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Self-Empowerment among Adults with Severe Physical Disability: A Case Study

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An independent living residential setting for severely physically disabled adults was studied through overt observation methods for twenty-two months. The purpose was observation of residents' council actions and expressions of group interests. The council displayed several phases of political structure and behavior. These phases were related to staff and administrative considerations as well as the residents emerging demonstrations of self-empowerment at the group level. The capacity for self-advocacy emerges as a dynamic enterprise which is clearly related to the structure and interests of the service agency.

Like other minorities, people with disabilities have often been inhibited from exercising political self-determination. Given the many constraints of disability, lack of experience with democracy is not surprising. The combined effects of physical, communicative or emotional impairments, social stigma, and, very often, isolation, are substantial obstacles to overcome on the path to self-determination (Safilios-Rothschild, 1970). Furthermore, having experienced at least some degree of dependency upon others, adults who have disabling conditions may tend to perceive themselves as more subordinate than autonomous and therefore choose not to assert themselves in political processes (Sussman, 1977). What are the possibilities, then, of people with disabilities acquiring the appropriate skills, experience, and self-image which will allow them greater opportunity to participate in decision making? If democracy is defined as "the opportunity of members of the society to participate freely in the decisions, in whatever realm of life, which affect their lives individually and collectively" (Gould, 1964), then how many people with disabilities gain access to the skills and experience which will facilitate their participation in these activities?

This study examines the evolutionary process of self-empowerment experienced by adults with severe physical disabilities in an independent living residential program. Development of a residents' council and selected actions taken by service providers supportive to the functioning of the council are described. In an effort to document how collective self-empowerment actually occurs for a seriously disadvantaged group that is supported by a service agency, detailed qualitative observations are reported.

Guidelines proposed by DeJong characterize the independent living environment as a fertile ground for self-empowerment of people with severe disabilities. He argues that collective actions taken by consumers toward obtaining rights and entitlements as well as the striving for barrier removal to adult life resources are essential features of independent living (DeJong, 1979, p. 443). By addressing shared concerns about policies and regulations, people with disabilities are constructing a new role that demonstrates advocacy, self-determination, and construction of shared expectations for living arrangements. Consumers and service providers jointly work toward the ultimate goal of community integration in the political arena through consumer education in group functioning and skill acquisition for exercising power. Because many persons with disabilities have not seen themselves as decision makers for themselves or others, changes at the self level occur and can be observed as the group addresses political concerns (Frank, 1988, p. 112). Until a window is opened on the collective perspective, however, willingness and skills for holding group responsibilities are likely to emerge slowly.

Independent living settings provide many such windows for enabling the processes of self-empowerment. Persons with severe disabilities that impede mobility and communication can utilize these settings for the personal and social development that leads to group and community practices of self-determination. Like other socially stigmatized categories, people with severe disabilities are likely to find in the self-empowerment process a new set of experiences from which to gain the tools needed to confront social and physical obstacles (Solomon, 1976, p. 22). In so doing, people with disability benefit from

empowerment that teaches fundamental political processes such as creating alliances, building coalitions, overcoming organizational barriers, and engaging in political action (Pinderhughes, 1983, p. 334).

According to Charles Horton Cooley, people in general have allegiance to the community ideal, and "would devote themselves to it with some ardor and sacrifice if they saw clearly how they could do so with effect" (Cooley, 1911, p. 52). This encouraging description is challenged by consistent observations that in most societies some groups are less likely than others to participate in community matters. Groups with low community involvement are those which are likely to experience problems in acquiring necessary skills and access to collective processes (Dahl, 1956, p. 71).

The physically disabled population is one such group. However, an important social movement, the Independent Living (IL) movement, has brought substantial changes to the thinking and procedures that link persons with disability to the general community (DeJong, 1983). The IL movement has clear political goals for altering community integration patterns with populations that have disabilities. Fundamentally a civil rights movement, IL efforts have been directed toward achieving acceptance into community political processes and greater access to community decision-making systems. What makes the IL movement a distinct social and political challenge is its demand for incorporating the disabled person's physiological characteristics and life experiences into the existing system that is designed for ordinary people. Thus, the demand for wheelchair ramps, braille reading materials, and signing interpreters is a call for recognizing the particular ways physically different people communicate and meet with others, actions fundamental to interaction and shared decision making.

The emergence of environments conducive to self-empowerment as enacted by adults with severe physical disabilities is one aspect of recent changes in the social meanings given to disability. Scotch sees a significant modification in new views which perceive the source of disability-related issues as social problems rather than as individual traumas. Although he observes that general social change is extremely slow in this area,

he proposes that a new "mind set" is evolving that views activism appropriately suited to people with disabilities. However, Scotch does note that activism is rare among persons in organized residential settings (Scotch, 1988, p. 161). It is here that principles of self-empowerment are engaged to grasp the process of confronting the very environments that sustain dependency (Pinderhughes, 1983).

As people with disabilities develop toward full community cooperation and participation, they are utilizing various formats to assist them. One of these arrangements is the supported residential environment. This setting serves much as the settlement house did for immigrants; it provides some services (such as education and transportation) at the same time that it offers training in group relations and collective decision making (Deegan, 1986, chaps. 10, 11). Like excluded groups before them, people with disabilities must work to remove barriers to their social participation. The goal is reduction of a socially devalued ascribed status so that disabled people can develop potentially more positive achieved status in the general community. The mechanisms of education, improved communication, and democratic methods are being used to alter social inequalities.

Independent Living Movement

The independent living movement arose during the late 1970s, demanding greater independence and broader social participation for disabled persons. Along with accessible housing, supporting services, and assistive devices, a greater degree of self-determination was sought as a move away from dependency. Crewe states, "Independent living develops individual power, both as process and as an outcome," and she proposes that individual responsibility as well as personal goals will be furthered by the movement (Crewe, 1979, p. 433). The attainment of self-determination is an especially significant goal for the IL (Independent Living) movement since severely disabled individuals are specifically included in its aims, both in concept and in law (P.L. 95-602). to consider severely disabled persons as actively controlling their own lives and perhaps the lives of

others through democratic processes is to be introduced to the depth and scope of the IL concept.

The IL concept provides a new perception of people with disabilities. In contrast to the more passive images given disability by the medical and rehabilitation models, the IL concept presents disabled persons as capable of political advocacy, self-help, and consumer control of services (Stoddard, 1978). As such, the IL concept has formed the basis for many consumer-directed environments (DeJong, 1983). While each independent living setting is comprised of its own particular arrangement of services to disabled people, a basic philosophy is noted by Humphreys as the "disabled citizen's right to share fully in community life and the responsibility to contribute to that community" (Humphreys, 1978). Independent living means more than a barrier-free environment; it also means consumer initiative and potential consumer control over adapted living environments and support services. IL settings are potential testing grounds for skills of group organization, group decision making, and delegation of representatives.

The Independent Living movement also recognizes that disabled persons need to learn how to utilize the democratic system. Because many people with disabilities have led isolated, protected lives, they may lack group-participation skills and observations of groups that have attempted the democratic system. Since an IL residential environment offers opportunities for developing democratic skills among a politically marginal group, it is appropriate to study evolving self-government within a residential facility emphasizing IL aims for physically disabled adults.

The purpose of this investigation was to observe the changing structure and functions of a residents' council as members acquired skill in group organization and democratic procedures. Also, the study examined the relationship between residents' representatives and the sponsoring management and how residents practiced democratic processes within a planned, structured residential setting which is administered not by residents but by a sponsoring agency. Specifically, the following report addresses the role of resident representation to management which is not consumer-controlled, but which does attempt to

train disabled individuals for greater independence. These observations offer insight into other dependent groups' efforts to alter their devalued positions in favor of more responsible places in the general community.

Setting and Method

Sociological investigation of two residential settings for physically disabled adults was conducted over a period of twenty months. Both facilities were located in Wichita, Kansas, and were managed by Cerebral Palsy Research Foundation of Kansas. The population in both facilities consisted of young adults having a wide range of disabling conditions such as cerebral palsy or spinal cord injury. A high proportion of residents had severe developmental disabilities and had previously lived in institutions, nursing homes, or highly protective family environments. During the first eight months of the study, research occurred at the Urban Residential Center (Urban). The Urban then was closed and merged with The Timbers, a new and larger facility. The Urban consisted of two one-story four-plex apartments located in a working-class apartment neighborhood, and it housed 27 persons at the time this study began. When The Timbers opened, 24 Urban residents moved to the 100-person complex of one-story four-plexes, six-plexes and congregate area located tangentially to a middle class, single-family neighborhood. In addition to its increased size, The Timbers is different from The Urban, having numerous design adaptations for its disabled residents and receiving considerable local celebrity. The Timbers complex is located on a ten-acre site and is arranged in roughly concentric circles around the congregate building. Residents with the most severe disabilities live in apartments attached to or nearby the congregate area, and those with less severe disabilities live in the outer apartments. Residents receive services such as transportation, cooking, and personal care in a similar recognition of need.

Both facilities were operated by the same administration and provided the same services: housing, personal care, some cooking, transportation, and independence training. Also, both Urban and Timbers facilities were affiliated with the Wichita

State University Rehabilitation Engineering Center and Center Industries Corporation, a competitive industry for disabled and able-bodied persons. Through this combination of services, the Cerebral Palsy Research Foundation expresses its aim of assisting residents, many severely disabled, to reach their full potential in a community environment.

Throughout the twenty-month period, participant-observation methods of overt observation and interview were utilized, as the investigator and research assistants attended open meetings and council meetings. Nearly all council meetings and open meetings were attended for twelve months, and selected meetings were attended the last eight months. Interviews with council members and administrative personnel who had ongoing relationships with the Council were conducted at the conclusion of the observations. Since the research activities were conducted overtly, they allowed consumers and staff to clarify any uncertainties quickly. Although subjects understood that the direct observation could have been stopped at any time for reasons of confidentiality, such a request never occurred.

After collecting field notes, minutes, interviews, and written products of the Council (such as bylaws), the data were organized into the following areas: (a) how was the residents' council constructed? (b) what topics did the council consider? (c) what actions did the council take? and (d) how were the structure and functions of the council affected by service providers and the sponsoring agency? The following report summarizes research findings within the framework of four evolutionary stages which were characterized by distinct patterns of Council structure and function.

The Residents' Council was initiated by administrators and staff members of the sponsoring agency. Their intentions were to assist residents in discovering residents' interests and then represent those interests to management. Another aim was to teach basic parliamentary procedures and group-participation behaviors. Most residents had not had collective involvement previously and needed guidance in learning to see themselves as group members.

The Evolution of Decision Making

The Residents' Council consisted of five members elected at-large who then elected a president and determined committee chairpersons within the Council.

There was substantial consistency in the membership of the Residents' Council over the twenty-month period observed. The same individual was Council president throughout the study, and only two members resigned during their terms of office and were replaced by special elections. One general election was held during the study, when four new members were elected, along with reelection of the previous president. All Council members were severely or moderately disabled. Extent of disability was not observed to be a factor affecting influence in group decision making, as Council members listened and interacted with each other according to personal forcefulness regardless of delays in speaking or difficulties with handling written materials. Therefore, description of group processes can be viewed as analysis of a developing social unit rather than a study of disabling conditions. The four observed developmental phases were (a) the Initial Stage, (b) the Transitional Stage, (c) the Experimental Stage, and (d) the Plateau Stage.

Initial Stage

When the Residents' Council was initiated by staff members, it began its responsibility very slowly. Council members appeared not to have had earlier experience with committees or groups that made decisions intended to affect many people. The result was almost an internship period for Council and staff members while new roles were created.

At this initial stage, one staff member of the Urban Residential Center attended each biweekly meeting of the five-member Council and contributed substantially to the content and organization of the meetings. Meetings consisted of unstructured committee reports and discussion of topics introduced by the staff member.

Although the Council committees were arranged to deal with collective issues such as transportation, food, personal care aides, and recreation, actual functions tended to be directed

toward residents' personal complaints or the planning of recreational activities, resulting in little practice of group determination in the residential facility. When the attending staff member presented items of group concern, Council members rarely responded to the opportunity for making recommendations pertaining to group management. At this point, the Council functioned chiefly as a social collectivity, with more time given to personal topics than to group concerns. Critical events tended to be seen as the management's concern, including preparation for the move to The Timbers and reorganization of living arrangements after a fire destroyed two apartments and injured two severely disabled residents.

However, the foundation for group decision making was established here as the staff trained Council members in meeting procedures, suggested divisions of labor, and supported Council efforts in recreational arrangements.

Transitional Stage: May-October

The reconstituted Residents' Council faced the two basic tasks of reorganizing itself from its earlier format and addressing heated issues raised by residents. These tasks were accomplished even as staff began taking a more peripheral role in Council activities and responsibilities.

When the residents moved into The Timbers, the Urban Residents' Council was retained for three months, after which the first general election was held. This interim was an emotional period for the many residents who had never lived independently before, and discussion of the upcoming general election was intense. When the first open meeting occurred to establish election procedures and candidates, over eighty residents attended, and many contributed heatedly to disorderly discussions. Although the meeting was chaired by the Urban Council's president of two years, he was not able to control a large meeting in which few participants understood parliamentary procedure. As a group, residents demonstrated little comprehension of standard procedures for determining candidates, deciding terms of office or establishing the Council's purpose as a representative body. Compounding residents' lack of knowledge was the prevalence of severe disabilities. For example, votes were

finally cast by voice because "at least everybody can make a sound." Only the president from the earlier form, the Urban Residents' Council, became a candidate; and the new council also elected him president.

Staff members attended council meetings less regularly at The Timbers, becoming more auxiliary. An early distinction arose between severely disabled residents having apartments near the congregate area and less disabled residents whose apartments were some distance away. "Outsiders" gradually tended to perceive the Council as a representative unit for "the severes," although two council members lived in outside apartments. During the Transitional Stage, the initial interest of outside apartments residents in the Council declined. Structure and functions came to reflect interests of the residents with more severe disability.

Primary functions at this stage included: defining the Council with bylaws and regular procedures, hearing complaints from residents, and addressing the need for a crosswalk and crossing light across a wide, busy street to the nearest shopping area. The latter function both attracted residents' interests in the council and introduced its members to the workings of city government. A petition was written, signatures collected, testimony gathered, and appearances made before necessary city officials. As a first attempt at community advocacy, the Council established a successful precedent, as the crosswalk request was accepted and was scheduled ahead of several other requests.

The crosswalk issue described above occurred at the same time that other emotion-laden concerns came to the Council, such as the contention by some residents that alcoholic beverages and loud parties should not be permitted in the congregate area and that residents should not "loiter" around the congregate-building entrance, "making this look like a nursing home." These two demands occasioned formulation of the first two Council rules: no drinking in the congregate area except at general parties and no loitering around the entrance. Criticism of the Council followed, and residents' high expectations for Council accomplishments began to decline.

It is important to note that the Council members were not entirely alone in this period. Staff members contributed books

on parliamentary procedure, suggested appointment of a sergeant-at-arms to keep order at Open Meetings, and held two open classes on parliamentary procedure (abandoned thereafter for lack of interest).

Experimental Stage: October-February

Routine functions having been established, the Council now experimented with new representative arrangements. At the same time, management was redistributing its own responsibilities. Uncertainty characterized this experimental period.

In October, Council members recommended in Open Meeting that the Council structure be modified to include seven representatives who would be elected by apartment district. The suggestion was approved, and the experiment with a larger, more complex Council began: the five-member Council met weekly, the Council and district representatives met biweekly, and Open Meetings were held once a month. At this time, the group's name was modified, becoming the Residents' Advisory Council, as a reflection of the intermediary role played between management and residents. Also, staff members withdrew from attending meetings, and the Council president began to conduct more controlled meetings by agenda.

Council functions were also changing, primarily in response to funding problems experienced by The Timbers. Because of reductions in funding for food and personal care, major reorganization and restriction of services was occurring. It was at this point that the Council began to work actively as an intermediary between residents and management. Council members began to request information from management and to communicate concerns of residents about programs and services. In Open meetings, the council attempted to explain the funding constraints faced by The Timbers and elicit cooperation from residents. Furthermore, the overall confusion regarding funding affected Timbers staff as well as residents. While the Council experimented with communication to the management, management was reconstructing its own organization. The resulting structure not only responded to the pressures of funding and administrative needs, but also provided new channels for Residents' Council effectiveness in the larger system.

Plateau Stage: February-July

The Council achieved consistent procedures and expectations both vis-a-vis residents and toward management. Ironically, as the Council achieved more responsibility respecting both residents and management, resident interest and involvement dwindled.

Following the upheavals of the winter months, spring Council activities were observably more structured and purposeful and tended to carry out a more advisory function to the management. Regular meetings with administrators were scheduled in which staff and Council members exchanged information and discussed current issues. These meetings represented an opening of information channels, since the management's initial understanding of residents' needs for information had been protective, not collaborative. Likewise, Council members acquired more understanding of management's working procedures.

Further expansion of Council members' development was observed as the president exercised more effective leadership skills and as Council members encouraged other residents to take part in larger community problems related to people with disabilities. During this time, the Council achieved financial stability, largely due to its own efforts, and organized the second Council election. However, the gains in organization skills were not complete. Staff was required to rescue a Council-planned street sale because members "really didn't know what a committee was" (staff comment), and necessary arrangements were not accomplished by residents. And, prior to the election, three Council members reported having received negative comments from residents to the effect that "since the Council doesn't do anything, there's no need to vote." Having accomplished a year of self-definition and expanding communication with management apparently did not arouse absolute support from residents.

Acquiring Group-Organization Skills

To summarize, the evolution of the Urban-Timbers Residents' Council was characterized by observable changes in structure and decision-making functions. At the Urban, staff members both initiated and directed the five-member Council;

during the transition to the larger Timbers facility, the Council tended to deal with personal and controversial matters concerning residents; when The Timbers facility was affected by a funding reduction, the Council expanded and began an experimental intermediary relationship between management and residents. As The Timbers management settled into a new structure in the Plateau phase, procedures for implementing residents' representation were institutionalized.

Although circumstances such as an overall funding reduction stimulated much Council skill-learning, direct training by staff provided the foundation for developing abilities such as planning agendas, conducting meetings, writing bylaws, and appearing at community hearings. Just as important to this evolution was the development of administrative responsiveness to the Council. If the management had not opened channels for communication and negotiation with the Council, the development of Council structure and functions would have had less meaning for self-determination. Staff training efforts and administrative modifications did, however, facilitate self-determination. Staff training efforts and administrative modifications did, however, facilitate self-determination. Not unlike attempts to organize other American minorities during the 1960s (Alinsky, 1969), these actions at The Timbers contributed to disabled residents' opportunities for influencing the very organization upon which they depended for basic services. The Council members, district representatives, and interested residents have confronted shared problems and, through the assistance of staff and the push of external demands, developed a sense of political process. These are the beginnings of participatory democracy (Bennello, 1971).

The detailed observations reported here underscore the length of time required for seriously disadvantaged people to acquire collective perspectives and the necessary skills for meeting group needs. When the disadvantaged group has had only minimal opportunities for practicing group awareness and responsibility, self-empowerment begins with small steps. Those steps include utilizing the participation and support of service providers. Nevertheless, the empowerment process has been observed here to function for people with severe disabilities in the

sense defined by Pinderhughes: gaining "the capacity to cope constructively with the forces that undermine and hinder coping" (Pinderhughes, 1983, p. 344). Although the process was far from complete during the time of observation, important collective perspectives and structures were initiated in the name of independent living.

But the evolutionary process continues. A formal means exists for management and Council communication, although the question of Council capability to enforce its decisions upon either management or residents remains. This is the crux of the problem. Within an agency-managed residential setting, can a residents' council actively exercise power, or will a council function primarily as a symbol of residents' interests?

Conclusions

A residents' council within an agency-sponsored residential setting may fulfill an advisory role to the management by communicating residents' needs and negotiating for administrative decisions favorable to residents. Because many persons with disability lack experience with group processes, very gradual development of representative democratic skills is likely. Such evolution of group-organization skills is appropriate to residents' transitional status in settings such as The Timbers which provide training for more extensive independent living. In these launching stations to greater community participation, the process of learning democratic skills parallels other practice with independent living skills.

Resources for training persons with disability in self-advocacy are available (Woodyard, 1980; Bowe, 1978) and can be supplemented with literature from the self-help movement (Zola, 1979). Specific training is required, because individuals who have been isolated from group decision making may begin their participation at the level of the first Hans Knudsen Pladsen residents' council in Copenhagen, whose initial interests were "to have more sugar in the tea" (Hoybe-Mortenson, 1979). Merely having shared living arrangements does not guarantee having shared political concerns. As an adjunct to independent living aims, then, learning to perceive group interests and to act on behalf of others is an advance toward broader social participation.

Although agency-managed residential facilities may not conform to an ideal model of the Independent Living concept (Maluccio, 1979), they provide the group context for skills to be exercised following transition to greater social involvement. Since many community-based living environments are sponsor-managed rather than peer-managed (Laurie, 1977), a realistic assumption based on the Urban/Timbers observations would be to predict that group self-determination skills can be taught and practiced in residential settings and included as elements in the Independent Living skills tool kit.

Since the U.S. political system is highly decentralized, it requires endless bargaining and negotiation, even at local levels. Yet Dahl argues that this characteristic allows any active and legitimate group to make itself heard at some point in decision making (Dahl, 1956, p. 150). The Timbers Residents' Council case study shows that other factors as well as desire for participation must be addressed when a politically marginal group seeks involvement. Not only must skills for bargaining and negotiation be acquired, but also the ordinary means for voting, communicating with peers and representatives, and group assembly may require modification. Furthermore, groups which have been systematically excluded from decision-making processes must have the opportunity to obtain social training in the norms of political process (Dahl, 1956, p. 135). Certain other emerging political minorities, such as children, the frail elderly, and the mentally ill, share the protected yet devalued status that is ascribed to physically disabled adults. Perhaps the Independent Living movement will contribute ideas and momentum to integration of these groups.

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