The Lazarus Project: The Politics of Empowerment

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The problems associated with institutionalized care of the frail elderly are complicated and require interdisciplinary problem solving. This paper explains the conceptual framework and initial implementation of the Lazarus Project, a pilot project in a nursing home that offers an alternative governing philosophy for residential living. The framework is a community model based on democratic governance, which empowers those who work and live within the nursing home facility. Implementing a community model in an institution is a political process that requires an awareness of power relationships and structures. Strategies for institutional change are directed at alteration of the hierarchical power structures so that power is shared and decision making collaborative.

Our vision for long-term care describes a possibility for reshaping institutional aging in this society. The creation of an empowering environment requires the involvement of diverse groups: institutionalized elderly who receive human services, their families, the staff who work in nursing homes, and staff in administrative and policy-making positions. The vision is one of fundamental change that requires both a political process and a conceptual framework, or roadmap (see the Appendix).

This paper discusses current nursing home models of governance and the conceptual development of an alternative model for institutional long-term care. The community model is interdisciplinary in nature and was influenced by a group of people from a broad range of disciplines and practices, such as sociology, psychology, theology, political theory, public policy, economics, nursing, education, and occupational therapy. This model is being implemented in a pilot study called the Lazarus Project. The conceptual development of the community model comes from the Lazarus Project.

The Lazarus Project

The Lazarus Project is a 3-year pilot project that is co-directed by an occupational therapist and a political educator (i.e., the first and second authors, respectively). It is being done in collaboration with the Augustana Home of Minneapolis, a nursing home that employs an administrator, an assistant administrator, 12 managers, and 400 staff members for its 360 residents. The facility is part of a larger campus of 700 apartments in four adjoining high-rise buildings. The apartments and nursing home share a variety of services, including a grocery store, post office, bank, beauty shop, and health clinic.

The intent of the Lazarus Project is to develop and evaluate the feasibility of an alternative model for the existing hierarchical models of governance that organize service provision and institutional living for elderly persons. In hierarchical models, power and authority are held by those at the top of the organization. Decisions are made by the administrator and managers for the good of the organization. Limited opportunity exists for nonmanagerial staff, residents, and families to access information or to influence important decisions affecting them. We believe that hierarchical models of governance are not sufficient to deal with the difficult issues facing institutional long-term care, such as meeting physical needs without diminishing the autonomy of the frail elderly; recruiting and sustaining a competent, well-trained work force; or providing quality care in the face of diminishing economic resources.

The community model proposed by the Lazarus Project is based on democratic principles. Democratic governance means that all members of the community have a voice in shaping the environment in which they
live or work, thereby creating a broader, more flexible base for problem solving. The community model should not be confused with a resident enrichment program, which provides more choices or services for people.

What democratic governance does mean is that residents and staff can choose among options that they have helped create rather than from among options offered by others in authority. Our assumption that residents wish to participate in shaping their lives was verified through public discussions held in the nursing home. In these discussions, the residents indicated that they would like opportunities to create meaningful rituals for death and loss. They suggested possible solutions for maintaining privacy. They stated that they wanted to help create ways in which they could assume meaningful roles in their daily lives.

Effects of Institutionalization on Elderly Residents

The problems associated with institutional care of elderly people are documented (Cohen, 1989; Rosenfelt, 1965; Vladeck, 1980). Many persons experience nursing home placement in terms of loss, that is, loss of individuality and privacy, loss of connectedness to earlier lives, loss of meaningful roles, and loss of control over the living environment. Resulting behaviors may include hostility, withdrawal, depression, passivity, and incapacitation. In addition, the frail elderly have physical deficits related to chronic health conditions. In health care institutions, these problems are framed and treated from a medical perspective, thus emphasizing disease and functional loss. Ultimately, the elderly person internalizes the identity of dysfunction (Kalish, 1979). Incapacity and powerlessness become self-fulfilling prophecies when institutionalized persons acquiesce and accommodate to the limited roles of patient and recipient of services rather than the fuller role of community resident. Caregivers who believe that disabled elderly persons are victims and are unable to change their situation assume paternalistic attitudes, thus reinforcing powerlessness. Decision-making structures that distribute power unequally so that professionals and staff in authority have most of the power help maintain residents in a powerless situation.

Powerlessness of Staff in Nursing Homes

Nursing home staff members, including health professionals and nurse's aides, can also experience disempowerment. Williams (1988) described a powerlessness that many staff feel in their inability to bring about change in the long-term-care system. Several problems related to nursing home staff were identified by Tellis-Nayak and Tellis-Nayak (1989) and Vladeck (1980), including low morale, a low-level commitment to the organization, and a high rate of turnover. Aides in nursing homes are often associated in the media with an apparent lack of care for residents. The media, however, often ignore the morass of mixed expectations that the elderly, families, and society, place on long-term-care staff. Complex nursing home regulations reflect this ambiguity. Is it the nursing home staff's responsibility to make decisions on behalf of residents, or should the staff members respect the residents' autonomy? If an injury occurs, the legal system makes it clear that the staff is responsible. Negotiating this ambiguity falls most heavily on nurse's aides, who constitute about 70% of the personnel within nursing homes. These workers earn low wages and often do not have adequate training (Tellis-Nayak & Tellis-Nayak, 1989). Like the residents, aides are at the low end of the organization's hierarchical structure and, therefore, have little access to policy-making or decision making, yet they have essential knowledge of residents' lives. Their lack of influence affects the institution's ability to provide quality care. Furthermore, their low position in the hierarchy encourages turnover, which is costly. Society ultimately pays this addition to the price of nursing home care.

Nursing home aides and residents are not alone in perceiving themselves as unable to influence forces shaping their work and their daily lives. For example, many occupational therapists in long-term care are unable to develop a practice that reflects the broad, holistic philosophy of the profession, primarily because their practice has been narrowly redefined by parties outside the field, such as third-party reimbursers and state and federal regulators. Additionally, they see themselves as unable to make change within the existing organizational structure. But influencing change within systems is a political process that requires one to learn how to analyze and affect power relationships and decision making within an organization. Political skills are usually not part of the preparation for work in long-term care. Most students are taught the necessary professional skills to practice their work within the existing governing structures of long-term-care institutions.

Traditional Models of Governance in Long Term Care

Models of governance have great influence in shaping the mission, procedures, and interactions within an organization. The model of governance is embedded within the institution's philosophy and decision-making processes. Models carry with them a powerful language that is used to frame problems, define solutions, and guide what can be imagined as appropriate possibilities.

Most nursing homes embody the medical or therapeutic model (see Table 1). The medical model emphasizes the isolation and treatment of residents' problems related to disease and dysfunction, and medical personnel have the greatest authority. The roles of other staff members, residents, and family members carry less au-
Table 1
Models of Organizational Governance

<table>
<thead>
<tr>
<th>Medical Model</th>
<th>Therapeutic Model</th>
<th>Community Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focuses on acute care, disease, and disability.</td>
<td>Focuses on the provision of a variety of services.</td>
<td>Focuses on capacities and the ability to contribute.</td>
</tr>
<tr>
<td>Facilitates dependency on staff.</td>
<td>Facilitates dependency on staff.</td>
<td>Encourages interdependency among all members.</td>
</tr>
<tr>
<td>Information and knowledge are seen as technical expertise.</td>
<td>Information and knowledge are compartmentalized and perceived as serving the client.</td>
<td>Information and knowledge are perceived as wisdom gained from experience.</td>
</tr>
<tr>
<td>Uses specialized language, which creates dependency.</td>
<td>Uses specialized language, which creates dependency.</td>
<td>Uses a common language accessible to all.</td>
</tr>
<tr>
<td>Focuses on patients' rights.</td>
<td>Focuses on clients' consumer needs.</td>
<td>Focuses on contribution and reciprocity among staff and resident members.</td>
</tr>
<tr>
<td>Uses a reductionistic, scientific approach.</td>
<td>Uses a programmatic approach that tends to fragment spiritual, physical, and social well-being.</td>
<td>Uses a holistic approach that addresses physical, social, and spiritual well-being.</td>
</tr>
<tr>
<td>Creates a social structure based on a hierarchy.</td>
<td>Creates a social structure based on a hierarchy.</td>
<td>Creates a democratic, egalitarian social structure.</td>
</tr>
<tr>
<td>Is staff intensive.</td>
<td>Is staff intensive.</td>
<td>Includes nonprofessional and mutual caregiving.</td>
</tr>
<tr>
<td>Activities geared toward improved physical functioning.</td>
<td>Activities geared toward personal development and entertainment.</td>
<td>Opportunities for public decision making and contribution.</td>
</tr>
<tr>
<td>Holds staff responsible.</td>
<td>Holds staff responsible.</td>
<td>Holds all accountable.</td>
</tr>
<tr>
<td>Empowers staff.</td>
<td>Empowers staff.</td>
<td>Encourages relational empowerment.</td>
</tr>
</tbody>
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through and are ancillary to medical roles. Although we acknowledge that the medical model is essential in acute care settings, we question its adequacy as a governing structure that organizes the whole of daily life of the institutionalized elderly. As a democratic society, we believe that each person is capable of creating a common good and exercising decision making to that end, then a hierarchical model that highly values decisions made by experts does not allow residents to create a meaningful life for themselves.

The therapeutic model is a derivative or a modification of the medical model. It is used by rehabilitative and therapeutic personnel to identify needs and provide appropriate health services. In this model, health (sometimes referred to as wellness) can be viewed more holistically, with consideration given to the person’s emotional and spiritual dimensions. Although rehabilitative approaches are generally problem oriented (i.e., focusing on skill deficits), they also consider individual strengths and capacity for adaptation. The therapeutic model is effective when the person needs an enhanced environment or a specific program to facilitate individual change. We question, however, whether this model promotes the skills needed to create and maintain an empowering environment. If residents and other staff are to have an active voice in shaping their environment, the skills that allow people to make public contributions are required (e.g., agenda setting, decision making, role negotiation, management of conflict arising from diverse interests).

When a living environment is organized according to either of these two models, a hierarchy of relationships is created. The staff are the experts who have the knowledge and techniques to identify the needs, name the problems, and provide the solutions. Those served become the recipients. Although skilled clinicians collaborate in goal setting and provide choices for their patients, the institution’s organizational structure still defines the parameters and expectations for role behaviors of both the service providers and the residents. These two traditional governing models exclude the concept of reciprocity. Daily life for those living within the institution can become compartmentalized and focused on receiving services to alleviate dysfunction or participating in activities that primarily fill time.

A model of democratic governance was introduced in the Lazarus Project. In this model, residents, staff, and families learn to collaborate in creating their institutional community. This project proposes fundamental changes in the institution’s philosophy, from providing an enriching environment and quality services for residents to empowering residents and staff members to create an environment reflective of their interests. For this to be accomplished, decision-making structures must shift from hierarchical to collaborative processes.

Theory Base of the Lazarus Project

The conceptual framework of the Lazarus Project is based on social support theory (Gottlieb, 1985; Minkler, 1981, 1984; Minkler, Frantz, & Wechsler, 1982; Pilisuk & Minkler, 1980, 1985), which is used by human service disciplines to understand the role of the community in promoting health, and on a political theory called citizen politics, developed from the work of Project Public Life, a national initiative to engage citizens in governance of their communities. Project Public Life is based at the Humphrey Institute of Public Affairs at the University of Minnesota, Minneapolis.

Social Support Theory

Social support theory describes relationships between social support and a person’s sense of control and health.
status. A social support network was defined by Minkler (1981) as the network of people through which a person's social identity is maintained. This network is also a resource base that provides emotional support, material and information resources, services, and new social contacts. Social support theory has three primary hypotheses (Minkler et al., 1982):

1. Support networks positively influence a person's health behaviors.
2. Social support increases one's ability to cope with problems of living and, in this way, may influence resistance to disease.
3. The person's experience of support from others leads to a generalized sense of perceived control over his or her environment.

Social support theory identifies key ways in which a person maintains health within a social environment. The Lazarus Project uses these insights from social support theory to explain the need for a strong community within a health care institution.

Citizen Politics

Politics is the process by which a person becomes critically aware of power and control in relationships and social structures and then uses that knowledge to work collectively for change (Brookfield, 1988). Citizen politics, defined as the work of the citizen, assumes that citizens are at the center of decision making and problem solving. The core concepts that define citizen politics are self-interest (i.e., the person's direct concerns), public (i.e., the problem-solving arena in which people debate, render collective judgment, and learn to shape their environment), power (i.e., a dynamic relationship rather than a one-way force), and diversity (i.e., the variety of people, interests, cultures, and ideas found in public life that are needed to define and solve public problems) (Boyle & Lappe, 1990).

Citizen politics differs from partisan politics in that the former views community members as active participants in public decision making rather than as spectators who leave problem solving to such experts as lobbyists, politicians, or special-interest groups. Citizen politics has a deep respect for persons' capacities to determine their own destinies. These capacities are rooted in their histories, cultures, and understandings of their experiences. This knowledge is as necessary as professional expertise in solving the problems of a specific community.

It is important that we distinguish citizen politics of the Lazarus Project from the residents' rights movement. The residents' rights movement, which began in the late 1960s, offers impressive examples of the kinds of public involvement and influence that institutionalized elderly people can undertake (Holder & Frank, 1984; Kautzer, 1983). The establishment of resident councils, the legislation of a residents' bill of rights, and the creation of various citizen advocacy organizations are results of this movement. We believe that resident councils do not generate a form of politics that can create and maintain community by ensuring that diverse interests work together in naming and solving common problems; resident councils work within the established hierarchy to address grievances or advocate for particular resident issues. They focus on policy change but not on governance and therefore do not systematically alter power relationships.

Citizen politics defines a public arena, in which diverse self-interests are required to address the complexity of issues affecting society. It is within this arena that the public good is defined and used to guide the process of empowerment (Boyle & Lappe, 1990). The word power means "to be able." Empowerment, therefore, is not something one does to or for another person, but rather, is the ability to act collectively to solve problems and influence important issues. Empowerment occurs when parties influence each other. Citizen politics and social support theory form the framework for the community model used in the Lazarus Project.

The Community Model

The community model builds a collaborative rather than a hierarchical relationship and employs democratic governance in an institution's structures (e.g., decision-making processes and procedures for policy development). In this model, professionals have technical information required for problem solving, but all members of the community have part of the knowledge that contributes to the understanding and solving of problems. The concept of community refers to an interdependent, diverse group of persons who have a common purpose. Each member of the community has a role recognized by others. All members have the opportunity to participate in decision making, and all are accountable to the community. A community can influence a larger public world through the practice of public politics.

Distinctions exist between this concept of community and a therapeutic community. Although the Lazarus Project community recognizes the legitimate need for therapeutic and medical interventions, its primary function is not to accomplish individual therapeutic goals within a group setting. The Lazarus Project community is not designed or controlled by service providers, and members of this community are not categorized as patients, residents, health professionals, or staff members, but as citizens who govern.

The definition of community used in the Lazarus Project was influenced by the writings of Tuan (1986), Boyle (1984, 1989), Boyle and Lappe (1990), and Evans and Boyle (1986). Tuan, a geographer, described community as embodying an agreed-on "good life" (Tuan, 1986, p. 9). This good life has three dimensions: a physical
dimension based on the sensory experiences of sight, sound, smell, taste, and touch; a meaningful social connection; and an ethical purpose, or a power greater than oneself.

In a complex, diverse world, the creation of the good life is highly dependent on a conscious knowledge of the function of public values. Communities, whether they occur within institutions or neighborhoods, are composed of persons who have both public and private dimensions to their lives and who have the capacity to create a mutually agreed-upon good life. The concepts of public and private are linked, yet distinct. This integration allows one to imagine politics capable of creating a meaningful community of institutionalized citizens. Residents would have clearly defined private lives and spaces as well as public arenas in which they could assume leadership in shaping their immediate environment and, ultimately, the broader public. Private lives generally center on friends and family — people with similar views and values. Private relationships are based on loyalty and tend to be spontaneous and less reserved. The outcome of a healthy private life is unconditional love. The public aspect of life differs, although private values often initiate one's movement toward a public arena. Diverse relationships are established for the purpose of task accomplishment and problem-solving. A public relationship assumes accountability rather than loyalty. The result of a well-crafted public life is empowerment (Boyte, 1989).

The Lazarus Project community model is broadly inclusive. Its membership includes residents, family members, volunteers, and those who work within the institution (i.e., professional service providers, housekeepers and other staff, managers, and nurse's aides). To function effectively, each of these groups must have access to information and the ability to influence decision-making. Members learn and use public skills, such as negotiation, collaborative decision making, and evaluation. The anticipated outcomes are many: New friendships and peer relationships are established; meaningful rituals are created and celebrated; and persons expand and strengthen their ability to act on their values, shape the ethical purpose of their community, and influence the public world.

Implementation of the Lazarus Project

The Lazarus Project, consisting of three phases, is expected to last 3 years. At the time of this writing, only Phase 1, that is, the first year, had been completed.

Phase 1: Concept Development and Training of the Management Team

Planning began in 1989. A national group of interdisciplinary advisors was assembled and a 3-day retreat held in June 1989. The purpose of this meeting was to critique and deepen the interdisciplinary conceptual base and review strategies for implementation. A second advisory meeting was held 6 months later to critique the overall research design for the project. The project uses an action-research model, which applies the knowledge gained through practice and reflection on the concepts of citizen politics to shape subsequent strategies. Descriptive data are collected from journals, interviews, interactions occurring in training workshops, and conversations recorded from public forums to track learning of the concepts and events that trigger change.

Our focus in Phase 1 was to train the nursing home's administrators and management team how to incorporate the concepts of the community model. The training began with the creation of a common mission statement, which was used to guide strategies for implementation of the community model. The initial statement read, "The purpose of Augustana is to create and sustain a wholistic [sic] community which supports and promotes the opportunity for growth and ownership through contribution, for the enhancement of residents." The word enhancement was later replaced with empowerment.

During this first year, the management team at the Augustana Home worked together to establish a collaborative, public environment for problem-solving. Their training was presented within the context of issues affecting daily work, and strategies were generated to address tasks such as budgeting, fund-raising, planning and conducting more effective meetings, and negotiating roles for new positions. They learned the concepts of citizen politics (i.e., self-interest, public, diversity, and power), and they practiced such skills as collaborative decision making, conflict negotiation, public debate, role clarification, and work evaluation. Because they were able to begin creating a public, open process using a public language, the Augustana management team made some changes in its practice of decision-making within the institution. When problems were raised, members of the management team requested information so that the problem could be collectively defined, and they worked together to generate strategies for solutions. Management meetings went beyond information exchanges to later include debates and discussions. Most important, some of the managers began to integrate a deeper understanding of power relationships. Their own experience of working to create a public decision-making environment in which they were expected to influence and practice power allowed them to consider what role they would play as residents experienced empowerment. These changes have helped establish the environment for the next phase.

Key to Phase 1 was the development of a strong relationship with an on-site staff person who could develop the role of internal organizer. This person plays an important role in integrating the community model by adapting training workshops to fit the unique culture of
the nursing home. The person selected was the director of the therapeutic activities program.

Conclusions from the first year of the project concerning the person filling the internal organizer role were that this organizer have the following characteristics: (a) experience managing educational programs, (b) intellectual curiosity about the Lazarus concepts and the ability to think conceptually, (c) openness to change, (d) a high level of commitment to the mission of the Lazarus Project, (e) respect for everyone involved (i.e., residents, administration, managers, and all staff members), and (f) access to authority.

The decision to begin the project by training the Augustana management team was a strategic one given the reality of power relationships in a hierarchical structure. Without involvement and modeling from the nursing home managers and administrator, it would be difficult to access information to influence decision making from lower positions within the hierarchy. Although Phase 1 of the project focused on the training of managers, these managers will not unilaterally determine the process for implementing the community model.

The first year of the project provided important insights: (a) The project could not occur without administrative support and the willingness of people with authority to look critically at decision-making processes, (b) fundamental change from a hierarchical to a community model cannot be imposed or rushed – it requires time, (c) institutional change involves both personal struggle and conflict over professional turf, and (d) new knowledge and an agreed-on mission statement are motivators for change.

Phase 2: Building the Community Model

The goal of Phase 2 of the Lazarus Project is to build the community model. Implementation of this phase is in progress. The questions that guide this phase are (a) Can the staff imagine new roles? (b) What capacities do residents have to contribute to governance? and (c) Can the residents' family members create important roles for themselves in the governance of the institution? The answers to these questions will continue to shape the understanding of the community model.

Phase 2 of implementation begins with the selection of a steering committee composed of an equal number of staff and nonstaff members. This group will represent all subgroups associated with the nursing home community. The selection process will occur through a series of public forums and interviews designed to identify important issues, potential leadership, and existing support networks among residents. The purpose of the steering committee will be to establish a democratic governing body within the institution. An important function of the steering committee will be to teach the conceptual knowledge of the Lazarus Project, so that members can provide leadership in extending the model throughout the nursing home community.

Phase 3: Influencing the Broader Public

Phase 3 of implementation will address the capacity of the Lazarus Project community to influence the broader public (i.e., media, legislators, regulatory agencies, professional organizations, and educational institutions) on issues of aging. Effective public leadership must first be developed within the community before members can be successful with powerfully organized groups outside their community. This does not, however, preclude smaller-scale public strategies implemented during Phase 2 that allow members to practice influencing the broader public.

Occupational Therapy and the Community Model

Why should occupational therapy challenge the constraints of the medical and therapeutic models in long-term-care institutions? How can occupational therapists assume leadership in the broader long-term-care systems? Adaptation; mastery of one's environment; fulfillment of meaningful roles; and engagement in purposeful, goal-directed actions have always been the focus of occupational therapy. Empowerment is the ultimate goal. Occupational therapists have strongly argued that the therapeutic relationship must involve doing with, not doing for or doing to, the patient. Yet most occupational therapy practice in nursing homes is directed by the medical and therapeutic models. Thus, the primary role of occupational therapy is the provision of treatment to improve or compensate for dysfunction. The broader goal of the creation of an empowering environment in which persons can assume control over their lives and establish meaningful roles cannot be easily achieved. Traditional health models define limited expectations and roles for residents. They also limit the possibility for occupational therapists to act on their commitment to the improvement of the quality of life in nursing homes. The community model recognizes the need for medical intervention and therapeutic programming in nursing homes, but the provision of health care services is not its primary focus. Occupational therapy personnel can use the community model to reconceptualize and expand their roles within long-term-care institutions.

Challenging institutional governance is an interdisciplinary task and cannot be accomplished by occupational therapists alone. Occupational therapy does not currently have a theoretical framework that can bring about change in the governing structures of nursing homes. Health care professions generally do not explicitly address issues of power and governance. The Lazarus Project defines a political process for change that results in empowerment.
The Lazarus Project's Vision for Long-Term Care

Dignity. Empowerment happens when communities are created—communities that govern themselves by drawing on the diverse strengths of their members to address common problems.

The Lazarus Project believes this kind of community can be created in nursing home environments. This requires a broad, holistic understanding of health that goes beyond physical and emotional health. It must include the ability to have authority in one's life, to shape one's environment and to extend influence within a broader public world.

Aging is a public issue; it is not simply an individual experience. When people become older and more frail, their ability to be contributing members in society changes. In a society that measures worth in terms of contributions and influence, the loss of physical and cognitive capacity quickly defines the frail elderly as "a problem." One of the ways the public has chosen to address this "problem" is to separate itself from chronically ill and disabled elderly persons by institutionalizing aging.

The authors of the Lazarus Project believe that the focus on the medical and service missions of long-term care institutions views residents as incapacitated rather than as productive contributors. When this assumption becomes embedded in the institution's governing system, it can lead to a loss of influence and power for all involved—the residents, staff, administrators, and families. This loss of influence constrains an institution's ability to effectively respond to the "problems of aging" in a creative way.

Ultimately, the public is separated from the insights that come from the struggles in growing old. The lack of wisdom in public policies on aging reflects the loss of those insights.

Appendix

The Lazarus Project’s Vision for Long-Term Care

The Lazarus Project believes that the frail elderly can be contributing members to society. It is through contribution that persons exercise power and are able to live a life of meaning and dignity. Empowerment happens when communities are created—communities that govern themselves by drawing on the diverse strengths of their members to address common problems.

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References