An Ethnographic Study of Independent Living Alternatives

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The purpose of this ethnographic study was to compare 12 settings in which housing, attendant assistance, and transportation were shared by clusters of young adults with physical disabilities during the early years of the independent living movement. The settings that were studied were (a) a demonstration independent living program established by a medical rehabilitation facility, (b) a university dormitory, (c) four apartment clusters, and (d) six nursing homes. Data were gathered with ethnographic interviews of 109 subjects as well as by participant observation in each setting. Independent living alternatives are compared in terms of their ability to support residents' engagement in school, work, and leisure activities and their social and cultural similarities and differences. Findings are also reported on how residents viewed their experience in clustered living arrangements and how they believe these experiences shaped their future. Implications of the findings are discussed in terms of public policy issues, including the need for community-based support services, alternative models for organizing such services, and better planning of transitions from institutions to the community.

Prior to the start of the independent living movement in the early 1970s, persons with severe physical disabilities typically lived either in institutions or at home in the care of family members. Few persons with disabilities had the tenacity and the extraordinary financial resources to manage independent living arrangements in the community (Trieschmann, 1987). The independent living movement was based on the premise that, with reasonable support services, adults with physical disabilities could manage their own affairs and participate as full members of the community in all respects (Frieden, Richards, Cole, & Bailey, 1979). The independent living movement thus involved both a philosophy of full participation in community life and advocacy for a set of services that would meet the long-term support needs of citizens with disabilities.

The early years of the independent living movement are defined as the period before passage of the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments (Public Law 95-602), which established support for independent living organizations as a part of federal public policy (Verville, 1979). This consumer-initiated movement was organized by persons with disabilities; it is part of a long tradition of self-help movements in this country (Zola, 1979). Concurrent with initiatives of disabled consumers during the early 1970s, various organizations were also concerned about community adaptation of persons who had completed time-limited rehabilitation programs and who had remaining long-term, ongoing support needs. It was for this reason that in September 1972, The Institute for Rehabilitation and Research in Houston established a residential program called “A Cooperative Self-Support System for Severely Physically Disabled Young Adults” with funding from the Rehabilitation Services Administration. Within a few years, other medical rehabilitation facilities also established independent living programs in association with citizens with disabilities in their respective communities (Fay, 1974), and several state vocational rehabilitation agencies, including those in California, Massachusetts, Michigan, and Texas, provided state-level support for independent living programs prior to the passage of Public Law 95-602 (Galvin, 1975).

The Cooperative Living Project at The Institute for Rehabilitation and Research was designed to address classic independent living needs of young adults with disabilities, including accessible housing (Lifchez, 1979), attendant assistance (Dejong & Wenker, 1979), and accessible transportation (Bowen, 1979). The project was cooperative in several respects. Residents organized a management system for sharing attendant assistance and transportation to make these needed support services less costly. Cooperative funding mechanisms included rent subsidies from the Houston Housing Authority and support for attendant services and transportation from the Texas Rehabilitation Commission, in addition to the pro-

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Research sponsored by the Cooperative Living Project included a longitudinal study to track the activities and living arrangements of residents before they entered the project, during their stay, and after their departure to new living situations. In addition, an ethnographic study was completed to compare a variety of clustered living arrangements used by young adults with disabilities in Houston from 1974 to 1976 (Stock & Cole, 1977). The cluster, or residential, model of independent living refers to situations in which support services are shared by a group of persons with disabilities living in proximity, in contrast to the nonresidential model, exemplified by many independent living centers that help persons find housing or attendants or transportation but do not manage provision of these services in a single setting (Frieden, 1983). Ethnographic methods were chosen because the unit of study was the setting as a whole, including its physical environment, its social system, and its culture. The goal was not only to investigate specific research questions that I thought were important, but also to capture the views of residents themselves about important issues in their living arrangements.

The purposes of this paper were to describe findings of the comparative ethnographic study of clustered independent living alternatives and to examine whether changes have occurred over the past 15 years in key independent living issues that emerged at the time of the Stock and Cole (1977) study. These issues were (a) the need for the establishment of long-term support systems for persons with disabilities and a determination of the ways in which such systems can best be organized and financed, (b) the relative merits of living arrangements that foster cohesion among persons with disabilities versus those that foster the integration of such persons into the mainstream social structure, and (c) methods by which persons can best make adaptive transitions between time-limited rehabilitation programs and long-term support arrangements in the community. With substantial growth in populations of disabled and elderly citizens in this country and with a growing trend toward community-based service provision in health care, these issues remain important public policy concerns today. Occupational therapy’s commitment to helping persons function as well as possible in their own settings makes these issues particularly relevant to our profession.

Literature Review

At the time the ethnographic study of independent living alternatives was conducted and prior to the passage of Public Law 95–602 to amend the Rehabilitation Act of 1973 (Public Law 93–112), literature on independent living was limited. A study conducted by Miller and Gwynne (1972) in Great Britain showed some of the disadvantages of nursing homes as a living arrangement for young persons with disabilities. Surveys of housing needs of persons with disabilities had been conducted in various locations, including California and Massachusetts, and the Urban Institute had conducted a large-scale survey of general needs of persons with disabilities, which was mandated by Public Law 93–112. This research led to the publication of a widely cited report, the Comprehensive Service Needs Study (Urban Institute, 1975).

In the early years of the movement, few authors had described specific models of service provision for independent living (Brattgard, 1971; Fay, 1977; Urban Institute, 1976). Efforts were made to survey and document the range of existing independent living alternatives available (Farber, 1973; Fay, 1974; Laurie, 1977; Pflueger, 1977). These included a series of papers published as an outgrowth of a conference on independent living organized by the Berkeley Center for Independent Living in Berkeley, California, and funded by a grant from the Rehabilitation Services Administration (Berkeley Center for Independent Living, 1975), as well as a special issue of American Rehabilitation (Bourgea, 1978). Publications advocating a wider range of choices in living arrangements during this period included papers from the White House Conference on Handicapped Individuals (1977).

Following passage of Title VII of Public Law 95–602, which provided for funding of independent living centers in Part B, literature on independent living grew rapidly. For example, in 1978, the Rehabilitation Services Administration conducted a working conference devoted to the role of vocational rehabilitation agencies in independent living (Dowie, 1978). In 1979, a special issue of Archives of Physical Medicine and Rehabilitation was devoted to independent living (Crewe, 1979). A series of publications emerged from the Independent Living Research Utilization Project at The Institute for Rehabilitation and Research (Frieden et al., 1979). Book-length publications on independent living also began to appear (Crewe & Zola, 1983).

The role of occupational therapists in independent living programs was articulated in a position paper on this subject published in 1981 (American Occupational Therapy Association [AOTA], 1981). This paper emphasized the congruence between the philosophy of the occupational therapy profession and that of the independent living movement. Several therapists have described involvements in specific independent living programs (Friedlob, Janis, & Deets-Aron, 1986; Neistadt, 1987; Neistadt & Marques, 1984). Other writers in the profession have addressed community support issues for disabled or elderly citizens (Bachelder, 1985; Burnett & Yerxa, 1980; Frieden & Cole, 1985; Krefting, 1989; Leonardelli, 1989; Morgan, Patrick, & Charlton, 1984; Neistadt & O’Reilly, 1988; Yerxa & Baum, 1986; Yerxa, Burnett-Beaulieu, Stocking, & Azen, 1988), which are the larger subject of the present paper.
Method
The settings that were compared in the ethnographic study were the Cooperative Living Project, which had 14 residents with disabilities; the Moody Towers dormitory at the University of Houston, which housed 13 students with disabilities; and four apartment clusters in which groups of 10, 11, 18, and 20 residents with disabilities managed shared attendant and transportation services. In addition, six nursing homes were studied, because at that time, nursing homes frequently housed young persons with disabilities. These six homes had 1, 2, 2, 3, 6, and 9 young residents with disabilities. Thus, 109 subjects in 12 different clustered settings were interviewed for this study.

The subjects were adults between the ages of 18 and 50 years who had various physical disabilities, including acquired traumatic injuries such as spinal cord injury, diseases such as muscular dystrophy, and congenital disabilities such as cerebral palsy. All of the subjects used wheelchairs for mobility and required some attendant assistance to manage activities of daily living. The subjects were recruited primarily through the settings in which they lived, although personal contacts with members of the larger community of disabled persons were helpful in this process.

The dimensions studied in each setting were (a) the characteristics of the residence as a physical structure, (b) the location of the residence in relation to other elements of the surrounding community, (c) the demographic characteristics and support needs of the residents, (d) the social system and culture of the resident group, (e) the outside activities and social relationships of residents, (f) the advantages and disadvantages of support services provided, (g) the management system and procedures by which services were organized, (h) the costs and methods of financing the living arrangements, and (i) the opinions of residents about their living arrangements and about public policy issues that affect persons with disabilities. The purpose of the study was not to establish causal relationships or statistical associations between variables, but rather, to generate hypotheses or theories about the effects of alternative living environments on the behavior and attitudes of residents.

Data were gathered through intensive interviews with disabled residents of each setting as well as with other members of the social system, including attendants, management personnel, and nondisabled friends, when such persons were available and willing to participate. I conducted the interviews; at the time of the study I was an anthropologist but have since become an occupational therapist. A general interview schedule was used for all interviews, although many of the questions were open-ended and prompted lengthy departures from the standard set of questions. Quantitative data were gathered on demographic information, kinds of assistance used by the person, personal income and expenses, time spent in various activities, and types of social contacts and frequency of interaction. Some open-ended questions dealt with personal values and experiences, for example, "What factors were important in your decision to live in this residence?" or "Have your goals in life been influenced by your disability?" Other open-ended questions dealt with the residential environment, for example, "Have other persons who live here influenced you and in what ways?" or "What are causes of conflict between persons who live and work here?" A final cluster of open-ended questions dealt with public policy issues related to persons with disabilities, for example, "What changes would you recommend in the present system of providing support services and financial assistance to persons with disabilities?"

Participant observation was also an important means of data gathering, although this was more feasible in some settings than others. An effort was made to be present at times when disabled persons would be interacting with other members of the social system, such as at mealtimes in the dormitory cafeteria. This involvement provided an opportunity to generate hypotheses about what was going on, which later could be verified by interviews. For example, it was noted during one lunchtime that 2 of the dormitory residents with disabilities appeared to avoid sitting and eating with other students with disabilities. In later interviews, these persons clarified that they preferred to avoid being categorized with persons with disabilities as a group, because they considered such persons to have more severe (or visible) disabilities. I tried to verify such observations about the social system by discussing them with more than 1 person, a process often referred to as triangulation of data (Guba & Lincoln, 1987). Generally, observation of participants was less successful at most of the nursing homes and two of the apartment clusters, because members of these social systems seemed uncomfortable being observed. This could probably have been overcome if it had been possible to spend more time in each setting.

The data were recorded in field notes and were then analyzed through categorization according to content areas or themes. In some cases, these categories were anticipated before the study began, and in other cases they emerged over time and then formed the basis around which future data gathering was directed. For example, some time after the research began, it became evident that certain informal social roles seemed to appear in several settings, such as the roles of "contact broker," "goat," and "cruise director." Once these recurring roles became evident, future questioning could then be directed toward (a) whether some form of such roles existed in each setting, (b) clarification of the functions that these roles appeared to serve, (c) the kinds of persons who assumed or were cast in these roles, and (d) similarities and differences in how the roles were enacted in various environments.

Written interpretations of findings were generated
on an ongoing basis during the study to articulate and document hypotheses about how each residential system operated and to compare similarities and differences among settings as well as to begin drawing general conclusions about the study as a whole. In recent years, it has become commonplace in ethnographic research to include a systematic ongoing review of the findings by persons other than the main researcher in order to maximize the trustworthiness of the findings and to avoid interpreter bias (Guba & Lincoln, 1987). Such provisions emerged as ethnographic research methods originated with single anthropologists who studied remote cultures. Later, these methods were applied to the study of complex cultural systems in industrialized societies, where colleagues or teams of researchers were more readily available. The present study was conducted in the older ethnographic tradition of data gathering and interpretation by one researcher, so that a systematic review of the findings and interpretations by others was not a formal part of the study methodology. Such review, however, occurred on an informal basis by selected staff of The Institute for Rehabilitation and Research, by one of the residents of the Cooperative Living Project who had an academic background in social science research, and occasionally by other subjects. The matter of potential interpreter bias is important, because support for the researcher was provided by the same grant that established the Cooperative Living Project. A substantial effort was made to avoid prior judgments about the relative advantages and disadvantages of the alternative living arrangements studied and to consider these from the point of view of individual residents who had diverse values. Nonetheless, it is probably impossible to avoid value judgments concerning what factors contribute to quality of life.

Results

Short ethnographies were written about each living environment; they could not be included here due to their length. A report including these ethnographies is available elsewhere in limited quantity (Stock & Cole, 1977). Major findings that emerged from a comparison of alternative living arrangements fall within three broad areas. One is the ability of the logistical systems of each setting to support the involvement of residents in activities and the social roles and relationships that these residents valued. The second area concerns the social and cultural systems of the settings and the behavior and attitudes that these systems cultivated or reinforced in residents. The third set of findings relates to the part that the experience of living in a cluster setting seems to have played in the longer term life histories of residents.

Logistical Support Systems

The findings suggest that residents of each setting were able to sustain involvement in outside activities, including work, attendance at college or vocational training, and leisure activities. Such involvement, however, seemed to have been much easier to arrange and execute in some settings than in others. Residents in the Cooperative Living Project were all working or attending either college or a vocational program, and residents in the university dormitory were all attending school. These offer an interesting contrast, in that the Cooperative Living Project was located in a residential neighborhood and provided a shared van to transport residents to outside activities, whereas the Moody Towers dormitory was located on campus, which allowed residents to use wheelchairs for travel. The ease and spontaneity afforded by wheelchair travel alone was counterbalanced by the fact that such travel was restricted to the limited social system and activity options of an academic community, with residents rarely traveling outside of these settings. The four apartment clusters differed in the extent to which they supported involvement of residents in outside activities. Such support, however, appeared to be due more to the maturity and experience of the residents themselves than to substantial differences in the logistics required for mobility by the project van.

Residents from only one of the six nursing homes were able to attend college, and none of the nursing home residents were working. Attendance at the university for the 9 residents of this particular nursing home was feasible because of the incorporation of a nonprofit organization specifically for the purpose of purchasing a van to provide transportation. Because the drivers for this van were all volunteers, the van was available less often for leisure activities than were the vehicles belonging to the apartment clusters or the Cooperative Living Project, for which drivers were hired. The nursing home residents thus spent most of their time within these largely self-contained residential settings.

Attendant care systems in the various settings also differed substantially, although all of them seemed able to support residents' involvement in outside activities. The Cooperative Living Project and four apartment clusters each had a staff of attendants who were scheduled according to peak periods for activities of daily living in the morning and evening and who were shared by groups of residents on a sign-up basis. Attendants were hired, supervised, and paid by a management system operated by the residents themselves, sometimes with a single manager and sometimes with a group council serving this function. These shared attendant systems offered the advantages of efficiency and low cost in use of attendant time; less intense one-to-one relationships between a resident and attendant as compared with the other settings, in which each person had only one attendant; and a management system that handled the time-consuming tasks of recruiting, hiring, and supervising attendants, thus freeing the resident from these responsibilities. The disadvantage of this system was less personal choice in

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the selection of attendants and less direct control over the
attendants' performance. All of the students in the Moody
Towers dormitory had their own private attendants, many of whom were the students' roommates. This pro-
vided the residents with direct choice and control but
usually led to intense relationships that often dissolved at
the end of one semester, even if the two parties had not
had major quarrels or disagreements. Both the students
with disabilities and the attendants speculated that this
was due to the intensity or constancy of the relationship,
which seemed to occur despite the use, in some cases, of
back-up attendants. The intensity problem seemed less
troublesome for those who were not roommates, though
this meant that activities of daily living had to occur at a
scheduled time. Nursing home attendant systems were
operated on a nursing model that most young residents
with disabilities found somewhat restrictive, although a
few attendants at some homes were themselves young
persons who developed friendships with young residents
and interacted less formally.

Costs for basic living services of room, board, and
attendant care in these settings ranged from $340 to $513
per month. (These figures represent 1975 dollar values
that have not been adjusted for inflation.) The least ex-
pensive alternatives were the Cooperative Living Project
($345) and the Moody Towers dormitory ($340), due to
the relatively low cost of dormitory-style residential space
in facilities owned by nonprofit organizations. Residents
of the Cooperative Living Project, on average, paid an
additional $55 per month for van transportation, which
was not needed by the Moody Towers residents. The four
apartment clusters represented a middle-level cost of liv-
ing. Apartment rental was more costly than dormitory
housing, although residents had more space and privacy
in the apartment settings. Apartment cluster residents
typically paid about $180 per month for rent, $100 for
food, and $220 for attendant assistance, for a total of $500
per month in basic expenses, plus an average of $57 per
month for transportation. The persons with disabilities
who chose the above alternatives typically paid their ex-
penses with a patchwork of resources, including personal
and family income, Supplemental Security Income and
Social Security Disability Income, rent subsidies from the
Houston Housing Authority, and support of attendants
and transportation from the Texas Rehabilitation Com-
mission if the person were attending college or voca-
tional training. At one of the apartment clusters, the
residents received support for attendant assistance
through Title XX housekeeper and chore service con-
tracts with an older woman who managed the attendant
system at that site.

The six nursing homes were the most costly choice
for room, board, and attendant assistance, with a monthly
fee of $513 paid by the Medicaid program. This figure
does not include transportation costs, because this ser-
vice was not available. The subjects thought it ironic that
it was easiest to get public financial assistance to live in
the most costly living arrangement, which was also the
least desirable according to most of the young nursing
home residents. This irony holds true today in many
states, despite 15 years of efforts to improve public finan-
cial support for attendant assistance and accessible trans-
portation outside institutional settings.

Social and Cultural Systems

The 12 settings differed substantially in the extent to
which their cultures required or encouraged residents to
be involved in such outside activities as work, college or
vocational training, and leisure pursuits. In two of the
settings—the Cooperative Living project and the Moody
Towers dormitory—persons with disabilities knew ex-
plicitly before moving to the setting that such involve-
ment was expected by the organization that operated the
setting. In three of the apartment clusters, similar re-
quirements were established by the Texas Rehabilitation
Commission for their clients who received assistance
with attendant assistance and transportation. The legal
mandate of this agency at the time was to serve clients
who were working toward specific vocational objectives.
These requirements to be engaged in work or education
in order to live in a setting or to become eligible for
financial support did not pertain to residents of the nurs-
ing homes who were supported by Medicaid or to per-
sons in the one apartment cluster in which the residents
received Title XX funding for housekeeper and chore
services.

Beyond formal requirements for involvement in pro-
ductive outside activities, the informal role of contact
broker was a factor within the social system of some
settings that proved to be an important means of helping
residents learn how to initiate and manage outside activi-
ties. This role was found in the Cooperative Living Pro-
ject, the Moody Towers dormitory, two of the four
apartment clusters, and one of the nursing homes. The term
contact broker was adapted from the work of Wolf
(1956), who coined the term culture broker to refer to
persons who serve as linkages between the cultural sys-

tem of a local peasant village and the larger regional or
national culture in which the village is located. Such per-
sons understand the rules and expectations of each of the
two cultures and manage to operate successfully in both.
Persons who functioned as contact brokers in the cluster
projects possessed good social capabilities and valued
skills, such as how to apply and interview for a job; how to
negotiate with benefit systems personnel; and how to
interact in important personal relationships, such as ask-
ning for a date. Other residents usually recognized the
valuable experience of contact brokers and used them
frequently as consultants and teachers. The residents
agreed on the identification of specific persons who
served as contact brokers within their particular setting,
although they had never assigned this role a formal name.

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Interestingly, usually only 1 person within each setting was cast in this role by the other residents. When this key person left the particular setting, he or she was usually replaced, often by a resident who had been there all along.

As the study progressed, it became evident that having a good contact broker was a great advantage to fellow residents and that residents of settings that lacked this kind of role model and consultant were disadvantaged in learning independent living skills. Admiration for persons who engaged in outside activities, their investment in the social systems of most settings and continued beyond the tenure of any particular person in the role. I believe that many of the persons viewed as goats by fellow residents were actually asking for frequent external visits because they wanted social closeness rather than the performance of physical tasks. The residents themselves did not acknowledge this need for companionship or personal security as a legitimate use of attendant time. It appeared that social processes surrounding the goat role served the function of reinforcing a cultural value on independence and autonomy.

Another important social role that fostered involvement in outside social and leisure activities was that of cruise director. Persons who filled this informal role were those who spent personal time and energy organizing for their fellow residents such leisure activities as trips to the beach, rock concerts, ball games, restaurants, or bars. Cruise directors were found in the Cooperative Living Project, one apartment cluster, and one nursing home. Cruise directors usually invested substantial time and effort in this role for several months when they were new to the setting, and they particularly valued group socialization and cohesion. Over time, as these persons cultivated more personal friendships outside the cluster and more engagement in outside activities, their investment in the role of cruise director for the group often dwindled.

In addition to expectations for engagement in community activities, another important cultural value reinforced in most of the cluster settings was emphasis on persons with disabilities functioning as independently as possible. This expectation meant two things to residents. One was the notion that the person with a disability would do as many activities of daily living as possible for himself or herself (this matches the definition of independence used by most occupational therapists). The second component of this expectation was that residents would anticipate and plan their needs in such a way that these could be met in as short a time and with as few interactions with attendants as possible. Thus, it was considered much better to ask for three tasks grouped together in the morning, two at noon, and five in the evening rather than asking for attendant assistance on 10 separate occasions during the day. This emphasis on efficiency in use of attendant time was reinforced by strong social sanctions against persons who the residents believed were wasting too much attendant time. A number of persons gained reputations as being spoiled and demanding if, given their degree of impairment, they were unable or unwilling to be as independent as was expected by the other residents. The consumer-run management groups of various settings often asked such residents to modify their behavior for the stated purposes of keeping attendant costs down and to avoid expectations of being waited on. This practice led to identification of another informal social role of goat, which became established informally in the social systems of most settings and continued beyond the tenure of any particular person in the role. I believe that many of the persons viewed as goats by fellow residents were actually asking for frequent external visits because they wanted social closeness rather than the performance of physical tasks. The residents themselves did not acknowledge this need for companionship or personal security as a legitimate use of attendant time. It appeared that social processes surrounding the goat role served the function of reinforcing a cultural value on independence and autonomy.

The Clustered Living Experience

One of the most important findings of this study was the transitional nature of living in a clustered setting in the lives of residents. The average length of time spent by residents in the Cooperative Living Project was 15 months, with most (82.5%) of these persons moving to more independent settings after leaving the project. Living in clustered settings often seemed to provide a learning experience similar to that provided by living in a college dormitory. Such settings typically provide residents with an opportunity for close social cohesion with peers and an opportunity to manage some adult responsibilities, such as one’s financial affairs, while allowing other household management responsibilities, such as meal preparation, to be managed by someone else. Many residents indicated that an important aspect of the clustered living situation was exposure to role models who had more life experience and who knew the ropes.

After living for some months in a clustered setting, residents often described feeling that they had outgrown the need for social cohesion with other persons with disabilities and preferred greater privacy and more integration into the everyday life and social system of the larger community. Some persons have chosen to continue their active association with fellow citizens with disabilities through advocacy or service provision organizations, but most of the original Cooperative Living Project residents seem to have chosen not to emphasize their commonalities with other citizens with disabilities.

Moving into apartments or into single-family dwellings within the mainstream was characteristic of residents of the Cooperative Living Project, the Moody Towers dormitory, three of the four apartment clusters, and one of the six nursing homes. These settings served as a practice
ground in which persons could rehearse skills in a supportive environment. The cluster settings thus provided one model by which the important adaptive transition from medical facility or parental home to management of one’s own home could be achieved.

Discussion

Despite substantial progress since the mid-1970s when the present study was conducted, the central issues that seemed crucial in the independent living movement at that time still remain salient today. In its report to Congress in 1986, the National Council on the Handicapped identified organization and funding of long-term community support services as a priority. This review of federal legislation and programs indicated that although Public Law 95–602 made it feasible for vocational rehabilitation agencies to serve clients in independent living situations who did not have vocational objectives, and although waiver processes have been established to allow some states to tap Title XIX Medicaid funding to pay for attendant assistance, community support services remain substantially underfunded. Many persons with disabilities continue today to find it easier to gain public support to live in an institution such as a nursing home than to obtain support for the less expensive alternative of community-based attendant assistance (Nosek, 1985). The findings of the present study indicate that a variety of factors shape the living arrangement preferences of persons with disabilities and that these preferences often change over time for a given person. Few subjects actually preferred living in a nursing home. The need for a range of community living alternatives seems to argue for the provision of various forms of long-term support services in our society rather than an overwhelming allocation of resources to support persons in institutional settings.

A second important issue that remains salient today concerns the relative advantages of social cohesion among persons with disabilities versus integration as ordinary citizens in the mainstream of community life. Many subjects in this study found the social support and learning opportunities of a clustered living arrangement valuable at one point in their lives, but the majority believed that after gaining some experience they were ready to move on to situations in which they were part of mainstream neighborhoods, workplaces, and social groups. This developmental process suggests that we should offer a variety of living arrangements to meet the needs of various persons, rather than mandate a single (nonresidential) model for federally supported independent living centers. The nonresidential model is the position being urged today by many in the independent living movement. Many of the subjects in this study reported having debated with themselves about whether to join organizations to advocate the rights of citizens with disabilities or whether to choose not to identify themselves as part of this cohesive minority. Several persons reported finding it ironic that the social goal of integration is often sought by means that foster separation as a special group, a dilemma that has been identified in our society by Blacks as well as by persons with disabilities. When such persons become more fully integrated, they often believe that they are viewed as betraying the group from which they came.

Finally, the important issue of how to foster adaptive transitions from institutional service provision systems to the community remains a major challenge for health care providers. The importance of this issue has grown as reimbursement policies have pressed for shorter lengths of stay and the quick return of persons to the community, often with little time for discharge planning or assistance in making the transition. Despite the development of new alternative community-oriented service provision systems such as home health, outpatient, or day programs, the need for such services and the need for funding to pay for them appears to exceed available resources. The present study findings suggest that the acquisition and polishing of skills needed for successful community adaptation are greatly facilitated by the availability of good role models and by opportunities to practice needed skills with readily available social support. This suggests that the availability of contact brokers as well as social and logistical support should be important considerations in discharge planning from treatment facilities and in the design of transitional services.

All of these issues merit thoughtful consideration by therapists on their own behalf and in their roles as advisors to clients with disabilities who will be living in the community. Being informed about issues of public policy concerning health care and civil rights is an important part of our professional responsibility as therapists and as citizens (AOTA, 1980). This responsibility will increasingly require reflection about how the persons we seek to assist function in the larger community as well as within institutional settings and how we can increase their opportunities for quality of life based on choice and self-determination.

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References


American Occupational Therapy Association. (1981). Offi-


Yerna, E. J., & Baum, S. (1986). Engagement in daily occu-
