
New York, New York 10001

August 22, 1978

In reply
refer to:
306/021C

Director (122)
VA Hospital
130 West Kingsbridge Road
Bronx, NY 10468

Subject: Social Work Programs - Transportation -
Outpatients

1. You have requested our advice as to whether a hospital's buses may be utilized to take spinal cord outpatients on community activity programs.
2. Those vehicles may, of course, be utilized in accordance with priorities set with the hospital director to carry out the functions of the Veterans Administration, and, in particular, of the hospital and its various services.
3. M-2, Part XII, Par. 2.01b(1), directs the Social Work Service of the hospital to develop comprehensive programs of social services and supports along the full continuum of care, including outpatient treatment. M-2, Part XII, Par. 2.01b(3), states:

"Social Services will be directed toward (a) helping patients and families cope with the crisis of illness, (b) maximizing social and interpersonal functioning of patients, (c) promoting vocational and social rehabilitation, (d) facilitating the patient's return to community at the highest level of potential, (e) working with dying patients and bereaved families, (f) developing special approaches such as mutual assistance groups to provide solutions to unique social problems, (g) organizing community resources to augment services, and (h) delivering information and referral services."
4. Further, M-2, Part XII, Par. 2.01e, directs the Social Work Service to participate in planning and development of ambulatory care which encompasses all non-bed care

2.

Director (122)
VAH, Bronx, NY

and treatment settings, including clinics and even veterans' homes. The services include those outlined in M-2, Part XII, Pars. 1.01 and 1.03. It is of particular significance that M-2, Part XII, Par. 1.03a states that the function of Social Work Services is to enhance or restore functioning through the application of resources, including the provision of tangible goods and services.

5. Accordingly, to the extent that your planned Community Activities Program for outpatient spinal cord injury patients serves to further the functions assigned to the Social Work Services in M-2, Part XII, Pars. 1.01, 1.03, and 2.01, there is no legal objection to it. It is, of course, for the hospital to determine the appropriateness and adequacy of the program. But it is clear that such services may be rendered to outpatients as well as in-hospital patients.

S.M. Camm
District Counsel
Tel. (FTS) 660-6324

VETERANS ADMINISTRATION MEDICAL CENTER

130 West Kingsbridge Road
Bronx, New York 10468

1. The Joint Conference Council met on October 17, 1978 at 2:30 p.m. in the Director's Office. Those in attendance were:

Mr. Sturm	Hospital Director
Mr. Williams	Assistant Director
Dr. Wolf	Chief of Staff
Sheila Cullen	Special Assistant to Director
Evert Melander	Management Analyst
Eric Chaikin	Administrative Resident
David Emerson	Administrative Resident
Harry Wruble	Administrative Resident
David Gitelson	Social Work Program Coordinator

2. Hospital Based Community Activity Program for SCI Outpatients - Proposal by Mr. D. Gitelson

Approval was granted for a four month Experimental Pilot Project. At that time, program effectiveness will be evaluated and accomplishments assessed.

SHEILA CULLEN
Special Assistant to Director

APPROVED: _____
LLOYD V. STURM
Hospital Director

APPENDIX B

Participant 1 Date administered: August 12, 1978

Post-injury Activity (pre-program participation)

Always (once a week or more)

1. TV viewing
2. Reading

Routine (every two or three weeks)

1. Play cards, other indoor games

Occasionally (half dozen to a dozen times during period)

-

Rarely (one to five times during period)

1. Going to a party
2. Going out to a restaurant
3. Taking pleasure drives
4. Visiting with relatives, neighbors, friends
5. Going to nightclubs, bars
6. Going to watch sporting events
7. Going to the movies

Never (not at all)

1. Going to a service organization meeting
2. Going to the beach
3. Going on picnics
4. Working on crafts or hobbies
5. Shopping (except for groceries)
6. Going to fairs, museums, exhibits, etc.
7. Going to concerts, plays, etc.
8. Participating in sporting events
9. Going to classes or lectures
10. Going to church
11. Going to club meetings

Participant 1 (cont.) Date administered: August 12, 1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Going to a service organization meeting
2. Going to restaurants
3. Reading
4. TV viewing
5. Taking pleasure drives
6. Play cards, other indoor games
7. Visiting with relatives, neighbors, friends
8. Going to nightclubs, bars
9. Going to watch sporting events
10. Going to club meetings
11. Going to the movies

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times all year)

1. Going to a party
2. Going to the beach
3. Going on a picnic
4. Shopping (except for groceries)
5. Participation in sporting events
6. Going to classes or lectures

Rarely (one to five times during year)

1. Going to fairs, museums, exhibits, etc.
2. Going to church

Never (not at all)

1. Working on crafts or hobbies
2. Going to concerts, plays

Participant 1 (cont.) Date administered: August 12, 1978

Comfort Inventory (pre-program participation)

Not at All

1. Going to a service organization meeting
2. Going to a party
3. Going to a restaurant
4. Reading
5. TV viewing
6. Picnics
7. Going to nightclubs, bars
8. Watch sporting events
9. Club meetings
10. Going to movies
11. Play cards, other indoor games
12. Visiting with relatives, neighbors, friends
13. Taking pleasure drives

Somewhat

1. Going to the beach
2. Working on crafts or hobbies
3. Going to fairs, museums, exhibits
4. Going to classes or lectures
5. Going to church

A Little

1. Shopping (except for groceries)

Very

-

Extremely

1. Going to concerts, plays
2. Participating in sporting events

Participant 1 (cont.) Date administered: August 12, 1978

Social Situations (pre-program participation)

Situation #1

A.

1. Is the facility wheelchair accessible?
2. Where is it located?
3. What type of neighborhood is the facility in?
4. Dress--formal or informal?

B.

1. Ask someone who'd been there before.
2. Call place itself.

Situation #2

A.

1. Call town Recreation Department.
2. Obtain municipal booklets on subject.

Situation #3

A.

1. How qualify for team?
2. How often you have to meet?
3. Is travel necessary?
4. Will I have to go all the time?
Is there a minimum amount of time you have to go to
continue to participate?

B.

1. Call service organization.
2. Go to facility to see if it is wheelchair accessible.
3. Have a friend check it out for accessibility.

Participant 2

Date administered: August 19, 1978

Post-injury Activity (pre-program participation)Always (once a week or more)

1. TV viewing
2. Reading
3. Working on crafts or hobbies

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times during period)

1. Play cards, other indoor games

Rarely (one to five times during period)

1. Other (hosting parties)

Never (not at all)

1. Going to a service organization meeting
2. Going to a party
3. Going out to a restaurant
4. Going to the beach
5. Going on picnics
6. Taking pleasure drives
7. Visiting with relatives, neighbors, friends
8. Shopping (except for groceries)
9. Going to fairs, museums, exhibits, etc.
10. Going to concerts, plays, etc.
11. Going to nightclubs, bars
12. Participating in sporting events
13. Going to watch sporting events
14. Going to classes or lectures
15. Going to church
16. Going to club meetings
17. Going to the movies

Participant 2 (cont.) Date administered: August 19, 1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Reading
2. TV viewing
3. Working on crafts or hobbies
4. Play cards, other indoor games
5. Visiting with relatives, neighbors, friends
6. Shopping (except for groceries)
7. Going to nightclubs, bars
8. Going to club meetings

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times all year)

1. Going to a service organization meeting
2. Going to a party
3. Going to restaurants
4. Taking pleasure drives
5. Going to concerts, plays, etc.
6. Going to classes or lectures
7. Going to church

Rarely (one to five times during year)

1. Other (host parties)
2. Going on a picnic
3. Going to fairs, museums, exhibits, etc.

Never (not at all)

1. Going to the beach
2. Participating in sporting events
3. Going to watch sporting events
4. Going to movies

Participant 2 (cont.) Date administered: August 19, 1978

Comfort Inventory (pre-program participation)

Not at All

1. Going to movies
2. Other (host parties)
3. Going to a service organization meeting
4. Going to a party
5. Reading
6. TV viewing
7. Going to the beach
8. Taking pleasure drives
9. Working on crafts or hobbies
10. Play cards, other indoor games
11. Visiting with relatives, neighbors, friends
12. Going to fairs, museums, exhibits, etc.
13. Going to concerts, plays, etc.
14. Watch sporting events
15. Going to classes or lectures
16. Going to church
17. Going to club meetings

Somewhat

-

A Little

1. Going out to a restaurant
2. Going on picnics
3. Shopping (except for groceries)
4. Going to nightclubs, bars
5. Participating in sporting events

Very

-

Extremely

-

Participant 2 (cont.) Date administered: August 19, 1978

Social Situations (pre-program participation)

Situation #1

A.

1. Transportation--how I'd get there?
2. Time element--time of day of activity and time spent in activity?
3. Lavatory facilities--accessibility?
4. Are there stairs?
5. Comfort of viewing from wheelchair--within facility?

B.

1. Ask someone who'd been there.
2. Contact place itself--ask questions or have them send literature.

Situation #2

1. Neighborhood groups--try to find community agencies providing services to the physically handicapped. (look through telephone book)
2. Word of mouth (neighbors). Ask people to look out for activities (give them specific details).
3. Ask friends, family, for suggestions--ask them to check out activities for accessibility.

Situation #3

A.

1. Where are there such programs?
2. What kind of accessibility is available?
3. What transportation is available?
4. What would it mean to me? What would I get out of it?

B.

1. Word of mouth
2. Telephone or correspond with organization involved.
3. Newspapers/radio/TV/magazines
4. Check with friends/neighbors.

Participant 3Date administered: September 21,
1978Post-injury Activity (pre-program participation)Always (once a week or more)

1. TV viewing
2. Working on crafts or hobbies
3. Reading

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times during period)

1. Play cards, other indoor games
2. Visiting with relatives, neighbors, friends

Rarely (one to five times during period)

1. Going on picnics

Never (not at all)

1. Going to the movies
2. Going to watch sporting events
3. Going to nightclubs, bars
4. Taking pleasure drives
5. Going out to a restaurant
6. Going to a party
7. Going to club meetings
8. Going to church
9. Going to classes or lectures
10. Participating in sporting events
11. Going to concerts, plays, etc.
12. Going to fairs, museums, exhibits, etc.
13. Shopping (except for groceries)
14. Going to the beach
15. Going to a service organization meeting

Participant 3 (cont.) Date administered: September 21,
1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Working on crafts or hobbies
2. Going to church
3. Participating in sporting events
4. Play cards, other indoor games
5. Taking pleasure drives
6. Reading
7. TV viewing
8. Going to restaurants
9. Visiting with relatives, neighbors, friends

Routine (every two or three weeks)

1. Going to the beach

Occasionally (half dozen to a dozen times all year)

1. Going to a service organization meeting
2. Going to concerts, plays, etc.
3. Going to fairs, museums, exhibits, etc.
4. Going to classes or lectures
5. Shopping (except for groceries)
6. Going to a party
7. Going to the movies
8. Going to club meetings
9. Going to watch sporting events
10. Going to nightclubs, bars

Rarely (one to five times during year)

1. Going on a picnic

Never (not at all)

-

Participant 3 (cont.) Date administered: September 21,
1978

Comfort Inventory (pre-program participation)

Not at All

(all 21 activities)

Somewhat

-

A Little

-

Very

-

Extremely

-

Participant 3 (cont.) Date administered: September 21,
1978

Social Situations (pre-program participation)

Situation #1

A.

1. Accessible bathroom?

B.

1. Ask someone at the facility by telephone.

Situation #2

A.

1. Call library.
2. Watch TV and listen to radio for daily information.
3. Check in local paper.

Situation #3

A.

1. "Am I interested?"
2. Ask others who were participating in activity.
3. Check with newspapers re: activities.
4. What time factors would be involved?
5. Financial considerations

B.

1. Look in newspapers.
2. TV
3. Radio
4. Books on subject

Participant 4Date administered: September 26,
1978Post-injury Activity (pre-program participation)Always (once a week or more)

1. Going to watch sporting events
2. Participating in sporting events
3. Reading
4. TV viewing

Routine (every two or three weeks)

1. Going out to a restaurant

Occasionally (half dozen to a dozen times during period)

1. Going to the movies
2. Shopping (except for groceries)
3. Going on picnics

Rarely (one to five times during period)

1. Taking pleasure drives
2. Going to a service organization meeting
3. Play cards, other indoor games
4. Working on crafts or hobbies

Never (not at all)

1. Going to church
2. Going to club meetings
3. Going to classes or lectures
4. Going to nightclubs, bars
5. Going to concerts, plays
6. Going to fairs, museums, exhibits
7. Visiting with relatives, neighbors, friends
8. Going to the beach
9. Going to a party

Participant 4 (cont.) Date administered: September 26,
1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Going to watch sporting events
2. Participating in sporting events
3. Going to restaurants
4. Play cards, other indoor games
5. TV viewing
6. Reading
7. Visiting with relatives, neighbors, friends

Routine (every two or three weeks)

1. Other (going to dances)
2. Going to movies
3. Going to the beach
4. Going to a party
5. Going to club meetings
6. Shopping (except for groceries)

Occasionally (half dozen to a dozen times all year)

-

Rarely (one to five times during year)

1. Going to fairs, museums, exhibits, etc.
2. Going on a picnic
3. Going to church
4. Going to classes or lectures
5. Going to concerts, plays, etc.
6. Going to nightclubs, bars
7. Working on crafts or hobbies

Never (not at all)

1. Taking pleasure drives
2. Going to a service organization meeting

Participant 4 (cont.) Date administered: September 26,
1978

Comfort Inventory (pre-program participation)

Not at All

(all 21 activities except dances which was placed
in "Extremely" category)

Participant 4 (cont.) Date administered: September 26,
1978

Social Situations (pre-program participation)

Situation #1

A.

1. Steps--can I get in?

B.

1. Go to place to see for self.

Situation #2

A.

1. Look at Community Affairs section in newspaper.

Situation #3

A.

1. Accessibility of place--can I get into place?

B.

1. Call
2. Go down to see for self.

Participant 5 Date administered: September 26, 1978

Post-injury Activity (pre-program participation)

Always (once a week or more)

1. Visiting with relatives, neighbors, friends
2. Going to a party
3. Going out to a restaurant
4. Taking pleasure drives
5. Going to nightclubs, bars
6. Reading
7. TV viewing

Routine (every two or three weeks)

1. Play cards, other indoor games

Occasionally (half dozen to a dozen times during period)

-

Rarely (one to five times during period)

1. Going on picnics
2. Going to a service organization meeting
3. Going to the beach
4. Going to concerts, plays
5. Going to church
6. Going to watch sporting events
7. Going to movies

Never (not at all)

1. Working on crafts or hobbies
2. Going to club meetings
3. Going to classes or lectures
4. Participating in sporting events
5. Going to fairs, museums, exhibits, etc.
6. Shopping (except for groceries)

Participant 5 (cont.) Date administered: September 26, 1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Working on crafts or hobbies
2. Going to nightclubs, bars
3. Shopping (except for groceries)
4. Visiting with relatives, neighbors, friends
5. Going to restaurants
6. TV viewing
7. Reading
8. Taking pleasure drives
9. Playing cards, other indoor games
10. Going to church

Routine (every two or three weeks)

1. Going to a party
2. Going to classes or lectures
3. Going to a service organization meeting
4. Participating in sporting events

Occasionally (half dozen to a dozen times all year)

1. Going to the beach
2. Going to watch sporting events
3. Going to club meetings
4. Going to movies
5. Going on a picnic

Rarely (one to five times during year)

1. Going to fairs, museums, exhibits
2. Going to concerts, plays

Never (not at all)

-

Participant 5 (cont.) Date administered: September 26,
1978

Comfort Inventory (pre-program participation)

Not at All

(all activities except shopping which was placed
in the "Somewhat" category)

Participant 5 (cont.) Date administered: September 26,
1978

Social Situations (pre-program participation)

Situation #1

A.

1. Transportation?
2. Will someone be there to help who knows how?

B.

1. Call someone who could drive you.
2. Call someone who could go with you.
3. Call the hospital to see if someone could go with you.

Situation #2

A.

1. Call social worker.

Situation #3

A.

1. Who is in charge of sport?
2. When do they get together?
3. Requirements for participating?

B.

1. Call someone involved.

Participant 6Date administered: September 28,
1978Post-injury Activity (pre-program participation)Always (once a week or more)

1. Reading
2. TV viewing
3. Play cards, other indoor games

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times during period)

1. Taking pleasure drives
2. Going out to a restaurant
3. Visiting with relatives, neighbors, friends

Rarely (one to five times during period)

1. Going to church
2. Going shopping (except for groceries)
3. Going on picnics
4. Going to fairs, museums, exhibits, etc.

Never (not at all)

1. Participating in sporting events
2. Going to watch sporting events
3. Going to nightclubs, bars
4. Going to the beach
5. Going to classes or lectures
6. Going to club meetings
7. Going to a party
8. Going to movies
9. Working on crafts or hobbies
10. Going to concerts, plays
11. Going to a service organization meeting

Participant 6 (cont.) Date administered: September 28,
1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Visiting with relatives, neighbors, friends
2. TV viewing
3. Reading
4. Participating in sporting events
5. Going to the beach
6. Going to nightclubs, bars
7. Taking pleasure drives

Routine (every two or three weeks)

1. Going to church

Occasionally (half dozen to a dozen times all year)

1. Going to restaurants
2. Shopping (except for groceries)
3. Going to the movies
4. Going on a picnic

Rarely (one to five times during year)

1. Play cards, other indoor games
2. Going to watch sporting events
3. Going to a party
4. Going to fairs, museums, exhibits, etc.

Never (not at all)

1. Working on crafts or hobbies
2. Going to club meetings
3. Going to concerts, plays, etc.
4. Going to classes or lectures
5. Going to a service organization meeting

Participant 6 (cont.) Date administered: September 28,
1978

Comfort Inventory (pre-program participation)

Not at All

1. TV viewing
2. Reading
3. Taking pleasure drives
4. Working on crafts or hobbies
5. Play cards, other indoor games
6. Visiting with relatives, neighbors, friends
7. Going to watch sporting events
8. Going to a restaurant

Somewhat

1. Going to club meetings
2. Going to fairs, museums, exhibits, etc.
3. Going on picnics
4. Shopping (except for groceries)

A Little

1. Going to classes or lectures
2. Going to a service organization meeting
3. Going to a party
4. Going to concerts, plays, etc.
5. Going to church
6. Going to nightclubs, bars

Very

-

Extremely

1. Going to the movies
2. Going to the beach
3. Participating in sporting events

Participant 6 (cont.) Date administered: September 28,
1978

Social Situations (pre-program participation)

Situation #1

A.

1. Steps?
2. Who I'd go with?
3. Transportation and parking?
4. Distance?

B.

1. Call place.
2. Ask friends who've been there who know about wheelchair accessibility.
3. Ask family.

Situation #2

A.

1. Read paper.
2. Check with service organization.

Situation #3

A.

1. Transportation
2. Accessibility
3. Who would he go with?

B.

1. Telephone place.
2. Ask a friend.

Participant 7Date administered: September 29,
1978Post-injury Activity (pre-program participation)Always (once a week or more)

1. TV viewing
2. Reading
3. Working on crafts or hobbies

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times during period)

1. Taking pleasure drives
2. Visiting with relatives, neighbors, friends
3. Play cards, other indoor games
4. Shopping (except for groceries)

Rarely (one to five times during period)

1. Going to a party

Never (not at all)

1. Going to nightclubs, bars
2. Going to a restaurant
3. Going to the movies
4. Going to watch sporting events
5. Going to church
6. Going to concerts, plays, etc.
7. Going to the beach
8. Going to a service organization meeting
9. Going on picnics
10. Going to fairs, museums, exhibits, etc.
11. Participating in sporting events
12. Going to classes or lectures
13. Going to club meetings

Participant 7 (cont.) Date administered: September 29,
1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Taking pleasure drives
2. Reading
3. TV viewing
4. Going to a restaurant
5. Visiting with relatives, neighbors, friends
6. Working on crafts or hobbies
7. Going to fairs, museums, exhibits, etc.

Routine (every two or three weeks)

1. Going to movies
2. Going to concerts, plays, etc.

Occasionally (half dozen to a dozen times all year)

1. Shopping (except for groceries)
2. Participating in sporting events
3. Going to a party
4. Going to the beach

Rarely (one to five times during year)

1. Going to church
2. Play cards, other indoor games
3. Going to nightclubs, bars

Never (not at all)

1. Going to a service organization meeting
2. Going to classes or lectures
3. Going on a picnic
4. Going to club meetings
5. Going to watch sporting events

Participant 7 (cont.) Date administered: September 29,
1978

Comfort Inventory (pre-program participation)

Not at All

(all 21 activities)

Participant 7 (cont.) Date administered: September 29,
1978

Social Situations (pre-program participation)

Situation #1

- A.
1. Check date of activity against physical condition.
 2. Can I get someone to go with me?
 3. Accessibility of facility?--steps; do they allow a wheelchair user?
- B.
1. Call directly and ask.
 2. Ask someone who might know (e.g., service organization).
 3. Ask someone who'd been there.

Situation #2

- A.
1. Subscribe to various magazines
 2. Get on mailing list of facilities interested in.
 3. Listen to radio station that has community activity program.

Situation #3

- A.
1. Do I want to participate in the activity?
 2. Would I be neglecting something at home (e.g., housework)?
- B.
1. Make up own mind.

Participant 8

Date administered: October 3, 1978

Post-injury Activity (pre-program participation)Always (once a week or more)

1. Play cards, other indoor games
2. TV viewing
3. Reading

Routine (every two or three weeks)

1. Taking pleasure drives.

Occasionally (half dozen to a dozen times during period)

1. Shopping (except for groceries)
2. Going to movies

Rarely (one to five times during period)

1. Visiting with relatives, neighbors, friends
2. Going to a restaurant
3. Going to a party
4. Going to the beach
5. Going to nightclubs, bars

Never (not at all)

1. Going to fairs, museums, exhibits, etc.
2. Going on picnics
3. Going to church
4. Going to a service organization meeting
5. Going to concerts, plays, etc.
6. Working on crafts or hobbies
7. Going to club meetings
8. Going to classes or lectures
9. Going to watch sporting events
10. Participating in sporting events

Participant 8 (cont.) Date administered: October 3, 1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. TV viewing
2. Reading
3. Going to movies

Routine (every two or three weeks)

1. Taking pleasure drives
2. Going to nightclubs, bars
3. Visiting with relatives, neighbors, friends
4. Shopping (except for groceries)
5. Going to restaurants
6. Going to a party

Occasionally (half dozen to a dozen times all year)

1. Going to the beach
2. Participating in sporting events
3. Play cards, other indoor games
4. Working on crafts or hobbies

Rarely (one to five times during year)

1. Going to fairs, museums, exhibits, etc.
2. Going to watch sporting events

Never (not at all)

1. Going to church
2. Going on a picnic
3. Going to a service organization meeting
4. Going to classes or lectures
5. Going to concerts, plays, etc.
6. Going to club meetings

Participant 8 (cont.) Date administered: October 3, 1978

Comfort Inventory (pre-program participation)

Not at All

1. Visiting with relatives, neighbors, friends
2. Play cards, other indoor games
3. Working on crafts or hobbies
4. Taking pleasure drives
5. TV viewing
6. Reading

Somewhat

1. Going out to a restaurant
2. Shopping (except for groceries)
3. Going to fairs, museums, exhibits, etc.
4. Going to nightclubs, bars
5. Going to church
6. Going to a party
7. Participating in sporting events
8. Going to the movies

A Little

1. Going to watch sporting events
2. Going on picnics
3. Going to a service organization meeting
4. Going to the beach

Very

1. Going to classes or lectures

Extremely

1. Going to club meetings
2. Going to concerts, plays, etc.

Participant 8 (cont.) Date administered: October 3, 1978

Social Situations (pre-program participation)

Situation #1

A.

1. Wheelchair accessibility?
2. Who could go with me?
3. Is the time of the event good for people who I'd go with?

B.

1. Call place.
2. Drive by and check it out.
3. Have someone else check it out (inside accessibility).
4. Call friends.

Situation #2

A.

1. Call social worker.
2. Call service organization.
3. Use neighborhood "grapevine."
4. Check in local newspapers.
5. Ride around looking.

Situation #3

A.

1. Can I participate?
2. How can I do it as independently as possible?

B.

1. Go to place and check out receptiveness of people to have him participate.
2. Contact people at the place.
3. Get outside information--rumors.

Participant 9

Date administered: October 4, 1978

Post-injury Activity (pre-program participation)Always (once a week or more)

1. Working on crafts or hobbies
2. Reading
3. Shopping (except for groceries)
4. TV viewing
5. Play cards, other indoor games
6. Visiting with relatives, neighbors, friends
7. Going to church

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times during period)

1. Taking pleasure drives

Rarely (one to five times during period)

1. Going to a party
2. Going to club meetings
3. Going on picnics
4. Going to concerts, plays, etc.
5. Going to movies
6. Going to restaurants

Never (not at all)

1. Going to classes or lectures
2. Participating in sporting events
3. Going to fairs, museums, exhibits, etc.
4. Going to a service organization meeting
5. Going to the beach
6. Going to watch sporting events
7. Going to nightclubs, bars

Participant 9 (cont.) Date administered: October 4, 1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Visiting with relatives, neighbors, friends
2. Going to restaurants
3. Going to the beach
4. Reading
5. Taking pleasure drives
6. Going to concerts, plays, etc.
7. Going to movies
8. Participating in sporting events
9. Shopping (except for groceries)
10. Going to church
11. Play cards, other indoor games
12. Going to nightclubs, bars
13. Watch sporting events
14. Going on a picnic
15. Going to classes or lectures
16. Going to a service organization meeting

Routine (every two or three weeks)

1. Going to a party

Occasionally (half dozen to a dozen times all year)

1. Going to a club meeting

Rarely (one to five times during year)

1. Going to fairs, museums, exhibits, etc.
2. TV viewing

Never (not at all)

1. Working on crafts or hobbies

Participant 9 (cont.) Date administered: October 4, 1978

Comfort Inventory (pre-program participation)

Not at All

(all 21 activities)

Participant 9 (cont.) Date administered: October 4, 1978

Social Situations (pre-program participation)

Situation #1

A.

1. Entrance accessible?
2. Steps inside?

B.

1. Call place and explain situation.
2. Riding by place.

Situation #2

A.

1. Contact community agencies like VA Social Services.

Situation #3

A.

1. Can't say.

B. (no answer)

Participant 10

Date administered: October 4, 1978

Post-injury Activity (pre-program participation)Always (once a week or more)

1. TV viewing
2. Reading
3. Taking pleasure drives
4. Visiting with relatives, neighbors, friends

Routine (every two or three weeks)

1. Going to church

Occasionally (half dozen to a dozen times during period)

-

Rarely (one to five times during period)

1. Shopping (except for groceries)
2. Going out to a restaurant
3. Going to club meetings
4. Working on crafts or hobbies
5. Going to fairs, museums, exhibits, etc.

Never (not at all)

1. Play cards, other indoor games
2. Going to the movies
3. Going to nightclubs, bars
4. Going to the beach
5. Going to a party
6. Participating in sporting events
7. Going to watch sporting events
8. Going to classes or lectures
9. Going to concerts, plays, etc.
10. Going to a service organization meeting
11. Going on picnics

Participant 10 (cont.) Date administered: October 4, 1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Going to the movies
2. Shopping (except for groceries)
3. Going to nightclubs, bars
4. Reading
5. Play cards, other indoor games
6. Going to restaurants
7. Working on crafts or hobbies
8. Participating in sporting events
9. Going to the beach
10. Going to club meetings
11. Going to classes or lectures
12. Going to a service organization meeting
13. Going to church

Routine (every two or three weeks)

1. TV viewing

Occasionally (half dozen to a dozen times all year)

1. Going to fairs, museums, exhibits, etc.
2. Going to a party
3. Visiting with relatives, neighbors, friends
4. Taking pleasure drives
5. Going to watch sporting events

Rarely (one to five times during year)

1. Going to concerts, plays, etc.
2. Going on a picnic

Never (not at all)

-

Participant 10 (cont.) Date administered: October 4, 1978

Comfort Inventory (pre-program participation)

Not at All

1. TV viewing
2. Reading
3. Taking pleasure drives
4. Working on crafts or hobbies
5. Play cards, other indoor games
6. Visiting with relatives, neighbors, friends
7. Participating in sporting events
8. Going to church
9. Going to fairs, museums, exhibits, etc.
10. Shopping (except for groceries)
11. Going to a service organization meeting
12. Going on picnics
13. Going to watch sporting events
14. Going to classes or lectures
15. Going to club meetings

Somewhat

1. Going to the movies
2. Going to a party
3. Going to nightclubs, bars
4. Going out to a restaurant
5. Going to concerts, plays, etc.

A Little

1. Going to the beach

Very

-

Extremely

-

Participant 10 (cont.) Date administered: October 4, 1978

Social Situations (pre-program participation)

Situation #1

A.

1. Distance and travel time.
2. What facilities are available (e.g., stairs, bathroom facilities, food and lodging)?
3. Weather conditions and time of day.
4. Length of activity.
5. Emergency procedures.

B.

1. Phone calls.
2. Personal contacts with people who are knowledgeable about wheelchair accessibility and the activity.
3. Literature about the activity or facility.

Situation #2

A.

1. Call veteran's groups.
2. Call friend.
3. Call neighbors.
4. Look at newspapers.
5. Collect resource file.

Situation #3

A.

1. What I'd have to wear.
2. What help I'd need.
3. How to schedule out the day.
4. Transportation?
5. Length of activity/time/weather conditions.

B.

1. Call facility.
2. Ask other knowledgeable people.

Participant 11 Date administered: October 19, 1978

Post-injury Activity (pre-program participation)

Always (once a week or more)

1. TV viewing (radio listening)
2. Working on crafts or hobbies

Routine (every two or three weeks)

1. Reading

Occasionally (half dozen to a dozen times during period)

1. Visiting with relatives, neighbors, friends
2. Going to a party
3. Play cards, other indoor games

Rarely (one to five times during period)

1. Going to fairs, museums, exhibits, etc.
2. Going to a restaurant
3. Going on picnics
4. Going to a service organization meeting
5. Going to classes or lectures
6. Going to watch sporting events

Never (not at all)

1. Going to nightclubs, bars
2. Taking pleasure drives
3. Going to club meetings
4. Shopping (except for groceries)
5. Going to concerts, plays, etc.
6. Participating in sporting events
7. Going to the beach
8. Going to the movies
9. Going to church

Participant 11 (cont.) Date administered: October 19, 1978

Pre-injury Activity (previous year)

Always (once a week or more)

1. Going to a service organization meeting
2. Going to club meetings
3. Reading
4. TV viewing
5. Working on crafts or hobbies

Routine (every two or three weeks)

1. Going to classes or lectures
2. Participating in sporting events
3. Going to restaurants
4. Play cards, other indoor games
5. Shopping (except for groceries)
6. Visiting with relatives, neighbors, friends

Occasionally (half dozen to a dozen times all year)

1. Other (camping, hiking)
2. Going to church
3. Going to the movies
4. Going to watch sporting events
5. Taking pleasure drives
6. Going to fairs, museums, exhibits, etc.
7. Going on a picnic
8. Going to concerts, plays, etc.

Rarely (one to five times during year)

1. Going to the beach
2. Going to nightclubs, bars
3. Going to a party

Never (not at all)

-

Participant 11 (cont.) Date administered: October 19, 1978

Comfort Inventory (pre-program participation)

Not at all

1. Going to club meetings
2. Going to classes or lectures
3. Going to watch sporting events
4. Going to a service organization meeting
5. Going to church
6. Play cards, other indoor games
7. Working on crafts or hobbies
8. Taking pleasure drives
9. Reading
10. TV viewing
11. Going to a restaurant

Somewhat

1. Going on picnics
2. Going to fairs, museums, exhibits, etc.
3. Visiting with relatives, neighbors, friends
4. Going to concerts, plays, etc.
5. Going to the movies

A Little

1. Shopping (except for groceries)
2. Going to a party

Very

1. Participating in sporting events
2. Going to nightclubs, bars

Extremely

1. Going to the beach

Participant 11 (cont.) Date administered: October 19, 1978

Social Situations (pre-program participation)

Situation #1

A.

1. Wheelchair accessibility?--ramps, elevators
2. Who would go with me?
3. Transportation? (time available)
4. Time element involved?
5. Costs?

B.

1. Call facility.
2. Speak to or call people to go with.
3. Ask people who have already gone.
4. Accumulate literature.

Situation #2

A.

1. Check local community paper.
2. Check with local organizations and join them.
3. Check with people who live in community.
4. Pre-selection of housing location to be near points of interest.
5. Listen to radio shows oriented to community activities.
6. Join community organizations.

Situation #3

A.

1. Time of activity.
2. Travel time.
3. Availability of transportation.
4. Would participants be peer group--age/disability
5. Cost factor.
6. Possibility for making friendships.

B.

1. Call organization directly.
2. Speak to people who are already participating.
3. Check local publications on activity.

Participant 12 Date administered: January 2, 1979

Post-injury Activity (pre-program participation)

Always (once a week or more)

1. TV viewing
2. Reading

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times during period)

1. Play cards, other indoor games

Rarely (one to five times during period)

1. Going to watch sporting events

Never (not at all)

1. Working on crafts or hobbies
2. Going to church (or religious activities)
3. Going to a party
4. Visiting with relatives, neighbors, friends
5. Going to classes or lectures
6. Going to a service organization meeting
7. Going out to a restaurant
8. Going on picnics
9. Going to fairs, museums, exhibits, etc.
10. Going to the movies
11. Going to the beach
12. Participating in sporting events
13. Going to concerts, plays, etc.
14. Shopping (except for groceries)
15. Going to club meetings
16. Taking pleasure drives
17. Going to nightclubs, bars

Participant 12 (cont.) Date administered: January 2, 1979

Pre-injury Activity (previous year)

Always (once a week or more)

1. Working on crafts or hobbies
2. Reading
3. Visiting with relatives, neighbors, friends

Routine (every two or three weeks)

1. Participating in sporting events

Occasionally (half dozen to a dozen times all year)

1. TV viewing
2. Shopping (except for groceries)
3. Going to restaurants
4. Going to fairs, museums, exhibits, etc.
5. Going to watch sporting events
6. Going to the movies
7. Going to church (or religious activities)
8. Going to a party
9. Going to nightclubs, bars
10. Going to the beach

Rarely (one to five times during year)

1. Play cards, other indoor games
2. Going to concerts, plays, etc.
3. Going on a picnic

Never (not at all)

1. Going to a service organization meeting
2. Going to classes or lectures
3. Going to club meetings
4. Taking pleasure drives

Participant 12 (cont.) Date administered: January 2, 1979

Comfort Inventory (pre-program participation)

Not at All

(all activities except going to the beach which
was placed in the "Somewhat" category)

Participant 12 (cont.) Date administered: January 2, 1979

Social Situations (pre-program participation)

Situation #1

A.

1. Wheelchair accessibility? (where sitting; are there elevators; parking)
2. Will I have someone to help me?
3. Transportation?

B.

1. Call facility.
2. Work out arrangements with friends, relatives, etc.

Situation #2

A.

1. Check with Community Planning Boards.
2. Check with "Y"
3. Check with local community organizations.
4. Check with organizations that plan trips.
5. Check with people in neighborhood, friends, relatives.

Situation #3

A.

1. What activities am I interested in?
2. How well could I participate in it?
3. Is activity available in nearby location?

B.

1. Check with Community Centers.
2. Check with local clubs and organizations.
3. Check with local schools.

Participation 13 Date administered: January 3, 1979

Post-injury Activity (pre-program participation)

Always (once a week or more)

1. Participating in sporting events

Routine (every two or three weeks)

1. Visiting with relatives, neighbors, friends
2. Play cards, other indoor games

Occasionally (half dozen to a dozen times during period)

1. Going to church (or other religious activities)
2. Shopping (except for groceries)
3. Taking pleasure drives
4. Going to nightclubs, bars
5. Going out to a restaurant
6. TV viewing
7. Reading
8. Going to the movies

Rarely (one to five times during period)

1. Going to a party
2. Going to the beach
3. Working on crafts or hobbies
4. Going on picnics

Never (not at all)

1. Going to club meetings
2. Going to fairs, museums, exhibits, etc.
3. Going to concerts, plays, etc.
4. Going to watch sporting events
5. Going to a service organization meeting
6. Going to classes or lectures

Participant 13 (cont.) Date administered: January 3, 1979

Pre-injury Activity (previous year)

Always (once a week or more)

1. TV viewing
2. Working on crafts or hobbies
3. Going out to a restaurant
4. Going to the beach
5. Going to nightclubs, bars
6. Taking pleasure drives

Routine (every two or three weeks)

1. Visiting with relatives, neighbors, friends

Occasionally (half dozen to a dozen times all year)

1. Participating in sporting events
2. Going to the movies

Rarely (one to five times during year)

1. Going to watch sporting events
2. Going to a party
3. Shopping (except for groceries)
4. Going to church (or other religious activities)

Never (not at all)

1. Going to club meetings
2. Going to concerts, plays, etc.
3. Going to fairs, museums, exhibits, etc.
4. Play cards, other indoor games
5. Going to a service organization meeting
6. Going on picnics
7. Reading
8. Going to classes or lectures

Participant 13 (cont.) Date administered: January 3, 1979

Comfort Inventory (pre-program participation)

Not at All

(all activities except going to the beach and taking pleasure drives which were placed in the "somewhat" category)

Participant 13 (cont.) Date administered: January 3, 1979

Social Situations (pre-program participation)

Situation #1

A.

1. Wheelchair accessibility? (ramps; width of doors; accessible bathrooms)

B.

1. Call facility.
2. Contact friends who might have been there.
3. Contact rehabilitation centers.

Situation #2

A.

1. See social worker.

Situation #3

A.

1. Can I do it?
2. Transportation?
3. Contact friends to see if they want to come along.
4. Costs?

B.

1. Telephone facility.

APPENDIX C

Participant 4

Date administered: May 1, 1979

Post-program Activity (post-program participation)Always (Once a week or more)

1. TV viewing
2. Reading
3. Participating in sporting events

Routine (every two or three weeks)

1. Shopping (except for groceries)

Occasionally (half dozen to a dozen times during period)

1. Going out to a restaurant
2. Taking pleasure drives

Rarely (one to five times during period)

1. Visiting with relatives, neighbors, friends
2. Going to a service organization meeting
3. Going to the movies
4. Going to concerts, plays, etc.
5. Going to watch sporting events
6. Going to nightclubs, bars
7. Going to club meetings

Never (not at all)

1. Going to classes or lectures
2. Going to a party
3. Going to church
4. Working on crafts
5. Going on picnics
6. Going to fairs, museums, exhibits, etc.
7. Going to the beach
8. Play cards, other indoor games

Participant 4 (cont.) Date administered: May 1, 1979

Comfort Inventory (post-program participation)

Not at all

(all activities)

Participant 4 (cont.) Date administered: May 1, 1979

Social Situations (post-program participation)

Situation #1

A.

1. Is the facility accessible? (steps; bathroom; parking)
2. Do you have to get tickets in advance?

B.

1. Call facility.
2. Speak to someone who has been there.

Situation #2

A.

1. Look in newspaper for local activities.
2. Call hospital to speak to patients who may have been there.
3. Get on mailing lists of community agencies.

Situation #3

A.

1. Read service organization's bulletins
2. Ask others who are disabled what is available.
3. How often do you have to go?
4. Is there accessible parking?
5. Accessibility of facility?

B.

1. Ask individuals who have participated in activity.
2. Call service organizations.
3. Read service organization bulletins.

Participant 13

Date administered: May 4, 1979

Post-program Activity (post-program participation)Always (once a week or more)

1. TV viewing
2. Reading
3. Participating in sporting events
4. Going to the movies

Routine (every two or three weeks)

1. Play cards, other indoor games

Occasionally (half dozen to a dozen times during period)

1. Visiting with relatives, neighbors, friends

Rarely (one to five times during period)

1. Shopping (except for groceries)
2. Going to fairs, museums, exhibits, etc.
3. Going out to a restaurant
4. Going on picnics
5. Going to a party
6. Going to classes or lectures

Never (not at all)

1. Going to church
2. Going to club meetings
3. Taking pleasure drives
4. Going to nightclubs, bars
5. Going to watch sporting events
6. Going to concerts, plays, etc.
7. Going to the beach
8. Going to a service organization meeting
9. Working on crafts or hobbies

Participant 13 (cont.) Date administered: May 4, 1979

Comfort Inventory (post-program participation)

Not at All

(all activities)

Participant 13 (cont.) Date administered: May 4, 1979

Social Situations (post-program participation)

Situation #1

A.

1. Wheelchair accessibility? (steps; ramps)
2. Costs?
3. Time of activity? (in order to prepare for participation)
4. Parking?

B.

1. Call the facility

Situation #2

A.

1. Call service organization.
2. Call friends.
3. Call social workers at hospital.
4. Look in newspapers.

Situation #3

(see above)

Participant 11 Date administered: May 10, 1979

Post-program Activity (post-program participation)

Always (once a week or more)

1. Working on crafts or hobbies
2. Reading
3. TV viewing

Routine (every two or three weeks)

1. Going to club meetings
2. Visiting relatives, neighbors, friends
3. Going to a service organization meeting

Occasionally (half dozen to a dozen times during period)

1. Shopping (except for groceries)

Rarely (one to five times during period)

1. Going to church
2. Going to concerts, plays
3. Going to fairs, museums, exhibits, etc.
4. Play cards, other indoor games
5. Going to restaurants

Never (not at all)

1. Going to movies
2. Going to classes or lectures
3. Watching sporting events
4. Participating in sporting events
5. Going to nightclubs, bars
6. Taking pleasure drives
7. Going on picnics
8. Going to the beach
9. Going to parties

Participant 11 (cont.) Date administered: May 10, 1979

Comfort Inventory (post-program participation)

Not at All

1. Going to club meetings
2. Going to church
3. Going to classes, etc.
4. Watch sporting events
5. Going to concerts, plays
6. Shopping (except for groceries)
7. Visiting relatives, neighbors, friends
8. Play cards, other indoor games
9. Working on crafts, hobbies
10. Going on a picnic
11. Going to the beach
12. Reading
13. TV viewing
14. Going to a service organization meeting

Somewhat

1. Going to movies
2. Going to nightclubs, bars
3. Going to fairs, museums, exhibits, etc.
4. Going to a restaurant
5. Going to a party

A Little

1. Taking pleasure drives

Very

-

Extremely

1. Participating in sporting events

Participant 11 (cont.) Date administered: May 10, 1979

Social Situations (post-program participation)

Situation #1

A.

1. Accessibility? (stairs; ramps; seating; aisles)
2. Transportation?
3. Length of event?
4. Alternative activities in case of poor weather?

B.

1. Call facility.
2. Speak to people who have been there.

Situation #2

A.

1. Read local newspaper.
2. Join organizations that schedule or announce events.
3. Join theater groups.
4. Speak to people in similar situations.
5. Call organizations servicing the physically disabled.

Situation #3

A.

1. Examine time schedule of activity.
2. What can I get to without transportation?
3. Who could I invite to apartment who might have similar hobbies?

B.

1. Speak to people active in community in similar activities.
2. Check in local paper.
3. Call veterans organizations.

Participant 6

Date administered: May 16, 1979

Post-program Activity (post-program participation)Always (once a week or more)

1. Play cards, other indoor games
2. Working on crafts, hobbies
3. Reading
4. TV viewing

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times during period)

1. Shopping (except for groceries)
2. Going to a restaurant

Rarely (one to five times during period)

1. Visiting with relatives, neighbors, friends
2. Taking pleasure drives

Never (not at all)

1. Going to movies
2. Going to club meetings
3. Going to church
4. Going to classes, lectures
5. Watch sporting events
6. Participate in sporting events
7. Going to nightclubs, bars
8. Going to concerts, plays
9. Going to fairs, museums, exhibits
10. Going on a picnic
11. Going to the beach
12. Going to a party
13. Going to a service organization meeting

Participant 6 (cont.) Date administered: May 16, 1979

Comfort Inventory (post-program participation)

Not at All

1. Play cards, other indoor games
2. Work on crafts, hobbies
3. Taking pleasure drives
4. Reading
5. TV viewing
6. Visiting with relatives, neighbors, friends

Somewhat

1. Going to church
2. Watch sporting events
3. Going to nightclubs, bars
4. Going to concerts, plays
5. Going to fairs, museums, exhibits
6. Shopping (except for groceries)
7. Going on a picnic
8. Going to a restaurant

A Little

1. Going to club meetings
2. Participate in sporting events
3. Going to a party

Very

1. Going to movies
2. Going to classes or lectures
3. Going to a service organization meeting

Extremely

1. Going to the beach

Participant 6 (cont.) Date administered: May 16, 1979

Social Situations (post-program participation)

Situation #1

A.

1. Accessibility? (steps; doors)
2. Parking?
3. Who would drive?

B.

1. Ask people who have been there.
2. Call facility.

Situation #2

A.

1. Call service organization.

Situation #3

A.

1. Transportation?
2. Architectural barriers?
3. How comfortable will I feel participating?

B.

1. Call place regarding architectural barriers.
2. Call relative regarding transportation.

Participant 3

Date administered: June 26, 1979

Post-program Activity (post-program participation)

Always (once a week or more)

1. Reading
2. TV Viewing

Routine (every two or three weeks)

-

Occasionally (half dozen to a dozen times during period)

1. Visiting with relatives, neighbors, friends
2. Play cards, other indoor games

Rarely (one to five times during period)

1. Working on crafts, hobbies
2. Going to a party

Never (not at all)

1. Going to movies
2. Going to club meetings
3. Going to church
4. Going to class, lectures
5. Going to watch sporting events
6. Participate in sporting events
7. Going to nightclubs, bars
8. Going to concerts, plays
9. Going to fairs, museums, exhibits
10. Shopping (except for groceries)
11. Taking pleasure drives
12. Going on a picnic
13. Going to the beach
14. Going to a restaurant
15. Going to a service organization meeting

Participant 3 (cont.) Date administered: June 26, 1979

Comfort Inventory (post-program participation)

Not at all

(all activities)

Participant 3 (cont.) Date administered: June 26, 1979

Social Situations (post-program participation)

Situation #1

A.

1. Contact someone to help get into the building.
2. Contact facility re: ramps; elevators; available assistance; seating?
3. Transportation?
4. Eating facilities?
5. Telephone facilities?
6. Medical aides availability?

B.

1. Telephone facility.
2. Obtain brochures on activities.
3. Contact senior citizens groups.

Situation #2

A.

1. Contact public library.
2. Contact senior citizens groups.
3. Contact social organizations in local area.
4. Contact other disabled individuals in the area.
5. Contact service organizations.

Situation #3

A.

1. What is wheelchair accessible?
2. Are medical attendants available?
3. Transportation?
4. What is available in community?

B.

1. Contact colleges, public schools; city information bureau.
2. Look in local newspapers.
3. Listen to TV and radio shows that announce programs.
4. Call museums and theaters.

Participant 10

Date administered: June 26, 1979

Post-program Activity (post-program participation)Always (once a week or more)

1. Going to church
2. Playing cards, other indoor games
3. Reading
4. Going to a restaurant

Routine (every two or three weeks)

1. Visit relatives, friends, neighbors
2. Taking pleasure drives
3. TV viewing

Occasionally (half dozen to a dozen times during period)

1. Shopping (except for groceries)

Rarely (one to five times during period)

1. Going to movies
2. Going to a service organization meeting
3. Going to classes, lectures
4. Going to concerts, plays
5. Going to fairs, museums, exhibits
6. Going to a party

Never (not at all)

1. Watch sporting events
2. Participate in sporting events
3. Going to nightclubs, bars
4. Working on crafts, hobbies
5. Going on a picnic
6. Going to the beach
7. Going to club meetings

Participant 10 (cont.) Date administered: June 26, 1979

Comfort Inventory (post-program participation)

Not at All

1. Going to movies
2. Going to church
3. Watch sporting events
4. Participate in sporting events
5. Going to concerts, plays
6. Going to fairs, museums, exhibits
7. Shopping (except for groceries)
8. Visiting relatives, neighbors, friends
9. Playing cards, other indoor games
10. Working on crafts, hobbies
11. Going to the beach
12. Reading
13. TV viewing
14. Going to a restaurant

Somewhat

1. Going to classes, lectures
2. Going to nightclubs, bars
3. Taking pleasure drives
4. Going to a party
5. Going to a service organization meeting
6. Going to club meetings
7. Going on a picnic

A Little

-

Very

-

Extremely

-

Participant 10 (cont.) Date administered: June 26, 1979

Social Situations (post-program participation)

Situation #1

A.

1. Emergency exits?
2. Accessible bathrooms?
3. Accessible eating facilities?
4. Architectural barriers outside facility?
(streets, curbs)
5. Parking?

B.

1. Call other disabled individuals regarding their experiences.
2. Call facility

Situation #2

A.

1. Contact Chamber of Commerce
2. Ask neighbors
3. Contact local churches

Situation #3

A.

1. How does my daily care schedule fit in with schedule of activity?
2. Transportation?
3. Architectural and climactic barriers?

B.

1. Look in local newspapers.
2. Contact facility.
3. Contact other disabled individuals.

APPENDIX D

Evaluation Questionnaire

(Administered informally to participants at the conclusion of the program, for general feedback.)

1. What was valuable for you about the program?
What would you have wanted done differently?
2. What did you think of the process of group meetings aimed at planning community trips?
3. What would you think of having the Recreation Service plan trips for you?
4. Why would it be important for the hospital to run this program for outpatients?
5. Do you think it would have been enough to focus on use of community social resources while an inpatient?
6. What are the advantages or disadvantages of going on community trips with other individuals with spinal cord injuries?
7. Should the group have consisted of a larger, or smaller number of participants?
8. What is your overall assessment of the program?

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