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Attendant Care and Occupational Therapy

Barbara Barrett Lucas

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ATTENDANT CARE AND OCCUPATIONAL THERAPY

by

Barbara Barrett Lucas

A Thesis
Submitted to the
Faculty of The Graduate College
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requirements for the
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ATTENDANT CARE AND OCCUPATIONAL THERAPY

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Western Michigan University, 1984

The purpose of this study was to explore the current status and future potential of the relationship between attendant care and occupational therapy. Survey results showed that a large number of occupational therapists are involved in attendant care, both in rehabilitation facilities and in independent living centers, and that there is potential for an increase of occupational therapy involvement in attendant care.
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Barbara Barrett Lucas
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# TABLE OF CONTENTS

ACKNOWLEDGEMENTS ......................................................... ii
LIST OF TABLES .............................................................. v

Chapter

I. STATEMENT OF THE PROBLEM ........................................ 1

II. REVIEW OF THE LITERATURE ........................................ 3
    Attendant Care and Independent Living. ....................... 3
    Attendant Care and Occupational Therapy ..................... 10
    Reasons for this study ........................................... 52

III. RESEARCH QUESTIONS ................................................ 53

IV. DESIGN AND METHODOLOGY ........................................... 54
    Samples ............................................................ 54
    Instrumentation .................................................... 57
    Procedure .......................................................... 58
    Data Analysis ....................................................... 58

V. RESULTS AND DISCUSSION ............................................. 59
    Survey of Occupational Therapists at Rehabilitation Facilities . 59
    Survey of Centers for Independent Living ..................... 73

VI. CONCLUSION AND RECOMMENDATIONS ................................ 82
    Attendant Care and Occupational Therapy--Practice ........... 82
    Attendant Care and Occupational Therapy--Theory ............. 84
    Attendant Care and Occupational Therapy--Education .......... 85

iii

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APPENDICES

A. Attendant Care Needs Analyses ......................... 86
B. Creating PCA Jobs--Recommendations ..................... 87
C. Attendant Management as a Occupational Therapy Modality 89
D. Survey of Occupational Therapists ..................... 95
E. Survey of Centers for Independent Living ............. 100
F. Definitions of Terms .................................... 105

BIBLIOGRAPHY ............................................ 106
LIST OF TABLES

1. Questions #2 & #4: What are the sources of attendants in your community? .............................. 62
2. Questions #2 & #4: Frequencies of sources as listed by respondents .............................. 63
3. Question #7: Do you feel that your community has enough attendant care programs to meet the need? .............................. 63
4. Question #8: What are the payment sources for attendant care in your community? .............................. 64
5. Question #10: Occupational therapists provision of attendant care support services .............................. 69
6. Question #6: Reasons for not providing attendant recruitment, screening, training, placement, and follow-up . 71
7. Question #15: Services provided by CIL’s .............................. 74
8. Question #16: What subject areas are included in your attendant training course? .............................. 75
9. Question #20: CIL’s perception of the appropriateness of OT involvement. .............................. 78
CHAPTER I

INTRODUCTION

Statement of the Problem

"Attendant care services are those performed by an attendant when assisting a severely disabled person in bathing, dressing, grooming, toilet care, and other activities of daily living" (DeJong & Wenker, 1979, p. 477). DeJong and Wenker estimated that in 1977, about 2.9 million adult Americans needed assistance with personal care. Their figure was based on national surveys (see Appendix A) which indicated that about 1.1% of all working age adults and about 6.5% of all elderly need personal care assistance.

There are people who live in institutions or residential care facilities who may have the potential for living independently in the community with the support of an attendant. There are others who live alone who attempt to manage on their own, without an attendant. A study by DeJong (1977a) found that in these situations, the "absence of additional help dramatically increases the risk of future institutionalization". The study also found that although in Massachusetts most people did have someone available to help them with personal care, "Usually that person is another household member" (p. 6). The study points out that relying on family members can result in a high amount of stress within the family. And, receiving free help from family or friends puts the handicapper in a dependent role, as opposed to the more independent role of directing a paid employee to provide the care. A person who is physically unable
to perform self-care tasks can gain control over this important aspect
of his or her life by employing and directing an attendant to provide
personal care assistance.

There is an emphasis in occupational therapy theory on
helping clients to achieve independence and control in the realms
of self-care, work, and leisure. Until a 1984 article by Neistadt
and Marques, there had been no discussion in the occupational
therapy literature concerning the role of occupational therapists
in helping persons who need attendant care in order to achieve
control over their self-care.

Administration of attendant care programming may be an
appropriate service that occupational therapy can offer to certain
groups of disabled persons. Also, attendant care may be an
important consideration in the treatment planning for the
recipients of occupational therapy services.

This study seeks to answer the question: What is the current
status and future potential of the relationship between attendant care
and occupational therapy?
CHAPTER II

REVIEW OF THE LITERATURE

Attendant Care and Independent Living

The Independent Living Movement

The "independent living" movement has promoted attendant care as an alternative to family or institutional help. DeJong (cited in Sigman, 1980, p. 67) has defined the independent living movement as "the process of translating into reality the theory that, given appropriate supportive services, accessible environments, and pertinent information and skills, severely disabled individuals may actively participate in all aspects of society."

A review of the writings of such independent living movement proponents as Cole (1979), Crewe (1979), DeJong (1979), DeJong and Wenker (1979), and Rice, Roeasler, Greenwood, and Frieden (1983) reveals that the philosophies embodied in the independent living movement arose from various other recent social movements. The current trend towards deinstitutionalization has contributed to independent living's goal of making community life possible for more disabled people. The civil rights movement has fostered the idea that community life is not just an ideal, but is a person's right, and that barriers to this life must be removed. The consumer, self-help, and demedicalization movements have promoted the concept that disabled persons can learn to take on responsibility for their own health and welfare and should avoid
unnecessary reliance on medical professionals.

Title VII of the 1978 amendments to the Rehabilitation Act of 1973 authorizes grants for the establishment and operation of Independent Living Centers (also called "Centers for Independent Living"). DeJong (cited in Sigman, 1980, p. 67) defines an Independent Living Center as "a community-based, non-profit, non-residential program which is controlled by the disabled consumers it serves, provides directly or coordinates indirectly through referral those services which assist severely disabled individuals to increase personal self-determination and to minimize unnecessary dependence upon others." In the Rehabilitation Act, attendant care is specified as one of the five core services which the independent living centers must make every effort to provide.

It is appropriate that attendant care is mandated as a core service, because it is considered by proponents of the movement to be basic to independent living ideals. Without an attendant, (or personal care attendant [PCA]), deinstitutionalization is impossible for many disabled persons. In a survey of 131 rehabilitation agencies in the United States, 71% had clients living in institutions that they felt could make the transition to independence if they had attendant care (Thornock, Hutchins, Meyer, Kenyon, & Williams, 1978). In another study of working-age adults living in care facilities, two-thirds of the 37 people surveyed said they felt they could leave their facility if they had attendant care (DeJong, 1977a). In his 1980 article on home health care, Shritter says: "The United States Accounting Office has
submitted three consecutive reports over the last six years indicating that 30% to 40% of patients in nursing homes could safely and effectively be treated in the home".

Without an attendant, the civil right of participation in the community may not be attainable for those who need help to get out of bed and dressed every day. Title V of the Rehabilitation Act establishes a civil rights provision for handicapped persons which makes barriers in architecture, transportation, employment and education illegal. In reviewing the literature, the question seems to be: What good are jobs and a barrier-free environment if a person is unable to get out of the house?

Independent living proponents (as cited earlier) feel that personal care assistance from the medical world (institutions or home health agencies) can infringe upon the handicapper’s responsibility for decisions concerning his or her health care, because of the emphasis placed on nurse and/or doctor supervision. Thus, the goals of consumerism, self-help, and demedicalization can not be attained. Although nurse or physician supervision is necessary in some cases, independent living writers feel that all too often the on-going presence of medical professionals in a handicapped person’s life unnecessarily places the person in a "sick" role. A principle of the independent living movement is that if a handicapped person’s condition is stable, then it is he or she, and not the medical world, who is in the best position to make decisions about his or her own health care needs.

To be in accordance with the ideal of the independent living
movement that handicapped persons be in control of their attendant care, attendant care services should be supportive, rather than directive. Services which can be offered are attendant referral lists which compile names of persons seeking employment as attendants, training programs provided to prospective attendants in personal care techniques and independent living philosophies, and attendant management training for handicappers in how to recruit and supervise attendants. With these services, ultimate responsibility and control remains in the hands of the handicapped employer. This is in contrast to home health agency services in which the handicapper is provided with home health aides who are hired and trained by the agency.

To avoid dependence on services, goal-setting is often a part of the program of a Center for Independent Living (CIL). For instance, a CIL in Colorado requires that clients work with CIL staff members to develop an individualized growth plan (Page, 1981). This process calls for assessment and goal-setting with the objective of total independence in the attendant care process. The growth plans are reviewed and revised periodically to assure progress towards this goal.

Types of attendant care

The physical condition of the disabled person helps to determine the type of assistance needed. A person who is recovering at home from an accident or illness after hospitalization often needs only temporary care, until the acute condition has stabilized. These
Persons with acute needs are not the focus of this exploration, as their conditions usually necessitate "skilled care" (skilled care is used here to refer to the performance of procedures that require the specialized skills of medical personnel). The focus of this exploration is on those people for whom skilled care is not necessary—people who have permanent or chronic disabling conditions which have stabilized, and who need ongoing assistance.

The age and cognitive ability of a person influences the type of care needed. Persons who are unable to live independently due to cognitive deficits (e.g. a developmentally disabled adult), or age (e.g. a handicapped child), may need intervention oriented towards helping family members to provide care. This can be in the form of respite care, which is planned, intermittent, short-term care designed to provide periodic relief to the family and/or the caregiver from 24 hours of continuous care (Hasselkus & Brown, 1983). The primary focus of this study is on persons who have the intellectual potential to live independently and to direct their own attendants. To manage attendants, a person must be able to identify what he or she needs, and then to convey this to others.

Some handicapped persons live in small group living situations in which one or more attendants are shared. Others live alone, but in close proximity to other handicappers in clustered housing arrangements, to allow the sharing of attendants. Some people elect to have a live-in attendant, often in combination with part-time attendants (to provide relief to the live-in helper). Others live with family members, but avoid a position of dependency on the family by hiring attendants.
Attendants are commonly needed for a few hours twice daily, to help with getting up and with going to bed. Some people have conditions which require an attendant to be present 24 hours, so that help is available in case of emergency. Others need assistance only intermittently, such as in changing position periodically throughout the night to avoid decubiti.

The tasks performed by attendants generally fall into two areas: personal care and housekeeping. According to a 1978 study by Hutchins, Thornock, Lindgre, and Parka which surveyed 21 attendants, the personal care activities most frequently performed included getting the employer into and out of bed, dressing, assisting with bowel and bladder programs, and bathing. The most frequent housekeeping activities reported were preparing and serving meals, and cleaning and straightening up the house. It was also common for attendants to accompany their employers on errands and to medical appointments, and to provide transportation to jobs or schools.

Status of attendant care today

The national profit and non-profit home health care system is growing. Marshall and Kerr (1981) point to the transition from acute hospital care to home care, and attribute it to the lower costs of home care and the trend towards deinstitutionalization. Home health care agencies are obviously fulfilling an important need by providing skilled, temporary care that is less expensive than institutional care. But due to overhead costs, personal care services contracted through a home health agency will necessarily
be more expensive than those contracted directly between the handicapped employer and the attendant. When skilled care is not needed, home health agencies become a costly source of attendant care. It is important that alternatives to home health agency care be developed.

From the number of federal, state, and university handicapper needs analyses that have been performed, it is apparent that the need for attendant care is being recognized as a valid concern (see Appendix A). Attendant care manuals and training guides (for both attendants and their handicapped employers) have been published by universities (Larson & Snoble, 1978), and by the Institute for Rehabilitation and Research (Cole, Sperry, Board & Frieden, 1979, 1980a, 1980b, 1980c). Several studies (to be discussed later) have been completed which survey attendants’ attitudes about their jobs, to gain insight into the causes of high attendant turnover rates (Atkins, Meyer & Smith, 1982; Stelmack, Postma, Goldstein & Shepard, 1981).

Less than half of the 75 CIL’s in a directory compiled in 1979 (AOTA, 1982) were noted to provide services related to attendant care (note that although this was a nationwide list, no reference to its completeness was found). Throughout the independent living literature the unavailability of adequate attendant care services is lamented. A study by Thornock et al. (1978) surveyed 131 rehabilitation institutions in the United States. The authors say:

Over 85 percent of the respondents indicated that attendant care was extremely or very important to disabled clients in the following areas: promoting independence, maintaining higher morale, maintaining restored physical condition, decreased hospitalization, and better overall health... Additional benefits in two areas were mentioned by some
respondents: reducing the necessity of institutionalizing disabled persons...and reducing the burden to families. (p. 148).

The authors go on to say:

Respondents suggested a number of possible solutions to the attendant care problem: more funding, better training for attendants, innovative programs, public education regarding the needs of the disabled, expansion of current agency services to include attendant services, needs surveys, political activism, and shared housing arrangements. (p. 151)

The data shows that the personnel are well aware that attendant care is a critical support for independent living among severely disabled people. Yet, most of the agencies do not involve themselves in providing any type of formalized access to attendants for their clients (Thornock, et al., 1978).

Attendant Care and Occupational Therapy

The relevance of attendant care to the field of occupational therapy

The goals of occupational therapy mesh well with those of the independent living movement. According to Rice, et al. (1983), "independent living emphasizes freedom of choice, personal control of one's life, and participation in significant roles of worker, homemaker, and provider" (p. 3). In the "Essentials of an Accredited Educational Program for the Occupational Therapist" (American Occupational Therapy Association [AOTA], 1983a), a description of occupational therapy includes this statement: "Its fundamental concern is the development and maintenance of the capacity throughout the life span to perform with satisfaction to self and others those tasks and roles essential to productive living and to the mastery of
self and the environment" (p. 817). The "Essentials" go on to say:
"...its concern is with factors which serve as barriers or impediments
to the individual's ability to function". Thus, like the independent
living movement, occupational therapy is concerned with freedom of
choice (reduction of barriers to function), personal control (mastery
of self and environment), and participation in roles of worker,
homemaker, and provider (performance of tasks and roles essential to
productive living).

Having established these basic philosophical similarities, the
occupational therapy literature was reviewed for discussion of
attendant care. This review included five books which relate to
occupational therapy theory and treatment for physical dysfunction
(Kielhofner, 1983; Mosey, 1981; Pedretti, 1981; Reed & Sanderson,
1980; and Trombley, 1983). Also reviewed were all issues of the
American Journal of Occupational Therapy from 1979 to the present,
the "Standards of Practice for Occupational Therapy" (AOTA, 1983c),
the "Standards of Practice for Occupational Therapy Services in a
Home Health Program" (AOTA, 1978), and "The Roles and Functions of
Occupational Therapy Services for the Severely Disabled" (AOTA,
1983b).

A 1984 article by Neistadt and Marques was found which
directly addresses the role of occupational therapists in
coordinating an independent living skills training program which
includes attendant management training. No other discussion of
attendant care was found in the occupational therapy literature.
Attendant care is a relatively new concept, which came about with

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the birth of the independent living movement in the mid-60's.

Although it appears that in the past occupational therapy has not emphasized attendant care, the article by Neistadt and Marques may mark the beginning of occupational therapy recognition of the importance of attendant care, and its appropriateness to the field.

The following discussion explores components of the attendant care and occupational therapy processes, to analyze the potential for increased occupational therapy involvement in this area.

Adaptation through interaction with the environment

A key strategy of the occupational therapy process is facilitating the client's control of the external environment. Johnson and Kielhofner (1983) say: "The occupational therapist is concerned with the ability of individuals to competently interact with the environment" (p.186). The "Essentials of an Accredited Educational Program for the Occupational Therapist" (AOTA, 1983a) also mention the occupational therapy concern with mastery of the environment. Because an attendant is a part of the handicapped employer's environment, perhaps the process of learning how to competently hire and direct attendants to provide self-care can be viewed as a therapeutic adaptation gained through interaction with and mastery of the environment.

Occupational therapy literature does not emphasize the use of the human environment as a therapeutic adaptation. Although Mosey (1973) does mention that humans have a mastery need which includes the desire to exert some control over other people, she limits herself to the
non-human environment when discussing the occupational therapy process: "Fundamental to the practice of occupational therapy is concern for and use of the non-human environment" (p. 3), and "The occupational therapist is concerned with helping clients to become adept in manipulating the non-human environment" (p. 8). A discussion of therapeutic adaptations in the "Essentials" is also limited to non-human environmental elements only (e.g. environmental adjustments, orthotics, assistive devices and equipment). Occupational therapy is a humanistic field, and perhaps the utilization of the non-human environment only is an unnecessary, self-imposed boundary.

**Technology versus humanism**

Occupational therapy appears eager to incorporate the therapeutic equipment and technology that is available on the market into its scope of practice. Zisserman (1981) says:

Facilitating adaptive responses is the key to placing many handicapped persons in the occupational mainstream, but as chronic disabilities become more sophisticated and severe, therapists must provide more sophisticated adaptive equipment. This implies the need for more technological education for therapists who must design and construct this equipment. (p. 17)

In a sense, this writer is acknowledging the fact that the more disabled a person is, the more difficult it is to design a substitute for human capabilities. But is the technological area the only direction in which occupational therapy should grow?

Laukaran (1977) discusses Reilly’s belief that the "over-mechanization" of the profession has produced therapists that are "accustomed to substituting the technological for the humanistic and
interpersonal aspects—the latter the essential roots of occupational therapy" (p. 71). Discussing the future of health care as it relates to occupational therapy, Gray (1983) says: "We will have a greater need for close interaction or high-touch as a compensation for increased technology. Interaction with other people must remain an important part of any delivery system, particularly the health care delivery system" (p. 528). Using an attendant would seem to easily qualify as a "high-touch" method of adaptation to disability.

It should be kept in mind that the use of human versus non-human aid need not be an either-or proposition. Severely handicapped persons who benefit from the use of complicated equipment may need assistance in its set-up and maintenance, as well as needing personal care assistance that only human help can provide. Trombley (1983, p. 396) mentions the need of quadriplegics for on-going assistance in both equipment and personal care areas.

**Human assistance and the question of independence vs. dependence**

There are differences in the ways in which occupational therapy and independent living writers discuss independence and dependence as they refer to the use of human assistance. The occupational therapy literature tends to associate the use of human assistance with dependence. This can be seen from the following quote from Malick and Sherry (1978):

"The loss of independence in these basic [daily living] activities has a traumatic effect on body image and may also affect those persons associated with the patient... Dependency in self-care is often the first sign of depression or the major cause of depression...a chronically disabled person who can be independent in self-care."
activities requires far less custodial care and thus can be
cared for in a more independent unit in a community setting.
(p. 184)

The following quote by an independent living writer (DeJong,
1977b), is also concerned with the psychological effects of self-care
dependence. But DeJong considers the use of human assistance (in the
form of an attendant) as the key to independence, not dependence:

The management of one’s own personal care is especially
important to one’s sense of independence and self-worth.
Dependence in the care of one’s own body is to renounce much
of one’s sense of personal autonomy and seriously
compromises a person’s willingness to be independent in
other spheres of life. (p. 21)

Both quotes seem to acknowledge that custodial-type care can have
deleterious effects on a person. But the independent living movement
offers attendant care as an alternative, whereas occupational
therapy tends to focus on developing skills so that human assistance
can be avoided. Independent living writers recognize that this is not
always an option for severely handicapped persons.

Writers of independent living literature emphasize that the need
for an attendant is for some people not only necessary, but a
prerequisite to independence in itself. McGwinn (1977) says: "An
attendant can easily be the most important person in a disabled
individual’s life. Without someone to activate his wishes and
intentions, a disabled person can become a non-functioning invalid"
(p. 84). Smith & Meyer (1981) say:

The life-threatening ramifications of PCA’s leaving their
jobs are obvious. Quite simply, if their disabled employers
cannot find replacements, the employers may have to quit
their jobs, sell their homes, give up their independence,
and move into nursing homes just so they can survive.
(p. 260)
A Massachusetts study (DeJong, 1977a) found that for many handicapped persons, attendant care is needed before vocational rehabilitation goals can be attained, thereby being a prerequisite to vocational independence.

A thorough search of the occupational therapy literature does reveal writers who discuss the use of human assistance in a positive light. Maguire (1979), mentions that human assistance can reduce dependence:

As most occupational therapists can attest, the absence of minimal-to-moderate help (such as transportation to the grocery store, or help in cooking or cleaning) can so handicap individuals that they are forced to become more dependent than necessary. (p. 99)

Trombley (1983) discusses the American ethic of "compulsive work achievement, over-independence, and high productivity" (p. 14), and suggests that therapists can help clients to view their diminished capacities in a more positive light, rather than reinforce this "over-independence" ethic:

In severe disability certain components of the dependent role are legitimate and necessary. Kutner discusses the need for the traumatically disabled patient to accept some aspect of a dependent role if he is to be successfully rehabilitated. Feldman describes positive and negative dependency. Depending on the degree of disability a patient needs to be pragmatic and accept care. Patients need to be encouraged in acceptance of positive dependency and permitted to practice those skills and attitudes which will allow receiving help to achieve maximal independence. Feldman states that the patient must learn to ask for help and not feel helpless or inadequate because of his need. (p. 19)

Quality vs. quantity of assistance

The phrase "custodial care" , as used in the quotation cited

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earlier from Malick and Sherry (1978), is often used in the occupational therapy literature in reference to human assistance. As taken from Webster's dictionary, custodial means "relating to guardianship", and a custodian is "one that guards and protects or maintains". The sense of a need for "guardianship" assumes an incompetency in the person needing assistance, thus the use of the phrase "custodial care" may suggest negative connotations to the reader.

The "The Roles and Functions of Occupational Therapy for the Severely Disabled" (AOTA, 1983b) discusses "skill levels" as affecting "the amount of custodial care that will be required" (p. 812). The emphasis is on the amount of care required, rather than the type, or quality of care. Occupational therapy is a field which is concerned with quality of life. As Yerxa (1983) says: "...occupational therapists perceive and value the right to a satisfying life for each person regardless of...disability" (p. 151). It follows that the field should be concerned not only with the quantity, but the quality, of care needed by its clients.

Attendant management as an occupation

Because the term "occupation" implies doing rather than receiving, using human assistance does not at first appear to qualify as an occupational activity. The American Occupational Therapy Association (1983a) refers to "occupation" as the "goal-directed use of time, energy, interest, and attention" (p. 817). Nosey (1981) prefers the phrase "life tasks", and describes
them as "those activities one must be able to perform in order to meet his or her own needs and to be a contributing member of a community" (p. 3). It is suggested here that the question of whether or not using human assistance is an occupation depends on the locus of control, i.e. who is in control of the situation—the handicapped person or the helper/attendant. The phrase "custodial care" implies that the helper is in control of the situation, and is the "doer" who "acts upon" the disabled person. For some people who are severely mentally impaired as well as physically disabled, this form of assistance may be the only option open to them. But independent living writers maintain that many handicappers can learn to manage personal care assistance so that the locus of control is within themselves. McGwinn (1977) states:

A person who is physically dependent must exert sustained effort to develop a sense of self and personal style. It is easy to become as psychologically passive as one is physically passive. The disabled individual is constantly being acted upon physically, his body is moved and positioned, and his tangible environment is moved by others. To retain control of his life and lifestyle under these dependent circumstances, the disabled individual must be almost constantly aware and able to direct his personal care and the running of his home, business, and social life. (p. 85)

Kielhofner (1983) discusses the traditional occupational therapy theme that humans are occupational creatures who derive pride and satisfaction from their occupations. Johnson (1973) acknowledges that occupations provide feedback to persons about their worth and value as individuals. The following quote from McGwinn (1977) shows that pride can be derived from using human assistance in an occupational manner:

You can learn to have enough confidence in yourself and how to take care of yourself so that you can take a stranger off
the street at a moment’s notice and calmly, intelligently explain to that person how to take care of you...You will feel like you’re taking care of yourself through other people’s hands. (p. 98)

Johnson and Kielhofner (1983) discuss enabling clients to gain control of their lives and personal affairs as central to the occupational therapy process. Yerxa (1983) discusses the development of patient autonomy and self-directedness, and enabling the patient to act upon the environment rather than be determined by it as among those factors which contrast occupational therapy values with those of medicine. It seems, then, that helping persons to gain control over their self-care through the employment of attendants is ideally suited to the occupational therapy process.

Social versus physical independence

Reilly (1971) says: “Occupational therapists could stand accused by history of reducing the richness of their humanistic mandates to an ADL self-care list” (p. 244). Independent living writers might agree, as can be seen by this quote from DeJong (1977b):

Traditional medical rehabilitation focuses on personal limitations such as muscle strength, endurance, mobility, and self-care...Success in medical rehabilitation is usually measured by the degree to which a person regains his/her capacity for physical functioning. Maximum physical functioning does not, however, automatically translate into maximum “independence” in matters such as personal care. Nor does needing help from another person automatically constitute “dependence” as these terms are used here. Those who need human assistance can still be independent. For the person who needs human assistance in personal care, maximum independence includes the ability to independently direct a care provider. Thus, there is a social component as well as a physical component to achieving maximum independence in self-care. Independence is more than the absence of need for human or mechanical assistance. While medical rehabilitation has generally been successful in restoring
physical independence, it has not been equally successful in promoting social independence. (p. 80)

Cole, et al. (1980c) describe the independent living movement's definition of independence:

Independent living means accepting adult responsibilities, using good judgement in making decisions, looking at all of the available alternatives and choosing appropriately. In short, independent living requires that the handicapped person be able to have control over his own life and to direct his own affairs as much as possible. (p. 6)

Some writers of current occupational therapy literature are calling for a move away from the physical-function model of health to a more holistic orientation. Rogers (1982) says: "While the disease model favors unitary, external causes, the occupational performance model recognizes multiple and multidimensional causes that may be intrinsic or extrinsic to the client" (p. 32). Johnson and Kielhofner (1983) discuss how occupational behavior and systems theory "greatly enhanced the field's ability to understand how the disease process and recovery is part of the dynamic problem of a much larger system" (p. 189). Johnson (1973), an occupational therapy writer, seems to feel that the "social independence" stressed by the independent living movement should be central to occupational therapy goals:

The crucial test comes when the individual is required to perform in his own social system. If we have fulfilled our responsibilities adequately, the individual should succeed for it will be possible for him and the social system to produce changes and adaptation necessary for compatible coexistence. (p. 3)

Attendant care as a compensatory technique

In a position paper on "The Roles and Functions of Occupational
Therapy Services for the Severely Disabled", AOTA (1983b) lists compensation as one of the three general categories of treatment. The term "severely disabled" is defined as "long-term or permanent physical, cognitive, or emotional impairment that may render the individual totally dependent upon others for performance of self-care activities" (p. 811). Therefore, people who are severely physically disabled but who are intellectually healthy are by definition included in the scope of this paper. Examples are given of compensatory strategies that occupational therapists can use to enable clients "to perform daily living tasks and activities that would not otherwise be possible" (p.813). Managing an attendant is not included here as a compensatory strategy.

The position paper says: "...occupational therapists capitalize upon the remaining functional assets of each individual", and the use of "residual intellectual capacities" are mentioned as assets. The paper does not discuss the fact that many severely handicapped persons have cognitive abilities which can be used to compensate for physical limitations, by directing attendants to provide self-care assistance (rather than to be supervised by "caretakers", as the paper refers to human help).

Compensation for deficits is a recurrent theme in the occupational therapy literature. For instance, Rogers (1982) states: "strengths in the person and in the environment...may be used to compensate for deficits or to develop new strengths" (p. 34). It follows, then, that it is appropriate for occupational therapists to help clients to capitalize on their intellectual ability by directing...
their self-care.

**Attendant care promotes a balance of activity**

Johnson and Kielhofner (1983) discuss the role occupational therapists have in helping clients to achieve a balance of work, play, rest, and leisure, to "assist persons to organize their daily activities, schedules, and routines to maintain physical and emotional endurance and strength while providing meaning and satisfaction and a continuing sense of competence and contribution to family, neighborhood, and other relevant social systems" (p. 190). Discussing occupational therapy, Mendoza (1969) says: "Disability results from an impairment of the biological, psychological or social efficiency of the individual, and prevents him from pursuing normal or usual activities" (p. 142).

The occupational therapy literature tends to view independence in self-care activities as healthy without first assessing the time or energy expended to achieve this self-care independence. It can be seen that self-care activities that disrupt the efficiency of the individual, or the balance of work, play, rest, and leisure, may be unhealthy in a traditional occupational therapy sense. A severely handicapped person who works full-time at employment or at raising a family may not be able to spare the time or physical energy that is necessary for him or her to independently complete self-care tasks.

The following quote from DiJoseph (1982) illustrates how a balance of activity can be more important than self-care independence:
In using motivation in treatment...we must be sure that we are actually motivating patients and not superimposing our motivation upon them. For example, take the 80-year-old "stroke patient", or the 22-year-old patient with a high spinal cord injury who we feel should be capable of independence in ADL. They may have the required motor control, cognitive and perceptual abilities to be independent in the activity of ADL. However, if it takes an hour and a half to complete ADL tasks in the morning and the patient is so exhausted afterward that he or she cannot enjoy meaningful activities such as gardening, needlework, or even soapbox operas, is independence in ADL REALLY a realistic goal? We may have compromised quality of life for quantity of activity--activity that WE as therapists find more meaningful than soap box operas. (p. 742)

This quote also points out the importance of putting a client's goals and values before those of the therapist. This is a recurrent theme in the occupational therapy literature. For instance, Verza (1983) stresses the importance of the patient's perspectives and self-directedness in the occupational therapy process, and Mosey (1981) and AOTA (1983c) discuss evaluation of a client's personal/family goals, and collaboration with the client and family in the planning process.

The creation of options

The achievement of independence for handicapped persons does not only involve the concern with removing barriers to function which AOTA describes (1983a, p. 817). Independence also requires the creation of options, as can be seen from this quote from Cole, et al. (1980c):

Many handicapped adults have related that independence for them means having choices--being able to choose where they live, where they work, how they get from place to place (transportation), how they spend their spare time, and who provides their personal care. (p. 6)

Johnson and Kielhofner (1983) feel that occupational therapists have a
role in promoting independence through options. They say that it is necessary "to identify options whereby the family has some relief from the stress and burdens of caring for a member who is increasingly dependent", and that occupational therapists should intervene "to seek new alternatives", when occupational patterns are disrupted (p. 191).

Because attendant care is a relatively new option for handicapped persons, many handicappers may be relying on their families to provide assistance, not because they prefer it this way, but because they do not know that attendant care can be a viable alternative. Occupational therapists have become involved in promoting respite care as an option for families (Hasselkus and Brown, 1983). In some cases where respite care is currently used, attendant care may be more beneficial to the individual and family.

Attendant care as a therapeutic modality for psychosocial dysfunction

It is not enough for occupational therapists to treat physical dysfunction while leaving family dynamics to other professionals. AOTA (1983 & 1978) includes psychosocial components within the areas to be evaluated and treated by occupational therapists. It follows that it is appropriate for occupational therapists to examine the psychosocial dynamics involved in relying on family members to provide personal care assistance. In some cases living with parents may be the best arrangement for the handicapper and his or her family, but independent living writers appear to feel that the tendency is otherwise. This can be seen in a quote from DeJong and Hughes (1982):

The assessment of living arrangements is particularly difficult in the case of adult children living with parents.
a living arrangement about which the IL [independent living] movement has critical views because of the uncanny ways in which parents often perpetuate natural parent child dependency into early adulthood and beyond. Thus, while living at home may appear less restrictive than living in a nursing home, persons can be equally institutionalized in their own homes when they are made unnecessarily dependent on parents or other household members. (p. 69)

Cole, Sperry, Board, and Frienden (1980c) discuss how it may benefit both the child’s and parent’s mental health to hire an attendant:

Using PCA’s [personal care attendants] at appropriate times can also prevent an overly dependent relationship between the handicapped child and the parent who provides most of his/her care. Not only is it natural for the child to cling to the security of the major care provider, there is also a danger that the parent will depend upon the child to fulfill the parent’s need for purpose and usefulness. (p. 11)

An unhealthy dependency between parent and adult child may make it difficult for an occupational therapist to accomplish treatment goals, as in the following situation related by Mendoza (1969):

...the author began with her an intensive program in personal hygiene, dressing and transfer activities, with the mother assisting...The total rehabilitation of this patient was always a complicated and difficult affair because of her own ambivalent motivation. She accepted help and wanted to be able to perform, yet she would provoke her mother to intervene and thereby prevent pressure from the therapist. The complexity of feelings, responses, and interaction between the therapist, the patient and the family concerning the dependence and independence of this patient could fill many pages. (p. 143)

It may not be necessary for the handicapper to move out of the parents’ house in order to lessen dependence. The following quote from Cole, et al. (1980c) concerns handicappers living with parents:

"By using PCA assistance, they acknowledge that they are able to take care of themselves in an adult manner with adult responsibilities"
rather than maintain a 'child'/parent relationship within the home environment" (p. 10).

DeJong (1977b) notes that for those who have grown up in institutions, this type of life can reinforce the natural dependency of childhood. He recommends, therefore, "that this dependency pattern be broken as early as possible. To that end, PCA services should perhaps begin with 14 or 15 year olds, or perhaps even younger" (p. 75). Cole et al. (1980c) suggest that families with disabled members might hire a PCA on a part-time basis "to provide self-direction practice for the disabled person" (p.11), or to "improve family and interpersonal relationships" (p. 12).

One of the problems with care provided by family members is that it is usually free of charge. This can have many ramifications as is recognized by the White House Conference on Handicapped Individuals (1977):

> Society requires many persons with disabilities to depend on the charity of other people...For example, a person with a disability who is in need of assistance to get in and out of bed must use the services of another individual. When the disabled individual is unable to pay for this service, he/she is dependent on the helpful individual. This type of relationship often fails to enable the disabled individual to get up at the most appropriate time. Rather, the disabled person must structure life around time available for the 'helpful' individual. (p. 326)

Cole, et al. (1977a) would seem to agree with the above when they say:

"When family members provide their care, the handicapped person often feels that he has nothing to say about how that care is given" (p. 4).

McGwinn (1977) says: "...you can be more exacting when you're paying for the service" (p. 80). DeJong (1977a) also recognizes the problems inherent in free, "charitable" help:
A severely dependent person who must rely on the generosity and goodwill of other household members often begins to accept that dependency as the norm for other aspects of life. By having a PCA, the disabled person accepts responsibility for his/her own care that frequently encourages his/her to be independent in other activities of life as well. (p. 7)

Cole, et al. (1980c) discuss how the use of PCA's can help lessen a disabled male's embarrassment when he is reluctant to have his mother or other female perform personal care. These authors also describe how PCA's can be used in marriage situations to reduce the burden on the non-disabled partner. McGwinn (1977) relates the advice that married couples should have attendants do most of the personal care, partly because "your mate will feel less tied down, a feeling which invariably leads to anger, a definite detriment to romance" (p. 80).

All of the discussions concerning the psychological benefit of attendant care over family care were found in the independent living literature. The only comment found in the occupational therapy literature which related to this was from Warren (1974), who alluded to this idea when discussing a volunteer program for the elderly: "...the therapist could develop and coordinate a corps of volunteer drivers...the same offer made by a relative or a friend is often perceived as a loss of independence or as 'being a burden'" (p. 336).

Attendant care as facilitator of occupational roles

The negative feelings involved in receiving free, charitable help as opposed to the positive feelings derived from employing and directing an attendant can be attributed to the difference in roles. Rogers
(1982) discusses how disorder in occupational therapy results from the inability to enact occupational roles. Reilly’s occupational behavior model also stresses the performance of life roles (Laukaran, 1977). Although not referring to attendant management, the following quote from Mendoza (1969) can be used to sum up the way roles relate to attendant care:

Perhaps the most challenging facet of this role as occupational therapist in home care is helping the patient to see himself as a DOER again in the home where, because of his disability and physical limitations, he feels insecure and a burden to his family. (p. 143)

The opportunity to enact proper occupational roles is important in family relationships, where “even as an adult, the disabled person may still feel like a child when his family ‘takes care of him’” (Cole, et al., 1980c, p. 11).

Stresses involved with family care

Several writers have pointed out that the modern American family may not always be capable of assuming total care of the handicapped family member, even if the desire is there. DeJong (1977b) says:

The problem that severely disabled people face is that although their family life may be stable, their family support systems may not be equally stable. To illustrate, a single disabled young adult may have a satisfactory relationship with his/her parents and siblings. However, as family members grow older, parents may become too frail to assist and siblings move on to raise their own families. (p. 33)

Zissersan (1981) discusses how the trend of smaller family size, and possible lack of relatives living nearby, can make it difficult for the family members to provide total care unaided. Citing Litman,
Zisserman says:

Modern medical technology has extended the lives of victims of formerly fatal conditions; however, when chronic disabilities remain, the disabled often return to families that, by their very nature, are ill-equipped to care for them properly: ...the common medical assumption of universal family understanding and preparation for home care would seem to be in need of considerable reassessment. (p. 20)

Zisserman (1981) and Hasselkus and Brown (1983) point out that women have traditionally been the caregivers in the home, and that the women’s movement (with the resulting increased number of women working outside the home) will further affect the availability of family members to provide care. DeJong (1977a) says: "One member caring for another member who is severely dependent may have to give up a career or a job that would enable the family to be independent of public welfare or other public sources of income" (p. 6).

Caring for a severely disabled family member can strain relationships within the family. DeJong (1977a) says: "Divorce and alcoholism are not uncommon among the severely disabled and their families" (p. 7). Unfortunately, abuse can be another result of the pressure and strain. Hasselkus and Brown (1983) discuss a study by Block and Sinnott:

...a majority of their population of abused elders were dependent in self-care tasks. Types of abuse included frequent lack of personal care, misuse of money, verbal assaults, and isolation. Overall, this exploratory study suggests that increased dependency is associated with increased risk of abuse. (p. 190)

Johnson and Kielhofner (1983) and Mosey (1981) discuss the occupational therapist’s responsibility to bring about stress reduction in their clients. In the past, attendant care was not mentioned in the occupational therapy literature as an option to
reduce stress in families (probably because of the lack of funding, lack of programming, and lack of general awareness of attendant care as an alternative). For instance, in all three of the case studies of occupational therapy home care clients which Mendoza (1969) describes, there appears to be a possible need for the hiring of an attendant, but no mention is made of this alternative. The first two studies involve severely handicapped adults who live with elderly mothers. For elderly persons, coping with the diminishing abilities and energies of one's own body can be difficult enough without having to compensate for those of another also. The third study involves a handicapped woman who had lived in a custodial setting but who wanted to return home. Mendoza says: "Her husband was never home and the patient became a prisoner in her own house and a stranger in her neighborhood. The patient returned to the custodial setting where two months later she died of a heart attack" (p. 144).

Kielhofner and Johnson (1983) mention the occupational therapist's responsibility to help a client's family to maintain a balance of activity. The husband in the case study from Mendoza mentioned above is an example of a family member who was not able to discontinue his pattern of activity to shoulder the burden of personal care assistance for his wife. Cole, et al. (1980c) mention that caring for a disabled person can cause family members to ignore their need for leisure time, and to feel guilty or resentful because they are unable to devote time to other family members.
Adapting occupational therapy to a changing world

Writers of occupational therapy literature have noted that "Acute medical conditions have decreased in incidence and prevalence. However, people with permanent handicaps are more common" (Zisserman, 1981), that "in the coming years there may be proportionally fewer jobs in acute new medical facilities due to cost-containment efforts that will reduce the length of inpatient hospitalization" (Baum, 1983, p. 597), and that there may be a "conversion of the occupational therapy services from the hospital to the community" (Reilly, 1971, p. 246). Because of this shift, many writers are calling for the profession to assess community needs, and change to meet these needs (Mendoza, 1969; Reilly, 1971; Walker, 1971; Johnson, 1973; Dunleavy, 1974; Grossman, 1977, Finn, 1972 and 1977, Laukarari, 1977; Baum, 1983; Johnson & Kielhofner, 1983; and Yerxa, 1983).

The independent living movement's attendant care model fits into the larger scheme of the changes our society is experiencing. For instance, several of Naisbitt's (1984) "megatrends" apply to attendant care, such as the shift from institutional help to self-help, and the shift from either/or to multiple options. When Hancock (1982) describes his vision of the ideal future of health care, he lists components which mesh well with those of the attendant care model:

- A focus on prevention rather than cure.
- The teaching of basic self-care skills to all.
- The development of extensive home-care support programs.
- A focus on out-patient rather than in-patient care.
- A de-emphasis of the role of physicians, with a corresponding increase in the role of para-medical workers and new health professional such as community health aides. (p. 13)
Attendant care as prevention

From its inclusion in the policy statements of the national association, (AOTA 1978, 1983a, 1983b, and 1983c), it is clear that the realm of prevention is firmly entrenched within the occupational therapy scope of practice. Thornock, et al. (1978) give a quote from a rehabilitation worker which illustrates how attendant care can prevent physical dysfunction: "Without attendant care, the patient deteriorates at home, goes to hospital, comes home, and [the] cycle of human and economic waste continues" (p. 149).

Attendant care can also prevent psychosocial dysfunction. Maguire (1979), an occupational therapist, recognizes that "the type and degree of assistance required [to keep elderly individuals living at home] might put such a strain on family members that the family's health or welfare might be compromised" (p. 99). It has been discussed how the stress a family can be under when shouldering the total burden of care may contribute to the incidence of divorce, alcoholism, and abuse. Dysfunctions of this type can affect an entire community. By promoting attendant care, occupational therapists can fulfill their mandate to prevent dysfunction on the levels of client, family, and community.

Assessing a community's attendant care needs

It has been established that the occupational therapy literature calls for therapists to assess the needs of their community. If an occupational therapist were to assess a community’s attendant care needs, what elements should be looked for? DeJong (1977b) makes
the following recommendations:

At a minimum, a personal care system should provide for the following elements or tasks:

**Evaluation**-- a mechanism to evaluate the amount of personal care needed by a severely disabled person.
**Recruitment**-- recruitment of personal care providers.
**Selection**-- criteria by which to select a provider from among those recruited.
**Training**-- a care provider needs to be trained by either the disabled person or by another source.
**Supervision**-- supervision of the care provider.
**Back-up**-- a severely disabled person needs more than one provider in the event the principal care provider becomes unavailable.
**Fiscal conduit**-- some means must be provided to channel the funds to the disabled person and ultimately to his/her care provider.
**Organization**-- there must be some mechanism that will link and supervise the various elements of the system.

In addition, the system needs a mechanism to provide leadership in acquiring resources needed to sustain or expand the system. (p. 133)

DeJong points out that these elements of a PCA system do not have to all reside within a single administrative unit, and that the handicapper should be mainly responsible for many of the tasks listed.

**Occupational therapy and the development of support systems**

One might feel that involvement with a support system of community resources is a social worker's role, not that of an occupational therapist. But it appears from the literature that collaborating with community resources, and/or teaching clients to use them, are traditional occupational therapy roles (AOTA 1978, 1983c). Active development of support systems by occupational therapists has been advocated by writers such as Warren (1974),
Maguire (1979), and Hasselkus and Brown (1983), as described below.

In her report, Warren discusses the development by an occupational therapist of a corps of volunteer drivers for the elderly. She says: "In the development of a support system within the context of providing freedom of choice to the individual in pursuing reality-based goals, there is clearly a role for the occupational therapist in helping to build such a system" (p. 336).

Maguire describes a community-based volunteer program coordinated by an occupational therapist which provides assistance to elderly persons in ADL areas such as cooking, cleaning, and transportation. The program's goals are to improve the quality of life of elderly in the community, to help keep individuals in their own homes and out of institutions, and to educate members of the community toward an acceptance of aging individuals within the community. These goals could be directly transferable (generalizing to handicapped persons, not just the elderly) to an attendant care program coordinated by an occupational therapist.

Hasselkus and Brown describe a respite care program that provides caregiver relief by routinely hospitalizing elderly family members (considering the high cost to society of hospital beds, it is wondered whether the hiring of an attendant on a periodic basis might not have been an adequate alternative).

Attendant care as community therapy

Dunleavey (1974) says: "...we must reach into the community and expand our interests from patient, to family, to neighborhood."
Occupational therapists must be willing to assert themselves to move in a different direction and to increase their responsibilities as 'environmental therapists'" (p. 487). Many writers both within and outside of the field of occupational therapy are calling for the grass-roots development of policies and programs to provide local solutions to community problems (Hancock, 1982; Gray, 1983; and Naisbett, 1983). Similar to Dunleavey's concept of "environmental therapists", the term "community therapist" is proposed here to define occupational therapy which is directed towards benefiting the community as a whole.

The creation of jobs

The development of an attendant program can be therapeutically beneficial on a community-wide scale though the creation of jobs. Usually it is necessary that far more attendants be available than the number of handicappers being served. In their study, Stelmach, et al. (1981) found that "multiple attendants were needed by 68% of the disabled people; of these, 52% needed 2 attendants, 33% needed 3-4 attendants, and 15% needed 5 or more attendants" (p. 132). Hancock (1982) describes how job creation can be "community therapy":

The role of employment in generating health is often overlooked. The sense of self-worth that comes from employment and the relationship of job satisfaction to longevity would be recognized in a health-creating society. Already, we are beginning to recognize that chronic unemployment, with the sense of hopelessness and powerlessness that it creates, may be an important cause of stress, depression, mental illness, suicide, and crime. (p. 9)

But it is not enough to merely create job openings. Many writers
have noted that attendant care jobs tend to attract less than desirable workers (McGwinn, 1977; Thornock, et al., 1978; and Smith & Meyer, 1981). Most writers attribute this mainly to the fact that PCA wages usually are minimum wage. But, if this is true, one wonders why so many other minimum wage jobs do not appear to have the same difficulty attracting hardworking and motivated young people. In examining the problem further, it is seen that additional factors are mentioned in the literature such as the low status of the job of attendant, the lack of positive reinforcers such as raises, the lack of fringe benefits such as paid sick days, the routine nature of the job, and the lack of emotional support from co-workers due to the isolation of the job. A study by Stelmach et al. (1981) found that a greater percentage of attendants surveyed listed “aspects of the work schedule” rather than “wages and benefits” as the thing they liked least about their job. The study also found that job satisfaction was positively related to working with those disabled adults requiring less than 25 hours per week of attendant care. These findings have led to the formulation of a list of recommendations to be considered when developing attendant care programming (see Appendix B).

The encouragement of community members to open foster homes can be community therapy in that it creates options for handicappers and provides a source of income for the foster home owner. DeJong (1977b) says:

A large number of severely physically disabled persons need a night attendant to turn them over. For each individual to have his/her own night attendant, other than a live-in companion or family member, can be a very expensive proposition. A foster home would enable several disabled people to share the expense of a night attendant who might
well be the foster home provider. (p. 78)

Promoting the employment of community members as attendants can also be viewed as community therapy in that it can help educate people towards an acceptance of handicapped persons within the community. The public awareness campaign mentioned above could include presentations by handicapped persons about their lives and their need for attendants. Many persons not acquainted with severely disabled persons do not realize how it is possible for them to live independently. Maguire (1979) felt that her volunteer chore provider program, which is similar to an attendant care program, did achieve the goal of promoting community acceptance of elderly citizens.

The existence of opportunities for able-bodied persons to help disabled persons can be therapeutic for those involved. But able-bodied persons are not the only ones who can help others, which can be seen from this quote by McGwinn (1977):

One disabled individual's abilities can make up for another disabled individual's disabilities. The blind can move for the disabled. The disabled can see for the blind and talk for the cerebral palsied. The mentally retarded can be the arms and legs for the disabled, and the disabled can explain to and organize for the mentally retarded. Whatever his disability, each person can help someone else in some way. (p. 88)

**Developmentally disabled adults as attendants**

It has been mentioned several times in the literature that developmentally disabled adults can be employed as attendants (Urie & Brolin, 1973; McGwinn, 1977; Bruck, 1978; Thornock et al., 1978; and Gayle, 1983), which is happening at various places across the country. Urie and Brolin discuss how developmentally disabled persons tend to
be hired into jobs which are very simple and may pay less than minimum wage, while "many could work successfully in more highly paid and challenging occupations" (p. 14). The authors go on to explain that when developmentally disabled persons fail at their jobs, it is not usually because of a lack of work skills or personal characteristics, but because of a lack of social skills. The PCA job may be ideal for this type of person because of the close supervision and instruction which is a part of it. Urie and Brolin say:

...the attendant does not need to understand medicine or even the reasons underlying basic nursing practice. He does not have to read or write. He does not need to be a superior physical specimen. His instructions come directly from the one who knows best what is needed—namely, the one being assisted. The basic requirement is that the attendant is available, healthy, willing, and patient in routine tasks. (p. 14)

It goes without saying that employment of developmentally disabled adults in PCA jobs would be excellent community therapy, in that the potential of this underemployed population would be given a better chance for realization. Both part-time and live-in positions may be possibilities. Some developmentally disabled persons may be just as anxious as physically disabled persons to live independently in the community, but are unable to do so without a "responsible" live-in companion. A live-in attendant position can be a way to provide a developmentally disabled adult with free or inexpensive housing, a job, a supervised yet independent lifestyle, and a companion who needs them (meeting both subsistence and psychological needs). Urie and Brolin (1973) say that "estimates place the number between 75 and 85% of mentally retarded who could adjust satisfactorily to society" (p. 14). Gayle (1983) and Urie and
Brolin mention that training developmentally disabled persons to become attendants should start in the school system. The traditional role of occupational therapists in prevocational training and in working with the developmentally disabled population makes them appropriate professionals to teach these persons to become attendants, and to teach handicappers how to supervise developmentally disabled employees.

**Occupational therapy and attendant care advocacy**

Whether or not an occupational therapist is directly involved with attendant care programming, he or she can become active in attendant care advocacy efforts. The importance of this can be seen from the following quote by Berrol (1979), an independent living writer:

> The able-bodied professional must participate in promoting the expansion of services to the disabled. Changes in local services, such as the disastrous limitations of attendant care responsibilities in California, has significantly altered the ability of the disabled to purchase services with existing dollars. Yet no professional organization lobbied the legislature or the governor; only the disabled were heard from. To develop a true collaborative relationship, we, as able-bodied professionals, must speak out publicly for those we serve. (p. 457)

As occupational therapists, Dunleavey (1974) feels it is our responsibility to "assume a larger role in shaping legislative policies that affect the homebound" (p. 487). Baum (1983) states: "The American Occupational Therapy Association, as an advocate for elderly and handicapped people, could become involved in litigation to preserve their rights and health care services" (p. 598). Neistadt and Marques (1984) directly address the role of occupational therapists
in attendant care advocacy. They state:

Occupational therapists also need to become active in their community's political process so they can promote and support the creation of additional appropriate housing units and attendant services for the disabled. A community prepared to receive and assist the disabled must be considered the final stage of an effective rehabilitation system. (p. 676)

Public funding of attendant care is of primary importance to advocacy efforts. DeJong (1977b) says: "Private health insurance coverage for long-term care services is almost non-existent, leaving most of the burden to two main sources of public funding--Medicare and Medicaid" (p. 194). DeJong describes how Medicaid and Medicare are "at odds with the attendant care model". He feels that "the nation's long-term care policy" is institutionally biased, medically oriented, income maintenance based, and time limited. To summarize DeJong's description of the guidelines, Medicaid and Medicare will pay for a helper (called a "home health aide") through a home health agency when nursing services, under a physician plan of treatment, are also being provided. Medicare is the primary medical assistance program for the Disability Insurance Program under Social Security (SSDI), while Medicaid is the primary medical assistance program for Supplemental Security Income (SSI) recipients. The Medicare regulations are geared to the provision of acute/restorative care. This emphasis is reflected in requirements that the person must have been hospitalized for three days, must be homebound, and must require skilled service under nursing supervision and within a physician's plan of treatment. Also, the care is not covered for more than one year, 100 visits per year, or 100 hours per month. Medicaid is for the most part not as restrictive as
Medicare, but still requires nurse supervision and physician direction (DeJong, 1977b).

It is not easy for a chronically disabled person to qualify for Medicaid/Medicare coverage of attendant care. As Shriver (1980) says: "It is shocking that only one percent of the Medicare dollar goes for home care; this results largely from excessively stringent conditions of participation, overregulation and inadequate reimbursement" (p. 24).

DeJong (1977b) describes the effect of the Medicaid/Medicare regulations:

In the American system of long-term care, it is easier to move toward the more dependent end of the continuum...The amount of public subsidy relative to cost diminishes as one moves toward the independent end of the continuum. Moreover, once in an institutional setting, our present method of financing long-term care makes it difficult for many disabled and elderly people to exit institutional care into community living...The financing of one end of the continuum, at the neglect of the other, has greatly disadvantaged the development of alternatives such as PCA's for those...who wish to live in the community. (p. 8)

Perhaps occupational therapists should support public subsidy of attendant care expenses, as expecting people to pay for their own attendant care is unrealistic. The White House Conference on Handicapped Individuals (1977) says:

According to the U.S. Census of 1970, 52% of those persons defined as being disabled have incomes below $5,200 per year. One may conclude that most persons in need of such [personal care] assistance are unable to pay for this service. Thus, dependency is created. (p. 326)

Also making independent payment difficult is the "discenventive to work" which is a part of public assistance--when a person begins working, and thus moves into a higher income bracket, he or she stands to lose benefits from the government. Finding a job that pays enough to support both the handicapper and the attendant's wages can be an
impossible task.

Some states provide financial assistance for attendant care services, the structure of which varies from state to state. According to the Department of Social Services in Kalamazoo, Michigan, residents who receive Supplemental Security Income can also receive up to $280 a month for "Adult Home Help". This form of assistance relies on the medical model. While the Home Help program allows the handicapper to hire a non-medical attendant, it does require that the handicapper obtain a physician's referral. And because $280 a month covers less than three hours a day of attendant care at minimum wage, persons who require more care than this are forced to supplement their usual help with other sources. For example, a person may arrange to have a nurse or aide from Visiting Nurses come one day a week to assist with a bath, not because skilled care is needed, but because it is likely to be covered by insurance. It is unfortunate that in many cases the structure and conditions of the payment system cause an unnecessary reliance on the medical world.

Legislators and the public should be made aware of the cost effectiveness of attendant care. Studies can be cited that illustrate this, such as the one in Maine (Richards, 1983) which found that cost of care per person per year is much higher in institutional settings ($42,142) and skilled nursing facilities ($21,900) than for an unsupervised apartment with a PCA 21 hours/week at $3.50/hour ($3,822). Another study (DeJong, 1977a) found that if 37 people living in institutions were to move to the community, the cost of their care could be reduced from a combined total of $748,000 to
DeJong (1977b) describes how in Massachusetts, the "working-age disabled do not have the same access to various home help services--particularly homemaker and chore services--as do the elderly", due to "various structural and policy barriers" (p. 11). It may be that the field of occupational therapy has also concentrated its community support programs towards the elderly. Of the few references to programs related to the delivery of home help services that were found in the occupational therapy literature (Maguire, 1974; Warren, 1974; and Hasselkus & Brown, 1983), all were in reference to the elderly, and not working-age handicapped persons. Perhaps occupational therapists should advocate that community support programs be made available to all handicapped persons who need them, and not be restricted by age requirements.

**Occupational therapy roles in attendant care programming**

**Assessment of attendant care needs**

Specific roles that occupational therapists may find appropriate to fulfill within an attendant care program include assessment of a handicapper's need for an attendant. This is happening at the Boston Center for Independent Living (DeJong, 1977b). DeJong feels that this should be done elsewhere as well:

We recommend that the PCA needs of an individual be evaluated by a team of two persons, one of whom should be an occupational therapist...Occupational therapists are especially qualified to consider the environmental constraints that a disabled person faces in performing his/her activities of daily living. Occupational therapists are also trained in the use of adaptive equipment. (p. 171)
Teaching attendant training classes

Another role occupational therapists may appropriately fulfill within an attendant care system is that of training persons to ready them for employment as attendants. Some handicappers may prefer to train their own attendants, in order to have maximum control over the type of care given. But a training program can be useful for more than just teaching job skills. By going through such a program, a potential attendant will be more sure of what the job entails before applying, and may be more committed to staying at the job after having invested time (and perhaps money) in a training course. Attendant training classes can be used to teach independent living philosophies, making it clear to prospective attendants that the locus of control in an attendant/employer relationship should be within the handicapped employer. Also, a training program does not take away a handicapper’s option to give an attendant individualized training specific to his or her needs, in addition to the more generalized information gained from class instruction.

There are many references in the occupational therapy literature to the role of occupational therapists in teaching family members or other caretakers to assist the client in ADL activities (Dunleavey, 1974; Levine, 1978; Zisserman, 1981; and AOTA, 1983b). Concerning volunteer programs for the elderly, Maguire (1979) discusses the need to teach methods such as transferring techniques to the volunteers. She says: “Occupational therapists could play a role in these programs by combining their teaching skills with their professional expertise in the facets of daily living” (p. 101). There are also
references in the occupational therapy literature to the benefit which can result when the caretakers whom the occupational therapist has trained are able to reinforce the occupational therapy program in the therapist's absence (Levine, 1978; and AOTA, 1983b).

Occupational therapists Malick and Sherry (1978) and Zisserman (1981) describe training apartments which are used as learning environments for clients and their families to "work out self-care techniques". Centers for Independent Living sometimes have transitional living facilities as a part of their programs. Also called "transitional housing", they are similar to the training apartments described by the above mentioned occupational therapists, except that the participants use attendants, rather than family help. Perhaps occupational therapists can play a significant role in the transitional housing setting by helping handicappers to "work out self-care techniques" with attendants.

**Teaching attendant management classes**

Another potential role for occupational therapists within an attendant care system is that of teaching handicappers how to manage (hire, train, and supervise) attendants. Throughout the independent living literature, the need of many handicappers for training in this area is noted. The New Options Transitional Living Project (Cole, et al., 1979) explains why attendant management training is included in their program:

...because most participants formerly received attendant care either from family members or nursing home personnel prior to entering the project. Consequently, they usually have had little direct responsibility for self-directed care
in the past and may not have had an opportunity to hire and supervise attendants, manage the financial resources to pay for this service, or confront problem areas such as the need for a back-up system. (p. 11)

Attendant management classes can help handicappers to learn skills to help avoid problem situations, and coping skills which can help handicappers to deal with stress situations as they arrive. McGwinn (1977) relates the feelings of several handicappers concerning the stress involved in the attendant care process:

The worst part for me is interviewing and training. I find it takes months to break one in completely and often we hire three or four before one sticks, as it's a demanding job requiring lots of patience. (p. 77),

and:

The disadvantages [of having 46 attendants in six years] are more subtle—the difficulty of maintaining a sense of continuity, the anxiety, the constant struggle to preserve one's self-image in the face of continual change...I have to know that someone will be here at a given time to perform a given task. Otherwise all my attention is directed toward worrying about basic necessities, and I can't function on any other level. (p. 76),

and:

Of course, advertising is not an easy way. You must answer numerous calls, many from people clearly unsuitable. Then you must interview promising callers in person. Anywhere from 25%-50% fail to show up for the interview...I have learned that attendants rarely stay six months, if that long. (p. 79)

It was discussed earlier in this report that occupational therapists are concerned with stress-reduction for their clients. Since this issue can be such a problem for many handicappers, perhaps attendant management training is an area in which occupational therapy should increase its efforts.

Neistadt and Marques (1984) describe an independent living skills
training program which was coordinated by a registered occupational therapist (OTR), at a long-term rehabilitation facility. The program included attendant management training as one of its 10 modules. The average length of institutionalization for the 17 participants was 11.9 years. After completing the independent living skills training program, 82.3% of the 17 participants either returned to the community or were placed on waiting lists for openings in accessible housing. The authors report that the post-test scores of the 17 participants were double that of their pre-test scores after completing the attendant management module. They also report that by combining the classroom format with individual treatment sessions, the one OTR was able to produce the same treatment hours of 2.6 OTR's. Neistadt and Marques state: "In addition to being cost effective, group instruction creates peer support, which contributes significantly to the cognitive and emotional growth of the class members" (p. 676).

To further examine the appropriateness of occupational therapy involvement with attendant management training, Appendix C compares components of attendant management with the occupational therapy process (as taken from the "Uniform Terminology for Occupational Therapy Services" [AOTA, 1979]).

Attendant care support services

We have seen how occupational therapists can become involved in attendant training, attendant management training, advocacy for the increased funding of attendant care, and development of community attendant care programs. It is likely that many therapists who work
within hospitals or institutions do not have the time for such pursuits, being that they are not within the scope of their job descriptions. But therapists can incorporate consideration of their clients' attendant care into their programs without major changes. They can offer attendant care "support services" (see Appendix F for definitions) to their clients which facilitate the effectiveness of attendant care resources located elsewhere in the community.

For instance, occupational therapists can evaluate their clients' attendant care needs. Occupational therapy prides itself on being a holistic profession, and should not leave out the important element of attendant care when helping a client to plan strategies for independent living. Yerxa (1983) says:

What occupational therapy values is what society has been seeking increasingly: a grasp of the whole picture, person and environment; encouraging persons to take responsibility for their own bodies and destinies; and recognizing the potential, dignity, and autonomy of each individual.

(p. 159)

Yerxa discusses the unique ability of occupational therapists to act as "life organizers" for their clients. Johnson and Kielhofner (1983) also feel that occupational therapists are uniquely qualified to engage in long-term life-style planning due to the holistic nature of the profession. The need for occupational therapy efforts as "life organizers" or "life-style planners" can be seen from the experience related by a handicapped person, as related by McGwinn (1977):

I had tried nearly full-time to coordinate housing, financial security, and some sort of attendant set-up for six months. Nothing ever lined up. As one thing got straightened out, another fell through. I finally gave up to God out of total frustration and extreme depression.

(p. 70)
Although this person finally managed to work out the support system required for her independent living, not all handicappers may be able to accomplish this without the help of life "organizers" or "planners".

Questions concerning a client's need for attendant care can be included in occupational therapy assessment forms. In AOTA's publication "Sample Forms for Occupational Therapy" by Hays, Kassimir, and Parkin (1980) four forms with questions relevant to "help outside the family" were found (pp. 75, 78, 292, and 293), although the questions included are brief, and limited to factors such as "times available", and "duties performed". Malick and Sherry (1978) reprinted a "Homemaking Follow-up Questionnaire" from the Harmsville Rehabilitation Center in Pittsburg, Pennsylvania, which includes the most extensive assessment related to assistance which could be found in the occupational therapy literature. Included are questions such as "Do you receive help for any of your personal care?", or "homemaking activities?" If so, "What type?", "How often?", and "By whom?"

Additional questions which would be useful on such an assessment are those concerning the client's satisfaction with the help received, the client's knowledge of the availability of attendants (if not already being used), and the client's perception of whether an attendant would be an asset, even if used only on a part-time or periodic basis. It is suggested that occupational therapists assess their client's need for attendant care early, and not wait until the discharge interview. This way elements of attendant management (such as how to explain to others methods of assisting with self-care) can be presented as part of
Several scales which measure performance of specific daily living skills are found in "Sample Forms" (Hays et al., 1980). Although they differ slightly, the performance levels of these scales usually are put into categories such as (a) independent in activity, (b) activity accomplished with physical assistance, (c) patient requires supervision of another to complete activity, and (d) patient unable to help in activity. If an assessment scale further subdivides the category of "assistance needed", it is usually delineated by the quantity of assistance needed. No mention of the quality of the assistance could be found amongst these scales. Questions could be added such as, "When assistance is provided, is the locus of control in the client or the helper?", in other words, "Is the client directing the helper in a manner which fully utilizes his or her intellectual potential?" Other questions could include: "Is the client able to give directions concerning the assisted activity in a manner which shows skill in interpersonal communication?", "Does the client 'help out' as much as is reasonably possible in the assisted activity?", and "Is the client satisfied with the manner in which the assistance is provided?"

Occupational therapists can also assess an attendant's capability to provide assistance. This can occur in the usual course of treatment on an individual basis (as opposed to the therapist being a teacher in an attendant training program as described earlier). "Sample Forms" (Hays et al., 1980) includes a "Home Visit Report" form from Mercy Hospital and Medical Center in Chicago, Illinois, which calls
for the therapist to assess the family’s ability to participate in the client’s care. Their assessment includes:

Description of Family Participation

A. Knowledge of safety precautions may include:
1. With wheelchair—brakes, etc.
2. Lack of sensation.
3. Poor judgement.
4. Poor balance.

B. Knowledge of techniques may include:
1. Nursing information—medications, etc.
2. Transfers.
4. Ambulation—include stairs.
5. Wheelchair propulsion—include taking wheelchair up and down stairs, curbs.

C. Practical demonstration of their ability to provide appropriate assistance or supervision in all areas.

Although written for family members, this protocol could easily be used as a guideline to assess attendants, or to assess a client’s ability to supervise an attendant in these areas.

Encouraging clients to seek attendant care

In many cases, the client and/or family may not even know that hiring an attendant is a possibility. Cole et al. (1980c) note:

Sometimes parents are so involved with dealing with the present that they do not have the energy to plan for the future of their child. Some parents believe there can be no future for their child outside of the home environment but this belief is usually because the parents do not have enough information or positive examples of other alternatives. (p. 5)

Shrifter (1980) says:

Several years ago, a survey of 600 physicians in Onandoga County, New York, revealed that one-fourth of the physicians had never heard of home health services...There needs to be a greater physician awareness of the advantages and uses of home health services. (p. 24)

Because it is relatively new, the concept of attendant care is
probably even less well known to physicians than are home health
services. If physicians are not well-acquainted with attendant care,
how many other members of the health care team are also uninformed
about the its benefits?

If other resources exist within the community to assist a client
with attendant care, then a simple referral to that resource may not
be enough. Authors such as Hancock (1982) and Naishbett (1983) feel
that the "networking" of services must become a part of our delivery
system of the future. This may be difficult for therapists who are
accustomed to doing therapy in a manner divorced from other
environmental resources. Zisserman (1981) points out:

While therapists often must judge their productivity in
terms of the number of hours spent in direct patient
contact, they often can be more 'therapeutic' by arranging
and coordinating other rehabilitation services for a
particular patient who, otherwise, might be lost in the
cracks of large rehabilitation bureaucracies. (p. 16)

Reasons for this study

The comparison of the literature of both attendant care and
occupational therapy has shown that, theoretically, there is potential
for a significant relationship between the two areas. The next
logical step is to establish a baseline measurement of the current
extent of occupational therapy involvement in attendant care.
Further, it is necessary to measure attitudes held by occupational
therapists, and professionals working in attendant care programs,
concerning the future potential of occupational therapy involvement in
attendant care.
CHAPTER III

RESEARCH QUESTIONS

Concerning occupational therapists within rehabilitation settings, what is the extent of:

(a) their perception of the need of their clients for attendant care, (b) their knowledge of attendant care resources or services available to their clients, (c) their involvement with attendant care programming and support services, (d) their perception of the appropriateness of occupational therapy involvement in these areas, and (e) their educational preparation in the area of attendant care, and their perception of its adequacy?

Concerning Centers for Independent Living which offer attendant care services, what is the nature of:

(a) the attendant care services provided, (b) the current involvement of occupational therapists in their attendant care program, and (c) their appraisal of the potential for increased occupational therapy involvement?
CHAPTER IV

DESIGN AND METHODOLOGY

Samples

Occupational therapists at rehabilitation facilities

To measure current practices and attitudes of occupational therapists concerning attendant care, the population chosen to be surveyed was rehabilitation facilities. It was felt that therapists in acute care hospitals do not usually work with clients whose conditions have stabilized, as opposed to therapists in rehabilitation facilities who work with clients after their conditions have stabilized, and for a greater length of time. Therefore, therapists in rehabilitation facilities are in a better position to correctly gauge a client's need for attendant care.

The American Occupational Therapy Association's 1975 Facilities Directory includes 150 facilities which employ occupational therapists that can be identified through their titles as rehabilitation centers, rehabilitation services, or rehabilitation hospitals, and as not primarily directed towards children, education, or vocational rehabilitation. The surveys (see Appendix D) were addressed to "Director of Occupational Therapy", and sent to each of the 150 facilities.

The 1975 Facilities Directory is the most recent in print. This imposed a limitation, as 12 of the surveys sent out were returned by the post office. It is not known how many of these were returned
because the facility had changed its address (and the forwarding order had expired), and how many of the facilities had closed. Two of the facilities that were sent surveys responded that they do not currently have occupational therapists on staff. The attempt to screen out facilities which are vocational rehabilitation centers or who serve children only (by examining the facility title) was not totally successful, which is seen through the 3 facilities who returned surveys but who did not fit these qualifications.

Seventeen is the total number of surveys which were returned but were unusable due to wrong address, no occupational therapist on staff, or wrong type of facility. It is not known how many of the surveys which were not returned may also have been sent to inappropriate addresses or facilities. But if 17 is taken as the total "inappropriate" surveys, then 133 becomes the total membership of the population. Fifty-eight usable surveys were returned, making the return rate 44%. The 58 were returned from 36 different states, and were fairly evenly distributed throughout all geographical sections of the nation.

Directors of Centers for Independent Living

Centers for Independent Living which offer attendant care services were chosen as the population to be surveyed concerning current and potential occupational therapy involvement in community attendant care programming. Although attendant care services may be offered by other types of agencies, CIL's offer services in accordance with the independent living philosophies which are harmonious with
those of occupational therapy. Theoretically then, there is potential
for occupational therapy involvement in CIL's.

Thirty-five CIL's nationwide which have attendant care services
were sent the survey instrument found in Appendix E. A current and
complete directory of CIL's which offer attendant care could not be
found. Various sources were used to obtain information concerning
which centers have attendant care services--the Center for Independent
Living in Kalamazoo, Michigan, the Institute for Rehabilitation and
Research in Houston, Texas, and the Region V Office of the
Rehabilitation Services Administration in Chicago, Illinois. Other
CIL's may exist which offer attendant care services, but which were not
known to these sources. Therefore, the 35 CIL's which were sent
surveys are not assumed to constitute a complete population.

Note that various different types of organizations may call
themselves independent living centers, or CIL's. This is one of the
factors which impeded the compiling of a complete list of CIL's that
fit the definition of a CIL which is used in this exploration (see
page 4). This definition includes the term "non-residential".

One of the CIL's responded that they do not currently have an
attendant care program. Another CIL indicated that they are a
residential facility which serves the developmentally disabled. When
these two "inappropriate" surveys are taken into account, 33 is left
as the total CIL's that fit the criteria. Eighteen useable surveys
were returned--a return rate of 55%. The surveys were returned from
13 states, with all sections of the nation being represented except
the northwest states.
Instrumentation

Two surveys were developed, one for rehabilitation facilities, and one for CIL’s. Both surveys consisted of four pages of questions. In order to learn about the respondents’ programs, both surveys asked for demographic information such as number of clients served, the four major disability groups served, number of counties served, and the number and titles of staffpersons. The rest of the survey items were developed to answer the research questions as stated in Chapter III.

When the survey to occupational therapists was being developed, questioned was the familiarity of this population with the independent living model of attendant care. Therefore, in order that all respondents fill out the survey with a similar idea of attendant care, the survey began by addressing factors such as what it is, who can benefit from it, why it can be preferable to family care, and how it is different from respite care. The survey also differentiated between temporary and permanent use of attendants, and between attendant care programming and attendant care support services (see Appendix F for definitions of these terms).

Limitations of the surveys

Both surveys contained fill-in-the-blank and open-ended questions whose answers proved difficult to translate into statistics due to the inconsistency of types of answers given. Checklists may have been easier to analyze, although they may also have provided less individualized information. Some items included on the surveys proved to be less valuable than others, and so were not discussed in
Chapter V. For example, the items on the CIL survey concerning funding sources were both difficult to quantify due to the variations of answers given, and were felt to be nonessential to this research.

Procedure

Self-addressed and stamped return envelopes were included with each survey. Respondents were not asked to identify themselves on the survey, but each survey was given a number code. This was done so that non-respondents could be identified in the event that a return rate of one-third had not been achieved, necessitating a resending of surveys to non-respondents. No follow-up resending was done, as both surveys surpassed the return rate limit.

Data Analysis

Dec-1099 at Western Michigan University was used for analysis of data. A file was created using opscan sheets. SOS was used to manipulate the data, and to create a variable list and a format. The BANK program was created from the files listed above, and a basic statistics program was run which gave means, medians, and ranges. Data was also entered into the FREQ program to obtain frequencies of responses.
CHAPTER V

RESULTS & DISCUSSION

The following is a report and discussion of the results of the research--first the survey to occupational therapists, followed by the survey to Centers for Independent Living.

Survey of Occupational Therapists at Rehabilitation Facilities

The survey respondents

Of the 58 respondents, the majority serve both inpatients and outpatients. Almost one-third of the facilities serve acute care as well as rehabilitation clients. Nearly all of the facilities have fulltime OTR's (registered occupational therapists) on staff--9 being the mean number of fulltime OTR's. More than half of the facilities have parttime OTR's--the mean being 2. Over half the facilities also have fulltime COTA's (certified occupational therapy assistants) on staff--the mean being 3.

Because many respondents did not give an exact number of counties served in answer to question #16, a mean number cannot be reported. The answers ranged from "one county" to "many states", or "not limited geographically", with 15 respondents giving an answer in terms of states, not counties.

The clients served

The rehabilitation facilities selected (by title as described in Chapter IV) all serve adults. Ninety percent serve persons who have
Chapter IV) all serve adults. Ninety percent serve persons who have suffered cerebral vascular accidents (CVA's), 66% serve the closed-head injured (CHI), and 57% serve the spinal cord injured (SCI). Other diagnostic groups such as amputees, cerebral palsied, and arthritics, are each served by less than 25% of the respondents.

Occupational therapists' perception of their clients' need for attendant care

Survey questions #1 and #3 differentiated between clients who need temporary help, and those who need permanent or on-going attendant care (see Appendix F for definitions), and requested an estimate of the number of clients seen per year who need such services. Of those who gave frequencies, 117 was the mean number of clients per year who need temporary help, and 62 the mean number who need permanent assistance. Seven respondents answered these questions by giving percentages of clients seen per year. Of these answers, the mean was 28% of clients who need temporary attendants, and 18% who need permanent attendants. One respondent reported the need as: "for those discharged into the community, an estimate of 100%". None of the respondents reported having 0 clients that need attendant care.

In summary, the occupational therapists in this study report that a sizeable number of their clients need attendant care, and more of their clients need temporary help than need on-going assistance. Perhaps the need for temporary home help upon discharge is related to the current emphasis on decreasing the length of hospital stays. The fact that a greater proportion of the clients need temporary help may also be a function of the types of diagnoses usually seen at
rehabilitation facilities. Ninety percent of the respondents serve CVA's, with 78% listing CVA as the most common diagnosis seen. Reasons why it would not be expected that a majority of CVA clients will need permanent assistance include (a) the prognosis for CVA is such that spontaneous improvement often occurs (Trombley, 1983), i.e. the client may continue to recover after being discharged from the rehabilitation facility, and (b) the disabling effect of CVA's can often be a function of impairments of perception, cognition, and language (Trombley, 1983), which decrease a person's potential for living independently with the aid of an attendant.

In contrast to this is the category of SCI clients, which, as will be reported, is the most common diagnostic group seen by the CIL respondents. Persons with SCI (especially quadriplegics) usually have severe motor but not cognitive limitations. Although the incidence of CVA increases with age, SCI does not (Trombley, 1983). Many persons with SCI are at an age in which independent living and a career is very important. Thus, an attendant may be more important to the average SCI client than the average CVA client. This differential need for attendant care is reflected in the comments of two respondents concerning the number of their clients needing attendant care: "30% of HI, 90% of Quads, or 40% of CVA's", and: "All of the SCI, HI, and more involved strokes".

Occupational therapists' knowledge of attendant care resources

One limit of this study is that because it is not known what resources exist in actuality for each of the respondents' clients, the
accuracy of the respondents' knowledge of resources is not known.

But some indication of the extent of the therapists' knowledge can be
gathered from the number of therapists who listed resources, and the
number of resources they listed. Survey questions #2, #4, #7, and #8
relate to this issue (see Tables 1 through 4).

Table 1

Questions #2 & #4: What are the sources of attendants in your community?

<table>
<thead>
<tr>
<th>Of 58 respondents, no. who...</th>
<th>Temporary</th>
<th>Permanent</th>
</tr>
</thead>
<tbody>
<tr>
<td>...listed sources:</td>
<td>50</td>
<td>40</td>
</tr>
<tr>
<td>...did not know:</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>...indicated that no source is available:</td>
<td>1</td>
<td>6</td>
</tr>
</tbody>
</table>
Table 2

Questions #2 & #4: Frequencies of sources as listed by respondents

<table>
<thead>
<tr>
<th>Source</th>
<th>Temporary</th>
<th>Permanent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private home health agencies</td>
<td>44</td>
<td>16</td>
</tr>
<tr>
<td>Visiting Nurses Association</td>
<td>17</td>
<td>10</td>
</tr>
<tr>
<td>CIL's</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Dept. of Vocational Rehabilitation</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>University students</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Dept. of Public Health</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Churches</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Local community groups/organizations (e.g. YWCA's &quot;Displaced Homemakers&quot;, the &quot;Senior Employment Program&quot;, and the &quot;Red Cross&quot;)</td>
<td>28</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 3

Question #7: Do you feel that your community has enough attendant care programs to meet the need?

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
<td>26%</td>
</tr>
<tr>
<td>No</td>
<td>31</td>
<td>53%</td>
</tr>
<tr>
<td>I don't know</td>
<td>12</td>
<td>21%</td>
</tr>
</tbody>
</table>

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Table 4

Question #8: What are the payment sources for attendant care in your community?

<table>
<thead>
<tr>
<th>Source</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare/Medicaid</td>
<td>25</td>
</tr>
<tr>
<td>Private pay</td>
<td>24</td>
</tr>
<tr>
<td>Private insurance</td>
<td>13</td>
</tr>
<tr>
<td>Vocational Rehabilitation</td>
<td>5</td>
</tr>
<tr>
<td>County funds</td>
<td>4</td>
</tr>
<tr>
<td>State funds</td>
<td>2</td>
</tr>
<tr>
<td>Blue Cross/Blue Shield</td>
<td>2</td>
</tr>
<tr>
<td>Workman's Compensation</td>
<td>2</td>
</tr>
<tr>
<td>&quot;I don't know&quot;</td>
<td>15</td>
</tr>
</tbody>
</table>

More respondents were able to list sources for temporary assistance (86%) than for permanent attendants (69%), and the respondents were able to list a greater number of temporary than permanent attendant resources. As noted in Chapter II, the national home health care system is growing, and insurances often cover the temporary assistance that these agencies provide in the form of home health aides. It has also been pointed out that there is a marked lack of attendant care programs, and of payment sources for attendants. Therefore, it is not surprising that the occupational therapists in this sample are more apt to know about resources for temporary help, and to list home health agencies (or Visiting Nurses
Thirty-two therapists, or 38% of the respondents, listed home health services as resources for permanent attendants. As noted previously in the literature review, the independent living movement views home health agencies as an unnecessarily expensive and medically-oriented source of attendant care for persons whose medical conditions have stabilized. It is not known how many of the respondents actually use (as opposed to just listing them as resources) home health agencies as sources for permanent attendants. Automobile insurance is the only coverage known to this researcher which will pay the home health agency aide's wages on a continuing basis.

Ten percent of the respondents indicated that they did not know what resources are available for permanent attendants. An additional 21% left the question blank, while 38% listed home health agencies (which do not fit the independent living model of attendant care). It is not known to what extent this apparent lack of knowledge is due to an actual lack of attendant care programs or to the occupational therapists' lack of awareness of existing resources. Note also that 26% of the respondents indicated that they did not know what payment sources are available to their clients for attendant care, while 21% said they did not know whether their communities have adequate attendant care programs to meet the need.

The apparent lack of knowledge concerning attendant care resources on the part of many of the respondents may be a function of the large area that many of the rehabilitation centers serve. The
larger the area served, the more difficult it may be to know about existing resources.

Many therapists are aware of a need in their community for more extensive attendant care services. This can be seen from comments added to the surveys, which most often concerned the lack of training for attendants, and the lack of funding ("...many clients fall in-between guideline cracks"). Other respondents noted problems of geographical access ("the closest sources of attendants are 3 1/2 hours away"), especially for rural residents. The high turnover rate for attendants was also cited ("An area that needs attention given to it is how to recruit and keep them on the job"). One respondent noted that private citizens need to be involved to reduce cost and to provide live-in situations, while another pointed to the lack of the public’s awareness of the availability of attendant jobs, and lack of awareness of handicappers of their potential to achieve independent living with the aid of attendants.

The occupational therapists’ involvement with attendant care

Concerning the provision of attendant programming (Question #5) such as attendant recruitment, screening, training, placement, and follow-up, these services were reported by 29 respondents as being provided by agencies other than the rehabilitation facility itself. For those 28 respondents who did answer that their facility provides any of these services, social work (or social services) was the department cited most often (in 11 cases). Nursing was cited by 6 respondents. Both social services and nursing were reported to be
involved in generally all of the service areas in question. In
contrast, the 10 occupational therapy departments that do offer any
of these services are not involved in recruitment or placement of
attendees. In these facilities, occupational therapists do more
attendant training (frequency of 10) than screening (4) or follow-up
(2). The respondents reported that in their facilities more
occupational therapists (frequency of 10) are involved in attendant
training than are social service workers (6), and nurses (5). Teachers,
vocational rehabilitation workers, physical therapists, physiatrists,
speech therapists, and home health department workers were also listed
as providing attendant care services, but infrequently (by 1
respondent each). Three respondents listed more than one department
as being involved in providing these services. Nine respondents
reported that these services are provided both within their agency and
elsewhere in the community.

A limit of this study is that although 28 respondents reported
that their facility is involved with providing either attendant
recruitment, screening, training, placement, or follow-up, the extent,
frequency, and commitment of the provision of these services is not
known. Questions such as "Is your facility known for having an
attendant care program?", or "Are the services provided informally, on
an as-needed basis?", may have helped to clarify this. Likewise, it is
also not known if the 10 occupational therapists who reported
providing these services are involved formally or informally.
Regardless, it is safe to say that social service department workers
are more involved in all these areas than are occupational therapists,
except in the area of attendant training, where occupational therapy is more involved than are other disciplines.

Consistent with these results which show a predominance of social work involvement in these areas were the answers to Question #9 concerning steps taken when a client needs attendant care. Thirty-three respondents answered that they refer the client to their facility’s social service department, who handles it from there. Six respondents reported that they leave the responsibility up to the client and family. Seventeen respondents described direct occupational therapy involvement through contacting the appropriate agency (resource for attendants) directly, or through screening and/or training potential attendants.

Table 5 illustrates the results of the section of the survey concerning attendant care “support services”—those which can be incorporated into regular treatment time without extensive program development or changes.
Table 5

Question #10: Occupational therapists provision of attendant care (AC) support services

<table>
<thead>
<tr>
<th>Service Description</th>
<th>% of 58 respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment of client’s need for AC</td>
<td>81%</td>
</tr>
<tr>
<td>Working with client’s attendant in how to provide help with activities of daily living</td>
<td>71%</td>
</tr>
<tr>
<td>Actively arranging for client to be linked up with other departments or agencies who can meet AC needs</td>
<td>55%</td>
</tr>
<tr>
<td>Education of client on agencies that provide AC services</td>
<td>48%</td>
</tr>
<tr>
<td>Training client how to direct/supervise an attendant</td>
<td>31%</td>
</tr>
<tr>
<td>Post-discharge assessment/supervision of client’s AC situation</td>
<td>31%</td>
</tr>
<tr>
<td>Orientation of client to possible AC arrangements</td>
<td>29%</td>
</tr>
<tr>
<td>Orientation of client to possible payment sources</td>
<td>14%</td>
</tr>
</tbody>
</table>

As can be seen from Table 5, a large number of occupational therapists report assessing their clients’ need for attendant care, and training attendants to assist with activities of daily living. A large number also report involvement in each of the other support service areas listed on the survey. Again, the extent of involvement in each area is not known. This survey instrument does not measure important differences such as that between (a) a therapist who introduces the independent living model of attendant care to all clients who may potentially benefit, and who devotes a considerable amount of treatment time to this area, and (b) a therapist who gets involved only when the occasional client presents an obvious need in

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Occupational therapists' perception of the appropriateness of occupational therapy involvement in attendant care

In general, the respondents do not appear to object to occupational therapy provision of attendant care support services. The few who answered question #14 ("If you don't provide support services, why not?"), indicated that they did not because the service is already being provided by another department, or another agency in the community.

Concerning the formal provision of attendant care programming (Question #6) such as recruitment, screening, training, placement, or follow-up, 36% of the respondents checked the item: "These services are not within the OT scope of practice". But because this section of the survey was multiple choice, respondents may have picked this answer although they would not have worded it exactly this way. In other words, how many meant that these services are not within the scope of their particular job descriptions, as opposed to the scope of occupational therapy in general? And, how many of these persons would not object to the hiring of an occupational therapist to staff a new attendant care program, if it were developed as an addition to the regular rehabilitation facility services?

Table 6 shows the results of the answers to Question #6. Respondents were asked to chose as many reasons as applied. The answer "provided by another department or agency" was not a suggested reason, but is included in the table due to the frequency with which it was written by respondents after the open-ended item: "additional
reasons". Other reasons offered after "Additional reasons:" included insufficient time to provide the service, limitations of geographic location (i.e. the majority of clients not living in the area of the rehabilitation facility), and lack of communication with community organizations.

Table 6

Question #6: Reasons for not providing attendant recruitment, screening, training, placement, or follow-up

<table>
<thead>
<tr>
<th>Suggested reasons:</th>
<th>Frequency:</th>
</tr>
</thead>
<tbody>
<tr>
<td>These services are not within the OT scope of practice</td>
<td>21</td>
</tr>
<tr>
<td>Providing these services is not financially feasible in terms of reimbursement</td>
<td>20</td>
</tr>
<tr>
<td>Services are provided by another department or agency</td>
<td>16</td>
</tr>
<tr>
<td>Our OT staff is not trained in how to provide the services</td>
<td>13</td>
</tr>
<tr>
<td>We would like to provide these services, but our employer/agency doesn’t support the idea</td>
<td>9</td>
</tr>
<tr>
<td>These services are not needed by our clients</td>
<td>7</td>
</tr>
<tr>
<td>We feel family members should provide the care instead of attendants</td>
<td>5</td>
</tr>
</tbody>
</table>


Occupational therapists' perception of the adequacy of their educational preparation in the area of attendant care

A limit of this study is that because the "training in OT school in how to provide attendant care support services" of question #12 is not qualified on the survey, the nature of the training that 14% of...
respondents reportedly received is not known. It may be that some of those who answered "yes" to this question received "training" which merely consisted of being introduced to the need to teach others to assist clients (as in transferring techniques). It is not known whether the independent living model of attendant care (including the psychosocial benefits and cost-effectiveness of attendants, and attendant resources and payment sources) was presented to these therapists while students. However, it is safe to say that based on the fact that 86% reported that they received no training, a majority of the respondents were not educated concerning the provision of attendant care support services.

The ambiguity of the term "training" again limits interpretation of the answers to Question #14 ("Do you feel that OT schools should give training in how to provide the above services?"). The respondents could have had in mind anything from an entire course to a single lecture devoted to the subject when they answered this question. Sixty-seven percent of the survey respondents answered "yes" to this question, 21% answered "no", and 7% qualified their answer by saying it should be at least introduced in school (noting the unavailability in school for adequate time to cover all essential areas). One respondent noted that occupational therapy students should be educated concerning area resources, the function of attendants, payment sources, and cost-effectiveness issues.
Survey of Centers for Independent Living

The survey respondents

The number of counties served by the 18 centers who responded to the CIL survey ranged from 1 county to the entire state, the median being 3 counties. Thirty-five percent of the CIL's reported that they have transitional living facilities as part of their program. Spinal cord injury was cited by all but one of the CIL's as the most common disability served. Cerebral palsy was the second most commonly cited diagnosis, followed by multiple sclerosis and muscular dystrophy.

Attendant care services offered

The CIL's reported a mean of 60, and a range of 2 to 300, as the number of persons served per month in their attendant care program. When asked "What percentage of your clients have attendants?" (Question #9), the mean answer was 42%, the range being 2% to 100%. Of their clients who need attendants, a mean of 84% need them on an on-going basis, while a mean of 16% need only temporary assistance (until their condition stabilizes). Sixty-seven percent of the 18 respondents indicated that their community is in need of more attendant care services (Question #5).

Table 7 lists attendant care services with the corresponding percentage of respondents who indicated that they provide the service. Note that "writing growth plans" refers to goal-setting with clients to evaluate areas needing improvement before independence in attendant
care management can be met.

**Table 7**

**Question #15: Services provided by CIL's**

<table>
<thead>
<tr>
<th>Services</th>
<th>% who provide</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant management</td>
<td>89%</td>
</tr>
<tr>
<td>Assessment (in-home) of attendant care needs</td>
<td>78%</td>
</tr>
<tr>
<td>Attendant recruitment</td>
<td>72%</td>
</tr>
<tr>
<td>Writing growth plans</td>
<td>72%</td>
</tr>
<tr>
<td>Attendant placement</td>
<td>67%</td>
</tr>
<tr>
<td>Attendant reference checking</td>
<td>61%</td>
</tr>
<tr>
<td>Attendant interviewing</td>
<td>56%</td>
</tr>
<tr>
<td>Attendant training</td>
<td>44%</td>
</tr>
</tbody>
</table>

Items were included (part of Question #9) to discover the extent to which the CIL's clients need help with the attendant care process. One such question was: "Of those clients who have or need attendants, what percentage need training or counseling in how to obtain and supervise them?" The mean answer to this question was 68%. In answer to another question: "What percentage find the process of obtaining and keeping attendants to be a major source of stress?", the mean was 58%.

Eight CIL's indicated that they provide attendant training.

Table 8 lists subject areas which were suggested on the survey, and the corresponding percentage of the 8 centers that checked the topic.
as being included in their training program.

Table 8

Question #16: What areas are included in your attendant training course?

<table>
<thead>
<tr>
<th>Topics</th>
<th>Of 8 CIL's, % that include:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information on specific disabilities</td>
<td>100%</td>
</tr>
<tr>
<td>Body mechanics, transferring</td>
<td>100%</td>
</tr>
<tr>
<td>Independent living concepts</td>
<td>100%</td>
</tr>
<tr>
<td>Interpersonal communications</td>
<td>100%</td>
</tr>
<tr>
<td>Bowel and bladder routine</td>
<td>88%</td>
</tr>
<tr>
<td>Catheter care</td>
<td>75%</td>
</tr>
<tr>
<td>Prevention of pressure sores</td>
<td>75%</td>
</tr>
<tr>
<td>First aid and dealing with emergencies</td>
<td>75%</td>
</tr>
<tr>
<td>Adaptations for activities of daily living</td>
<td>75%</td>
</tr>
<tr>
<td>Assist with range of motion exercises</td>
<td>63%</td>
</tr>
<tr>
<td>Sexuality</td>
<td>50%</td>
</tr>
<tr>
<td>Colostomy care</td>
<td>50%</td>
</tr>
<tr>
<td>Nutrition</td>
<td>50%</td>
</tr>
<tr>
<td>Wheelchair maintenance</td>
<td>50%</td>
</tr>
<tr>
<td>CPR (Cardiopulmonary resuscitation)</td>
<td>25%</td>
</tr>
<tr>
<td>Taking vital signs (blood pressure, temperature, and pulse)</td>
<td>13%</td>
</tr>
</tbody>
</table>

Five of the 8 CIL’s noted the number of hours that it takes to complete their attendant training program. The number of hours cited
ranged from 4 to 48. Three of the 8 centers which offer training classes certify those who pass their course (2 of these CIL’s noting that theirs is not a legal certification process, but rather that their graduates receive "certificates of completion").

Current occupational therapy involvement in the CILs' attendant care programs

One-third of the 18 respondents reported that OTR’s are involved in running their attendant care program. This was determined from Question #11, which asked CIL’s to specify the degrees or qualifications of the staff members who run their attendant care programs. The CIL’s reported registered nurses with a frequency of 8, occupational therapists--6, bachelor’s degrees (type unspecified)--4, and social workers--3. The following degrees were each cited by one respondent: a master’s in rehabilitation counselling, a master’s in public administration, an associate arts degree, a bachelor’s in vocational rehabilitation, and a physical therapy degree. Concerning the number of staff members running their attendant care program, the answers reported ranged from 1 to 5, the mean being 2.

In answer to the open-ended Question #8: "How are clients referred to your attendant care program?", 17 respondents listed self-referral, word-of-mouth, or family-referral, and 14 listed hospitals or agencies without specifying who at the facility is the referral source. Of those who did specify a specific professional as the referral source, 8 cited social workers, 5 cited vocational rehabilitation workers, and 2 cited nurses. Occupational therapists
were not listed by any of the CIL's, but in answer to the question "Do you ever receive referrals from occupational therapists?", 10 answered "yes", while 6 answered "no".

To summarize, nurses are slightly more involved than occupational therapists in running the CIL's attendant care programs, but occupational therapists were cited twice as often as were social workers. This contrasts with the results of the survey sent to rehabilitation facilities, which show that social service workers are more involved with attendant care programming than are occupational therapists. Consistent with this is the fact that 8 CIL's cited social workers as the main referral source from outside agencies (presumably a large number of which are rehabilitation facilities). It appears that in the CIL's surveyed, occupational therapists are more involved in attendant care than are social workers, while in the rehabilitation facilities, the opposite is true.

The CIL's perception of the potential for increased occupational therapy involvement in their attendant care program

The CIL's were asked in Question #19: "Do you see occupational therapy as a service which would be an asset to your program?" In response, 16 checked "yes", and 1 checked "no", noting that occupational therapy was already available from the local Visiting Nurses Association. One respondent checked both "yes" and "no", noting that "The concept of ILC requires a non-medical model and if an OT program fits in, fine".

Question #19 went on to ask why they felt occupational therapy
would be an asset. Ten of the responses to this question concerned general occupational therapy responsibilities such as training in activities of daily living, or in the use of adaptive equipment. Three respondents cited duties specifically related to their attendant care program (e.g. attendant training, and assessment of need for attendants).

Table 9 shows that a majority of the respondents see occupational therapists as appropriate professionals to be involved in each of the attendant care services listed:

Table 9

<table>
<thead>
<tr>
<th>Attendant care service</th>
<th>Frequency of yea responses</th>
<th>Frequency of no responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess handicappers' need for attendant care</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>Teach attendant training class</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>Coordinate an attendant care program</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Teach attendant management class</td>
<td>7</td>
<td>6</td>
</tr>
</tbody>
</table>

Thirteen of the 18 respondents reported some form of occupational therapy involvement in their over-all CIL program (note that only 6 respondents reported that OTR's run their attendant care program). Eight centers reported that they contract occupational therapy services, 7 CIL's have one fulltime OTR on staff, 5 have a parttime
OTR, 2 have two fulltime OTR's, and one reported 2 fulltime OTR's and an OT aide on staff.

The respondents were asked in Question #26 to check suggested reasons for not hiring occupational therapists. Five respondents chose "We lack money to hire additional staff", 3 chose "We desire to minimize reliance on medical professionals", one chose "Hiring people with other degrees is a higher priority", and one chose "The need or desire to hire handicapped persons limits the OT applicants that are considered".

In summary, 72% percent of the CIL's report that occupational therapists are involved with their center, while 33% have occupational therapists on staff which run their attendant care programs. Occupational therapists are seen as an asset to the CIL's in several ways, not just concerning attendant care.

The respondents overwhelmingly agreed that occupational therapists are appropriate professionals to assess handicappers' needs for attendant care (note that 78% of the respondents provide this service to their clients). Most all of the respondents also felt that occupational therapists are appropriate professionals to teach attendant training classes (44% of the CIL's provide this service). When the list of topics that the CIL's include in their attendant training program is reviewed, it is seen that roughly half of the topics are areas in which occupational therapists should have some educational background. Other topics may benefit from input from a nurse (for the more medically-oriented topics), and a disabled peer (who has personal experience to relate). In general, although
attendant training classes may benefit from a team approach,
occasional therapists are definitely felt to have skills to offer in
this area.

The CIL respondents were more divided concerning the questions of
whether occupational therapists should coordinate attendant care
programs, or teach attendant management classes. These are areas in
which the occupational therapist's traditional skills are not utilized
as evidently as they are in the realms of (a) assessment of need for
assistance in personal care, and (b) teaching attendant training
classes. Note that assessing needs and teaching attendants are also
the areas in which occupational therapists at rehabilitation
facilities report being most involved.

An assumption was held when preparing the CIL survey that these
centers might not be interested in hiring occupational therapists due
to a possible need to run programs on a shoe-string budget, forcing a
reliance on volunteer help and/or the offering of low salaries to
staffpersons. Although 5 respondents did choose "We lack money to
hire additional staff", none of the respondents checked the suggested
item "We desire to run our CIL on volunteer help". And when CIL's were
asked to choose amongst salary ranges for the attendant care staff, the
answers clustered between $13,000 and $19,000, and 3 respondents
checked the "above $22,000" range. These ranges do not appear to
exclude the hiring of occupational therapists.

Another preconception was that CIL's might not be interested in
hiring occupational therapists due to the CIL philosophical basis which
shuns a reliance on "medical professionals". Surprisingly, only 3
CIL’s chose the item "We desire to minimize reliance on medical professionals". And nursing, which may be identified more readily than occupational therapy as a medical profession, was cited as the degree most likely to be held by the staffperson running the attendant care program (a frequency of 8 as opposed to occupational therapy’s 6).

Salient here are comments written by several respondents such as "The concept of ILC requires a non-medical model, and if an OT program fits in, fine", "it depends on the person more than the degree", "it depends on [the person’s] knowledge of disability", and "we are neither consciously looking for an OT nor attempting to screen them out".

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CONCLUSION AND RECOMMENDATIONS

Attendant Care and Occupational Therapy--Practice

It appears that occupational therapists are currently playing a major role in rehabilitation facilities as the assessors of clients' needs for attendant care—with the therapists' referrals then being sent on to social service departments. If occupational therapists are so involved (in many cases they may be the ones whose responsibility it is to "get the ball rolling" concerning a client who may need attendant care), should they not be well informed as to the benefits of attendants, and the different types of arrangements and resources available? Unfortunately, it appears that occupational therapists are not very knowledgeable concerning attendant resources and payment sources. Most (at least 86%) did not receive training in school in these areas. Excellent readings on attendant care are available which can be assigned as part of the occupational therapy curriculum. Therapists employed at hospitals and rehabilitation facilities can arrange to have inservices presented on attendant care, perhaps by members of local CIL's. The independent living movement is a powerful force in the health care world of today—one that occupational therapists should be well aware of.

Occupational therapists can use their position of influence by speaking with clients and their families about attendant care. In this way occupational therapists can both increase the public's
awareness of the availability of attendant jobs, and increase
handicappers' awareness of their potential for independent living with
the support of attendant care. And if educated on the subject,
occupational therapists may be more apt to become involved in
attendant care program development efforts. One respondent noted that
the reason for not offering attendant care services was that it was
"Not in my scope--as of now--but I will change that. We have
vocational rehabilitation here so it may be a class to train
attendants in the future...Need to educate myself so as to educate
administration".

There are many directions that program development efforts can
take. For instance, one occupational therapist at a rehabilitation
facility described a multidisciplinary program of modules which train
clients to recruit, screen, train, and direct attendants on their own.
Another occupational therapist at a rehabilitation facility reported
a cooperative program under a special grant which involves
occupational therapy with nursing to train mentally retarded persons
to be attendants.

The occupational therapists in this study do recognize that a
large number of their clients need attendant care, and the therapists
are involved in this area, although the involvement was generally
shown to be informal in nature (i.e. offering support services vs.
attendant care programing). Occupational therapists should be
made aware that help is needed in this area (the CIL's reported that
a majority of people need training or counselling in how to obtain or
supervise attendants, and a majority find this area to be a major
source of stress), and that occupational therapists have skills which are assets to attendant care programming.

A high proportion of the CIL's report occupational therapy involvement in their programs, and most see occupational therapy as an asset to attendant care services. It appears that there is considerable potential for an increase in occupational therapy involvement with attendant care—in CIL's and in rehabilitation facilities.

Attendant Care and Occupational Therapy—Theory

Finn (1972) points out the need to (a) reinterpret the professional body of knowledge, and to (b) think creatively about our particular understanding of man's needs and to start to build new images around this knowledge, in order to extend occupational therapy into the community. If occupational therapy is to become involved in attendant care in a significant way, then occupational therapy theory must include the concept of attendant care as a therapeutic modality.

Occupational therapy should not limit its use of therapeutic adaptation or compensation to the non-human environment. AOTA's "Uniform Terminology" (1979), says that "physical daily living skills refer to the skill and performance of daily personal care, with or without adaptive equipment". The words "and with or without a personal care attendant" could be added here.

Rogers (1982) advocates that the profession establish concepts of order and disorder in occupational performance, as a prerequisite for establishing an effective referral system. An example of an
occupational performance disorder could be "the inability to supervise self-care", while in this case order would be achieved by "the competent direction of an attendant to provide self-care".

**Attendant Care and Occupational Therapy--Education**

The physical and psychological elements of attendant care (such as what types of arrangements are possible, and what attendant management can mean to independent living and locus of control) should be introduced to students in the occupational therapy curriculum. Baum (1983) says: "Undergraduate, graduate, and continuing education programs for occupational therapists will need to respond to the changes that will occur in society and the health care system" (p. 598). Johnson and Kielhofner (1983) predict that occupational therapists will assume the role of managing resources and supports in communities, and will assess elements which could limit or enhance occupations of persons: "This will require therapists to develop more fully the profession's knowledge base concerning social systems and their impact on individuals" (p. 191). DeJong (1977b) notes that "it requires a human services renaissance person to fully comprehend all the complexities involved in providing personal care services to persons with severe physical disabilities" (p. 198). Yerxa (1983) notes that "currently, occupational therapists are educated to help patients seek and use community resources" (p. 159). If this is true, then attendant care must be included as a community resource about which occupational therapists are educated.
APPENDIX A

ATTENDANT CARE NEEDS ANALYSES

Of the many needs analyses that were cited by those authors which
have been included in the literature review of this study, the following
have been published since 1970:

Allen, K. H. (1976). First findings of the 1972 survey of the
disabled: General characteristics. Social Security Bulletin,
39, 18-37.

Branch, L., & Fowler, F. (1975). The health care needs of the
elderly and chronically disabled in Massachusetts. Boston:
University of Massachusetts, Survey Research Program.

Branch, L. & Pratter, F. (1975). Understanding the needs of the
chronically disabled, aged 18-64. Boston: University of
Massachusetts, Survey Research Program.

United States. Columbus, OH: Mershon Center of Ohio State
University.

National Center for Health Statistics (1972). Home care for
persons 55 and over, United States, July 1966-June 1968
(Vital and Health Statistics, Series 10, No. 73). Washington, DC:

National Center for Health Statistics (1976). Health characteristics
of persons with chronic activity limitation, United States, 1974
(Vital and Health Statistics, Series 10, No. 112). Washington, DC:
HRA 77-1539).

(Social Security Disability Survey, Rep. No. 2). Washington, DC:
SSA 77-11717).

Department of Commerce, Social & Economics Administration.

Office of Human Development, Rehabilitation Services Administration.
APPENDIX B

CREATING PCA JOBS--RECOMMENDATIONS

It is recommended here that the following elements be built into an attendant care system:

1. An awareness campaign to increase the public's knowledge of the job's existence. The public relations efforts should also concentrate on upgrading the image of the job. Included in the campaign should be presentations to various groups, such as high school and college students, women's groups, and church groups. Benefits of the PCA job should be emphasized, such as the fact that it is an excellent way to obtain human service experience and references. Many persons who plan to pursue health or human service careers take minimum wage jobs as nurse's aides in nursing homes and institutions. PCA jobs can be promoted as a more individualized alternative to such jobs.

2. The job should be structured so that it is part-time. The predictability of the routine, and the slow pace involved, can produce monotony, especially if the job is full-time (Smith & Meyer, 1981). Disabled persons who need a lot of care should be encouraged to hire several attendants. An example of an arrangement such as this would be to hire one attendant to handle early morning care, another for evenings, and a third for week-ends and holidays. This may reduce dissatisfaction such as that found among attendants in the study described above who disliked "aspects of the work schedule". Part-time work is attractive to persons who may make good attendants--students and homemakers who need extra income and desire a rewarding experience outside of their usual routine, but who do not depend on the job as their livelihood.

3. Some form of fringe benefits and positive reinforcement should be designed for the PCA jobs. It is felt that offering raises and promotions is one reason why businesses are able to keep their employees longer than do handicapped employers who do not offer such reinforcements. Even if minimal, some raise and/or bonus schedule should be offered to PCA's. Psychological reinforcements such as appreciation ceremonies can also be used to reward PCA's who stay on the job.
4. Get-togethers of attendants should be organized so that they have a chance to share experiences and to voice and/or work through concerns. This can be in the form of periodic group process meetings led by the occupational therapist, and/or social groups such as monthly potlucks. Organizing the same type of get-together for the handicapped employers may be equally important.
APPENDIX C

ATTENDANT MANAGEMENT AS AN OCCUPATIONAL THERAPY MODALITY

This appendix is an analysis of the "Uniform Terminology for Occupational Therapy Services" (AOTA, 1979), in an effort to determine the relevance of the attendant care management process to occupational therapy. This type of analysis can aid in program development efforts when designing (and justifying) an attendant management module to be taught by an occupational therapist.

First on the list of terms included within occupational therapy treatment in the "Uniform Terminology" is "independent living/daily living skills". The first element of this category is "physical daily living skills", which is the performance of daily personal care. In this sense, directing an attendant through a personal care routine is a physical daily living skill.

"Psychological/emotional daily living skills" is the next category, which includes "self-concept/self-identity". This subcategory involves "clearly perceiving one's needs". The process of learning to direct an attendant is a way of identifying one's needs.

Referring to the identification of needs, Cole, et al. (1980a) point out:

This is often very difficult for the person who has had his care done to or for him by his family. Some handicapped people are not even aware of their own care routines because someone else has always assumed that responsibility for them. (p. 10)

These authors also mention that "people with medical training such as nurses or nurse's aides often perform tasks in a specific,
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APPENDIX C

ATTENDANT MANAGEMENT AS AN OCCUPATIONAL THERAPY MODALITY

This appendix is an analysis of the "Uniform Terminology for Occupational Therapy Services" (AOTA, 1979), in an effort to determine the relevance of the attendant care management process to occupational therapy. This type of analysis can aid in program development efforts when designing (and justifying) an attendant management module to be taught by an occupational therapist.

First on the list of terms included within occupational therapy treatment in the "Uniform Terminology" is "independent living/daily living skills". The first element of this category is "physical daily living skills", which is the performance of daily personal care. In this sense, directing an attendant through a personal care routine is a physical daily living skill.

"Psychological/emotional daily living skills" is the next category, which includes "self-concept/self-identity". This subcategory involves "clearly perceiving one's needs". The process of learning to direct an attendant is a way of identifying one's needs. Referring to the identification of needs, Cole, et al. (1980a) point out:

This is often very difficult for the person who has had his care done to or for him by his family. Some handicapped people are not even aware of their own care routines because someone else has always assumed that responsibility for them. (p. 10)

These authors also mention that "people with medical training such as nurses or nurse's aides often perform tasks in a specific,
‘cookbook’ manner, again with no input from the person who is receiving the care” (p. 4). Because of this, even persons who are newly disabled (having led lives of “responsibility”) and are returning to community life after hospitalization, may need help learning to be responsible for perceiving their own needs.

“Clearly perceiving one’s values and expectations” is a skill in the "self-concept/self-identity" category of the "Uniform Terminology". This can be an important part of preparing oneself for attendant management, as can be seen from this quote from Cole et al. (1980b):

"Knowing the type of person you are looking for will require you to carefully examine your own values as well as your motivations for wanting to live independently" (p. 6). These authors ask the handicapper to examine whether they want an employee only, or a friend-companion, a housekeeper and/or a substitute mother.

“Realistically perceiving others’ needs, values, and expectations” is another subcategory listed which is important to attendant management. McGwinn (1977) says:

Predictable types of personalities are attracted to the disabled...The attitudes and actions projected from these motivations are not always palatable to a disabled individual, and certain tensions result...it becomes imperative for the disabled individual to determine exactly what type of personality he works best with and develop the perception to recognize it. (p. 85)

"Knowing one’s performance strengths and limitations" and "sensing one’s competence and goals" are other subcategories of self-concept/self-identity as listed in the "Uniform Terminology". These skills are important in attendant management, because, as Page (1981) notes, handicappers can become more dependent on their PCA’s than is
necessary. Smith and Meyer (1981) also recognize this, and suggest that achieving independence may take patience: "In some situations, the individual may be capable of independence if they are given a little extra time to try new techniques" (p. 263). There was one reference found in the occupational therapy literature related to this dilemma. Warren (1974), when writing about the dynamics involved in a volunteer chore service program, says: "In older people the dependence-independence balance is especially delicate, requiring an inordinate degree of awareness on the part of the therapist and others lest one err toward overprotection or toward unrealistic expectations" (p. 336). In order to help avoid unnecessary dependence, some Centers for Independent Living (such as that described by Page, 1981) require contracts to be agreed upon between all parties involved—the handicapper, the attendant, and the agency. This encourages the realistic identification of the handicapper’s strengths, limitations, and goals.

"Sensing one’s... self-esteem and self-respect" is another skill listed which can be promoted through the competent direction of an attendant. Competent attendant management can be a valuable source of pride to meet esteem needs for the severely handicapped. McGinn (1977) points out that:

For the person not born with his disability, there is the arduous adjustment to the reality of another person taking care of his body, his personal possessions, and his home. Not only has he lost control of his body movement, but of body maintenance. (p. 84)

The “Uniform Terminology” also lists “situational coping”, which is "skill in handling stress and dealing with problems and
changes...". We have seen how hiring an attendant can be a solution to stress resulting from total care provided by family members. But we have also seen how hiring an attendant has the potential for producing another set of stressors. Teaching attendant management can be seen as an appropriate modality for promoting situational coping skills in specific clients.

"Community involvement" is listed in the "Uniform Terminology" as the "skill and performance in interacting within one's social system". The category of community involvement includes "planning, organizing, and executing daily life activities in relationship to society". Activities are listed such as "budgeting, time management, social role management, arranging for housing, nutritional planning, and assessing and using community resources". Attendant care management can be seen as an interaction with one's social system, and would seem to fit well alongside the other activities listed.

"Problem-solving", is listed in the "Uniform Terminology" as a subcategory of "cognitive integration" skills. The steps listed are: 
"(a) defining or evaluating the problem, (b) organizing a plan, 
(c) making decisions/judgements, (d) implementing plan..., [and,]
(e) evaluating decision/judgement and plan". These steps could be used to cope with a variety of situations which may be encountered by handicappers within the attendant care process. For instance, a sample problem could be "How to hire an attendant that is right for me", or "How to deal with an attendant that is not working out". Learning to solve these types of attendant care problems can be a skill transferable to promote more general independent living competencies.
In the "Uniform Terminology", the psychosocial component of "self-management" includes "self-expression". Learning how to clearly explain instructions to an attendant can be a modality for acquiring self-expression skills. "Self-control" is another subcategory. McGwinn (1977) seems to recognize the importance of self-control when she relates advice to handicappers on avoiding emotional involvement with attendants, and on making a schedule and sticking to it, "whether you feel like it or not, so everyone knows what to expect" (p. 76).

Another psychosocial component of occupational therapy treatment listed in the "Uniform Terminology" is "dyadic interaction", which is the "skill and performance in relating to another person". It includes "understanding social/cultural norms of communication and interaction in various activities and social situations". Learning to relate appropriately to an attendant can be a way of understanding the social norms of dyadic interaction, as can be seen from this quote from Cole, et al. (1980a):

Disabled people who grow up with their handicap might have missed out on some experiences in their childhood causing them to be less skilled in some areas than their able-bodied counterparts. For example, some handicapped people in this group do not know how to relate to able-bodied people because they might have attended special schools where they were around only other children with handicaps. Often, children in this category are overprotected by their families, they might not have had the opportunity to make decisions or to learn appropriate behavior in public. (p. 7)

The "Uniform Terminology" also includes "setting limits on self and others", "compromising and negotiating", "handling...frustration [and] anxiety", and "cooperating...with others" as "dyadic interaction" skills. A successful attendant care relationship...
requires all of these elements. Smith and Meyer (1981) note that in attendant care "the issue of possible attendant-employer personality conflicts is multiplied threefold, for their interaction involves all three settings—social, business, and intimate" (p. 264). Another "dyadic interaction" skill listed in the "Uniform Terminology" is "responsibly relying on self and others". One could say that the difference between attendant care and custodial care is that in directing attendants, a handicapper responsibly relies on others, while in custodial care the reliance minimizes responsibility.
Dear Director of Occupational Therapy:

As a graduate student in occupational therapy at Western Michigan University, I am completing a thesis on the relevance of attendant care to occupational therapy. You have been randomly selected from a list of the adult physical disabilities rehabilitation settings across the country which have occupational therapy services. Your responses are very important since results of this survey will be reported in an article that will be submitted to the American Journal of Occupational Therapy. All data will be coded so that your responses cannot be identified, and all data will be reported as group data. I would appreciate your returning this questionnaire by February 15, 1984. Thank-you for taking the time to complete it.

Primary investigator: Barbara Barrett, BA, MA

Attendant care is defined as help with activities of daily living (bathing, dressing, bladder and bowel routine, household chores, etc.) given by a paid employee to a physically disabled person. Attendants are needed by people because the severity of their physical handicap is such that they are unable to complete their activities of daily living alone, or, it takes them so long to complete their daily living tasks that they don't have time or energy left to do other things, such as hold a job in the community.

The majority of people who need help with their personal care rely on family members, but this can result in a high amount of stress within the family. By employing an attendant, a handicapper can be in control of his or her personal care, rather than be dependent on the help of family or friends. The concept of attendant care is part of the "independent living" model, as opposed to respite care, which is oriented more towards providing occasional relief from 24-hour care to family members of a dependent disabled person.

1. Some people who are recovering at home need only temporary help until their condition stabilizes. Please estimate how many people have been served by your OT services in the last year who could benefit from having a temporary attendant:
2. What are the sources of temporary aides or attendants (such as from home health agencies) available in your area?

___ Don't know what is available

3. Other persons who are permanently physically disabled need attendants for the rest of their lives in order to attain independent living. How many people have been served by your OT services in the last year who could benefit from having an attendant on a permanent basis?

4. What are the sources of permanent attendants available in your community?

___ Don't know what is available

5. ARE THE FOLLOWING SERVICES AVAILABLE TO CLIENTS IN YOUR COMMUNITY? IF SO, PLEASE CHECK WHO PROVIDES THEM:

<table>
<thead>
<tr>
<th>Service</th>
<th>OUR OT DEPT.</th>
<th>A DIFFERENT DEPT. IN OUR AGENCY. IF SO, INDICATE WHICH DEPT.</th>
<th>A DIFFERENT AGENCY IN THE COMMUNITY. IF SO, INDICATE WHO:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant recruitment</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&quot; screening</td>
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<td></td>
<td></td>
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<tr>
<td>&quot; training</td>
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<tr>
<td>&quot; placement</td>
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<tr>
<td>&quot; follow-up</td>
<td></td>
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<td></td>
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<td>&quot; payment</td>
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</tbody>
</table>

6. If your OT department doesn't provide any of the services listed above, why not?
Rank those statements that apply (#1 being the most important):

___ a. Our OT staff is not trained in how to provide the services.
___ b. These services are not within the OT scope of practice.
___ c. These services are not needed by our clients.
___ d. We aren't interested in attendant care because we feel that family members should provide the care instead of attendants.
___ e. Providing these services is not financially feasible in terms of reimbursement.
___ f. We would like to provide these services, but our employer/agency doesn't support the idea.
___ g. Other reasons. Please describe: ____________________________________________
7. Do you feel that your community has enough attendant care programs to meet the need?  
   Yes  No  Don't know  
   Comments:  

8. What are the major sources of payment for attendants available in your area?  
   Don't know  

9. If your OT program has a client who needs attendant care, what do you do?  
   Briefly describe your usual procedure:  

   The following services differ from those in the chart on page 2 in that they can be offered without having to start an attendant recruitment and training program (thus, they require less program change to implement). Examples of these attendant care "support services" which could be offered by an OT department are listed below:  

   ATTENDANT CARE SUPPORT SERVICES  
   _ Assessment of client's need for attendant care.  
   _ Education of client on agencies that provide attendant care services in your community.  
   _ Actively arranging for the client to be linked up with other departments or resources who can help them meet their attendant care needs.  
   _ Orientation of the client to the possible payment sources for attendants.  
   _ Orientation of the client to the possible attendant care arrangements (live-in, parttime, clustered handicapped housing that shares attendants, etc.)  
   _ Training of client in how to hire an attendant without agency help (how to place an ad in the newspaper, effective interviewing techniques, etc.)  
   _ Training of client in how to direct/supervise an attendant (how to avoid dependence, how to deal with interpersonal conflicts, etc.)  
   _ Working with the client's attendant in how to provide help with activities of daily living (transferring techniques, use of adaptive equipment, how to avoid fostering dependency, etc.)  
   _ Post-discharge periodic assessment/ supervision of client's attendant care situation.  

10. Please put a check next to any of the services listed above that you provide.  

11. If you don't provide any of these services, do you think it would improve the effectiveness of your therapy for those who need an attendant?  Yes  No  

12. Did you receive training in your OT school as to how to provide the services listed above?  Yes  No  

13. Do you feel that OT schools should give training in how to provide the above services?  Yes  No  

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14. If you don't provide any of the attendant care "support services", why not? Refer to the possible reasons (a through g) in question #6, and list here in order of importance: 
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

15. Type of OT services you offer to physically disabled clients:
(Check all that apply and estimate number of clients seen per month)

- Acute care
- Rehabilitation beds
- Inpatient
- Outpatient
- Home treatment
- Home assessments of architectural barriers
- Vocational adjustment
- Transitional living facility
- Other (please list):

#clients/mo.:

- __________
- __________
- __________
- __________
- __________
- __________
- __________
- __________
- __________

16. What is the number of counties that you serve? ____________________________

17. What is the age range of your clients? ________________________________

18. What are the most common disabling conditions of your clients? List in order with #1 being the most common: 1. ____________________________
    2. ____________________________
    3. ____________________________
    4. ____________________________

19. How many OTR's do you have on your staff? Fulltime:
    Parttime (less than 25 hours a week) :

   How many COTA's do you have on your staff? Fulltime:
   Parttime:

20. Please add any further comments concerning attendant care: ______________

If you would like to receive a summary of the results of this study when it is completed, send a self-addressed, stamped envelope to Barbara Barrett
1803 N. 5th St.
Kalamazoo, MI 49009

THANK-YOU!
APPENDIX E

SURVEY OF CENTERS FOR INDEPENDENT LIVING
Dear Director:

I am a graduate student in occupational therapy at Western Michigan University. I am doing a study of the various attendant care programs offered by Centers for Independent Living nationwide, as part of a thesis on attendant care. The data will be analyzed for the relevance of attendant care to occupational therapy. An article will be submitted to the American Journal of Occupational Therapy on this topic, so it is important to receive your responses. I appreciate your taking time to complete and return this survey by March 8, 1984. All surveys will be coded so that no individual can be identified, and data will be reported as group data.

If you would like to receive a report of the results of this survey when completed, include a self-addressed and stamped return envelope with this survey, or send separately to me at 1803 N. 5th St., Kalamazoo, MI, 49009.

Thank-you for your participation.

Sincerely,

Barbara C. Barrett

(Note: I am asking that program directors complete the survey because some of the questions, especially page 4, require an over-all view of program objectives.)

1. How many counties do you serve? __________________________________________

2. Approximate number of people you serve per month (in general): _________________

3. How many people do you serve per month in your attendant care program? _________________

4. Do you have a transitional living facility as part of your program? _________________

5. Is your community in need of more attendant care services than are currently being offered? ____ If so, what kind? _________________

6. What is the biggest problem that people face concerning their attendant care? _________________

7. How do your clients pay for their attendant care? Include the maximum amount that each source provides per month:

   SSI $ _____  SSDI $ _____ Private Insurance $ _____

   State assistance (chore service allowance) $ _____

   Other (describe): __________________________________________________________ $ _____

8. How are clients referred to your attendant care program? _________________

   Do you ever receive referrals from occupational therapists? _________________

   If not, from whom? _________________

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OF YOUR CLIENTS:

APPROXIMATE PERCENTAGE:

9. What percentage have attendants? 

What percentage don't have attendants, but could use one? 

Of those who have or need attendants, what percentage need 
training or counselling in how to obtain and supervise them? 

What percentage find the process of obtaining and keeping 
attendants to be a major source of stress? 

What percentage have difficulty obtaining financial resources 
to pay for attendants? 

Of those who need attendants, what percentage need the help 
temporarily, until their condition stabilizes? 

What percentage need help permanently, on an on-going basis? 

10. What are the most common disability groups served by your attendant care program? 
(List in order with the most common being first) 

1. 

2. 

3. 

4. 

11. PLEASE CHECK APPROPRIATE COLUMNS AND FILL IN THE BLANKS FOR EACH OF YOUR STAFF 
MEMBERS WHO HELP RUN YOUR ATTENDANT CARE PROGRAM (include yourself if applicable):

<table>
<thead>
<tr>
<th>Position Title:</th>
<th>Experience and/or academic degree:</th>
<th>Duties performed for attendant care program:</th>
<th>Paid?</th>
<th>Volunteer?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
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<td>2.</td>
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<td>3.</td>
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<td>4.</td>
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<td>5.</td>
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</tbody>
</table>

12. What is the salary range of those fulltime staff who help run your attendant care 
program? under $10,000 $13,000-$16,000 $19,000-$22,000 
$10,000-$13,000 $16,000-$19,000 above $22,000

13. How are these salaries funded? Include percentage of contribution from each source:

<table>
<thead>
<tr>
<th>Title VII</th>
<th>State funds</th>
<th>United Way</th>
<th>Foundation grants</th>
<th>3rd party/private insurers</th>
<th>Other (list)</th>
</tr>
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<tbody>
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</table>

14. FOR THOSE CENTERS THAT DO NOT HAVE A NURSE OR DOCTOR SUPERVISING THEIR 
ATTENDANT CARE PROGRAM:

If you did, do you feel that you would be more apt to receive Medicare/Medicaid 
or private insurance reimbursement for the salaries of those who run your 
attendant care program? Yes No 

Or, for the payment of attendants? Yes No _____
15. ON THE RIGHT, CHECK THE APPROPRIATE COLUMN 
FOR THE SERVICE YOU PROVIDE: 

<table>
<thead>
<tr>
<th>Service Description</th>
<th>YES</th>
<th>NO</th>
<th>PLAN TO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant recruitment</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&quot; interviewing</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&quot; reference checking</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&quot; training</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Placement of attendant with client</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Ongoing supervision of placement</td>
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<td></td>
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<tr>
<td>In-home assessment of client's attendant care needs</td>
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<tr>
<td>Training client in attendant management (including</td>
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<tr>
<td>recruitment, supervision, and interpersonal communications</td>
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<tr>
<td>Writing &quot;growth plans&quot; (goal-setting with client,</td>
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<tr>
<td>evaluating areas needing improvement before</td>
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<tr>
<td>independence in attendant care management can be met)</td>
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<tr>
<td>Others? Please list:</td>
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<td></td>
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</tbody>
</table>

16. If you provide a training program to attendants, what areas are included in your course? Please check:

- CPR
- Bowel and bladder routine
- Catheter care
- Colostomy care
- Prevention of pressure sores
- Information on specific disabilities
- Sexuality
- Independent Living concepts (e.g. locus of control is within handicapper, not attendar
- Nutrition
- First aid and dealing with emergencies
- Body mechanics, transferring
- Wheelchair maintenance
- Adaptations for activities of daily living
- Interpersonal communications
- Assist with range of motion
- Recording vital signs:
  - Blood pressure
  - Temperature
  - Pulse
- Other (please list): ________________________________________________________

17. How many hours does it take to complete your training program? ________________

18. Do you certify persons who complete your training? _______ If so, how many have you certified, and over what period of time? _______________________________________________
An additional purpose of this study is to explore the possible role of occupational therapy within independent living and attendant care. The following definition is included in case you are not familiar with the field:

Occupational therapy is the use of purposeful activity with individuals who are limited in their ability to perform tasks, in order to maximize independence, prevent disability, and maintain health. Specific O.T. services include teaching daily living skills, developing prevocational and leisure capacities, designing and fabricating adaptive equipment, and evaluating and modifying environmental barriers.

19. Do you see occupational therapy as a service which would be an asset to your independent living center?  ____Yes  ____No  If yes, why or how?  

20. Do you think an O.T. would be an appropriate person to:
   Coordinate an attendant care program?  ____Yes  ____No
   Assess handicappers' need for attendant care?  ____Yes  ____No
   Teach attendants management to handicappers?  ____Yes  ____No
   Teach an attendant training class?  ____Yes  ____No

21. Do you have an O.T. on your staff part-time?  ____Yes  ____No
    full-time?  ____Yes  ____No

22. Do you ever contract O.T. services?  ____Yes  ____No

23. If you answered yes to questions 21 or 22, please describe the occupational therapy services given:

24. How are the O.T. services paid for (what funding source is used)?

25. If you don't currently, do you plan to hire or contract the services of an O.T.?  ____Yes  ____No  If so, when?

26. Please check any of the following statements that apply to you:
   CHECK: "We would like to hire an occupational therapist, but...
   ____ we lack money to hire additional staff."
   ____ hiring people with other degrees is a higher priority."
   ____ I can't find any O.T.'s in our community to hire."
   ____ I wasn't familiar with O.T. services before reading this survey."
   ____ the need or desire to hire handicapped persons limits the O.T. applicants that are considered."
   "We are not interested in hiring an occupational therapist because...
   ____ we desire to minimize reliance on medical professionals."
   ____ we desire to run our C.I.L. on volunteer help."
   Other reasons for not hiring an O.T. are:  

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APPENDIX F

DEFINITION OF TERMS

The following are definitions of terms as developed for the purposes of this study:

**Permanent attendants**—Hired by persons who are permanently physically disabled and who need on-going assistance in order to live independently in the community. This is the type of attendant care that is the focus of the independent living movement.

**Temporary attendants**—Used by persons recovering at home from accident or illness after hospitalization who need only temporary care, until their acute conditions have stabilized. Temporary attendant care is usually contracted through home health agencies in the form of home health aides, and is usually covered by insurances.

**Attendant Care Programming**—Formally provided services such as training courses (e.g., how to be an attendant or how to manage an attendant), which require program development and staffing to implement. Often provided by CIL’s.

**Attendant Care Support Services**—Services provided on an as-needed, individualized basis which can be incorporated into the normal occupational therapy treatment time of rehabilitation programs (e.g., assessment of a client’s need for attendant care).


Shrifter, N. (1980). The physician and home health care---costs are less and the patients feel better. LAMCA Physician, October.


