

1994 Eleanor Clarke Slagle Lecture

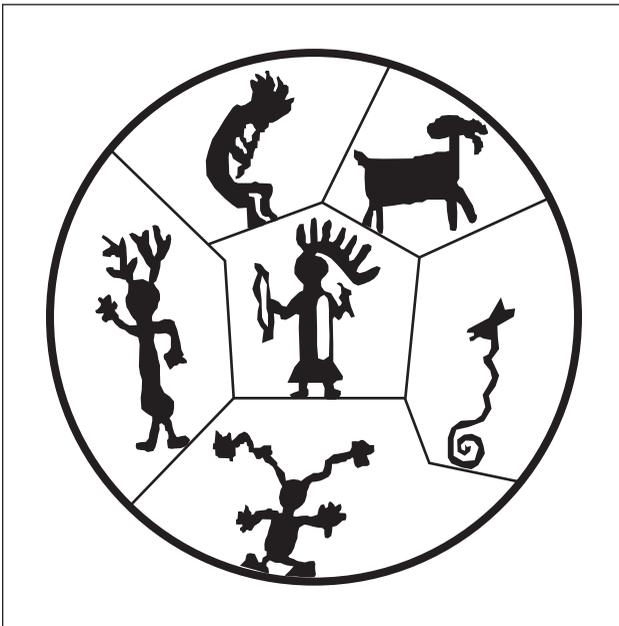
## Building Inclusive Community: *A Challenge for Occupational Therapy*

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Preparation of the Eleanor Clarke Slagle Lecture promotes reflection on the values and philosophy of occupational therapy. I chose the topic *Building Inclusive Community: A Challenge for Occupational Therapy* because it provided me with an opportunity to explore my own values and the values of the profession regarding inclusion of all persons into the community they choose and into the world community at large. The topic particularly led me to review my own work in adaptation theory developed with Elnora Gilfoyle (Gilfoyle, Grady, & Moore, 1990) in light of changes occurring or being promoted in society regarding opportunities for inclusion of all persons in all aspects of living. Ideas about inclusion; the meaning of community; the relationship between environment and community; the interaction between a person's past experience, present situation, and future hopes and dreams and its effect on the relationship that develops between an occupational therapist and a person seeking therapy services all became focal points for exploring our role in building inclusive community. The result has been some expansion of our understanding of the environment category of the spatiotemporal adaptation theory and exploration of the relationship between environment and community. In addition, exploring the concepts of the theory led to consideration of its relevance for enhancing our ability to plan with consumers of service who are creating or returning to their own community. Focal points for exploring the challenges related to building inclusive community include

- An understanding of the meaning of community building within a person's own environment and according to his or her choices.
- A review of current ideas about the nature of disability in relation to both philosophy and mandates for inclusion.
- An expansion of ideas about the role of environment in a person's adaptation to community living.
- A consideration of strategies for promoting choice and inclusion.

For as far back in time as we know, human beings have gathered together to share in daily living and use some form of symbols as means for communicating with each other, hence the building of community (Dance & Larson, 1972). To this day, we share meaning in our communities through symbols composed of pictures, words spoken in our own culturally determined language, and gestures or nonverbal expressions of our thoughts or feelings. Native Americans in the southwestern regions of our country choose to tell the stories of their community living and beliefs through petroglyphs, or rock art (Patterson-Rudolph, 1993). One expert in petroglyphs compared attempts at identifying subject matter and its significance to cloud watching in that no two people will interpret what they see in the same way. Petroglyphs were apparently not intended to represent words of a language as we know it, but instead were meant to convey more general concepts or global ideas about the society, such as ideas about religion, medicine, governance, art, war, and peace. An artist's rendition of petroglyphs titled "Circle of Friends" (see Figure 42.1) is chosen to represent ideas about community and inclusion that are central to the themes of this article. In rock art, spirals, concentric circles, and other geometric shapes are interpreted to be universal symbols used to convey conceptual ideas (Patterson, 1992). There are dozens of possible interpretations connected to each figure in the circle because rock art is interpreted not only according to the individual symbols present, but also by the figures that are combined in a panel, just like words in spoken language. For me, the Circle of Friends represents the encompassing nature of a community, whether it is the community that each of us constructs for ourselves or the larger environment in which we discover ourselves. The circle represents the wholeness of a



**Figure 42.1. Circle of Friends petroglyph.**  
*Note.* Original metal sculpture by Kevin Smith, Golden, Colorado. Appears with permission of Kevin Smith.

community, and the figures relate to diversity that can exist within the community. Just as the circle is considered a symbol of inclusion and wholeness, the extension of the circle as a spiral is well known as a symbol of growth and continuity. Spirals frequently appear as symbols of continuity in Native American culture (Patterson, 1992). The spiral reflects evolution and renewal with growth emanating from continuous learning and new challenges. The spiral and its embedded circles will be used in this article to represent change and continuity.

Why is the idea of building inclusive community important to us as people and as occupational therapists? The idea is both profound and simple. Simply, we believe that

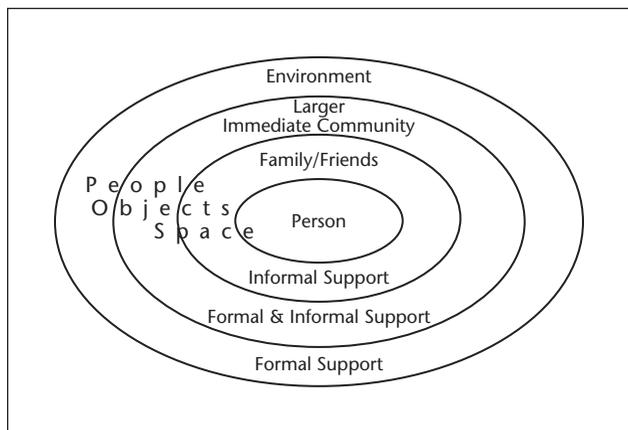
people belong together regardless of real or perceived differences. All persons have the right to choose where they wish to live, work, learn, and play, and with whom they wish to spend time. On a deeper level, we believe that people belong together *because* of differences. There is a richness that characterizes a community constructed with appreciation for both differences and similarities among its members. The idea is not new, but as Winston Churchill said, “Men [and women] stumble over the truth from time to time, but most pick themselves up and hurry off as if nothing had happened” (McWilliams, 1994, p. 413).

## The Nature of Community and Choice

Community provides a context for actualizing individual potential and experiencing oneness with others (McLaughlin & Davidson, 1985). The human condition yearns for a greater sense of connectedness, expressed as a need to reach out, deeply touch others, and throw off the pain and loneliness of separation. The term *community* encompasses *communication* and *unity*. Yankelovitch said that the community evokes in the individual the feeling that “here is where I belong—these are my people, I care for them, they care for me, I am part of them, I know what they expect from me and I from them, they share my concerns. I know this place, I am on familiar ground, I am at home” (1981, p. 224).

There are established communities such as towns, neighborhoods, schools, and workplaces, and there are personal communities we create for ourselves, which include family, friends, acquaintances, how and where we spend our time formally or informally, and the relationships we build over time. Our personal communities do not necessarily depend on specific location or specific time, although they are often embedded in established communities. Building inclusive community refers to both the larger, more formal community context and the smaller, informal community that a person identifies as a personal community. Ideas about diversity and inclusion in community in this article apply to all people, but we as occupational therapists have particular concerns for assuring choice in community living for persons with disabilities and chronic health problems, as well as persons for whom disability and health issues can be prevented.

Personal community building begins at the center of the circle, where the person is embedded in family and close relationships (see Figure 42.2). Networks of informal support develop in the center of a personal community. Relationships grow because persons choose to be connected. The unique culture of personal community is created



**Figure 42.2. Personal community building.**

from family experience. Values are established: heritage, myths, and traditions are communicated. The foundation for building personal community is established within the family.

We all come from families. Families are big, small, extended, nuclear, multigenerational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Our families create neighborhoods, communities, states, and nations. (Shelton & Stepanek, 1994, p. 6)

For both children and adults, family provides a personal culture of embeddedness. Each person creates a community of family culture in the broadest sense of the concept of community. Like all cultures, each culture we create within our community is based on our values and may differ substantially from another's uniquely consummated community. However the family is constituted, whether we judge it adequate or not according to our value system, a person is embedded in his or her family and that is our starting place for inclusion. *A challenge for occupational therapy practitioners is understanding each person's unique community, including its culture and the context in which it was formed.*

The concept of community is broadened to include relations with acquaintances, coworkers, and schoolmates as well as locations like neighborhoods, workplace, and town. The community circle includes both formal and informal sources of support. The environment provides the context in which communities are formed. It is composed of persons, objects, and space—all of which can be combined for personal or formal community building. The environment generally provides formal support to persons in community. Community is not a static structure in the environment, but an ongoing process of interaction among persons, objects, and space. Community provides familiarity with daily interactions that reduces the uncertainty experienced in new and challenging situations and creates a sense of belonging.

A sense of belonging in a community provides the comfort and security needed to explore and use one's gifts. According to Maslow's hierarchy, belonging is an important component in the development of self-esteem. Building blocks to self-esteem include a sense of safety in one's immediate community, a sense of self-acceptance, identity, affiliation with others and a sense of competence and mission. In some instances, we seem to expect children and adults with disabilities to demonstrate a sense of self-esteem before they can be included in a typical classroom or work or living environment, forgetting that belonging to a typical community is the means by which a person develops a sense of self (Kunc, 1994). *One of the challenges we often face is resolution of the conflict we have over the need for persons with disabilities to prove themselves capable before they are included in typical communities of their choice rather than creating opportunities for them to develop their capacities in their community with appropriate supports.*

Choice is a valued dimension of our community life. Choice means having alternatives from which to make a selection. As occupational therapists, we recognize the importance of choice in every person's pursuit of self-actualization, particularly as he or she fulfills occupational roles of daily living, work, school, and play and leisure. Choice in occupational therapy

has traditionally meant that the person seeking services takes an active part in planning and carrying out a therapy program. Yerxa (1966) maintained that one of the most important roles an occupational therapist plays is providing choice in selection of therapeutic activities, interaction with the activities and, most important, establishment of objectives for a therapy program. Exercising choice in a therapeutic environment provides opportunities to explore capabilities and options for life outside the therapy setting. Making choices is another way of exploring personal values about daily living, relationships, roles, and the physical, psychological, social, and spiritual communities in which living needs to occur to pursue self-actualization. Making choices in therapy is only a prelude to the choices people need to make regarding their life in the community. How will I make a living? Where will I live? Where will my child go to school? What supports will I need to live fully in the community of my choice? *A challenge for occupational therapy practitioners is fostering choice that reflects their consumer's priorities for living and accomplishing occupational tasks, even if there are differences between them regarding values or perceptions of expertise.* Schön (1983) wrote that the interactive practitioner realizes that he or she is not the only one in the situation to have relevant and important knowledge. The consumer interacts by joining with a service provider to make sense of the situation and, by doing so, gains a sense of increased involvement and action—or choice.

Being part of a community provides opportunities for lifelong development. Persons with disabilities and their family members have a right to pursue and participate in all levels of their community, whether it is one they have known well or one they wish to build to accommodate new circumstances and fulfill new or old dreams. Each person creates a community of his or her own culture in the broadest sense of the concept. Like all cultures, each culture we create within our community is based in our values and may differ substantially from another's uniquely consummated community. Creating community opens doors to new cultural vistas with opportunities to cooperate with each other and participate in community activities. Inclusion in a community also means an end to loneliness and helplessness and the beginning of empowerment to fulfill dreams (McLaughlin & Davidson, 1985). Building inclusive communities with all persons provides opportunities for members of the community to experience different relationships. Each of us has the capacity for creating inclusive community through our work with individuals as well as our ability to influence society and its established institutions.

## **The Nature of Disability and Inclusion**

A new sociopolitical environment is developing in which persons with disabilities are taking or creating social and political actions on their own behalf. Changing perceptions of disability and the histories of the civil rights movement in the 1960s and the women's rights movement in the 1970s resulted in substantial legislative action for disability rights. In his book *No Pity*, Shapiro (1993) chronicled the course of the disability rights movement in the United States. Shapiro stated that persons with disabilities insist simply on common respect and the opportunity to build bonds to their community as fully accepted participants in everyday life. In the past, disability was usually viewed as a medical problem with the expectation that, to

be accepted, persons with disabilities needed to be as much like persons without disabilities as possible without regard for their own uniqueness. Now, persons with disabilities are thinking differently about themselves. Many no longer think of their physical or mental differences as a source of shame or something to overcome in order to be like others or inspire others. In *Flying Without Wings*, Beisser, who contracted polio as an adult, said “When I stopped struggling, working to change, and found means of accepting what I had already become, I discovered that changed me. Rather than feeling disabled and inadequate, I felt whole again” (1989, p. 169). Beisser views disability as a difference among people. Considering disability as a difference is in itself neutral and changes the way persons with disabilities view themselves and are viewed by others. For example, in the village of Chilmark on Martha’s Vineyard Island in Massachusetts, more than half the residents in the 1800s were genetically deaf (Groce, 1985). All the people in the village were fluent in sign language. It has been reported that spoken and sign language were used simultaneously or, if a person who was deaf joined a speaking group, group members immediately started to use sign as well as speech. Deafness was not a disability in Chilmark. Disability is a dimension of diversity not unlike ethnic background, color, religious, or gender differences (Shapiro, 1993). Differences do not necessarily equal limitations, but rather create opportunities for meaningful interaction (J. Snow, personal communication, 1994) as long as people are living together naturally.

Just as perceptions of disability are changing, so are the reasons that disability was so often seen as a limitation. The difference within the person is no longer viewed as the main problem; instead, the environment that cannot accommodate the person is considered responsible for society’s failure to include persons with disabilities in the mainstream. Social considerations have led to a shift from the traditional medical view of disability to an interactional model that accounts for the relationship between person and environment. Gill (1987) summarized this shift in perspective as follows:

- According to the medical view, disability is considered a deficit or abnormality. In an interactional model, disability is a difference.
- In the medical view, being disabled is perceived as negative. In an interactional model, being disabled is in itself neutral.
- Medicine views disability as residing in the individual. In an interactional model, disability is derived from problems encountered during interaction between the individual and their environment.
- In medicine, the remedy for disability-related problems is cure or normalization of the individual. In an interactional model, the remedy for disability-related problems is a change in the environmental interaction.
- Finally, the medical view identifies the agent of remedy as the professional. An interactional model has proposed that the agent of remedy may be the individual, an advocate, or anyone who affects the arrangements between the individual and society.

The last interactional category in Gill’s summary can have a significant effect on the roles for occupational therapists. The shift from a medical perspective to an environmental framework is not difficult for us to understand. Occupational therapists have always recognized that disability was not an illness that could be cured by medicine. *The challenge for us is to*

*promote the interactive model for practice regardless of the venue of our practice. A concurrent challenge is to increase support for more practice venues in the community where engagement in real occupation takes place.*

Change in perception of disability has fostered the disability rights movement and legislative action. The disability rights movement has focused on the rights of persons with disabilities to be included in society according to the choices they make for themselves and their families. The rights movement could also be called an *inclusion* movement. Inclusion in community means that all persons regardless of differences participate in natural environments for living, learning, playing, working, resting, and recreating. For persons with disabilities, participation may be with specific support from others or with adaptations to the environment. According to Gill (1987), inclusion means removal of barriers to power, which results in a greater number of alternatives or choices.

Shapiro (1993) identified the 1960s as the beginning of the disability independent living movement started by Ed Roberts and other students at the University of California–Berkeley. The movement spread to include action in Washington, DC, that initiated funding for independent living. Groups of parents of children with disabilities began to form around the country at about the same time, primarily to provide support to other parents in the same situations. The groups were often connected to existing organizations like United Cerebral Palsy or the Easter Seal Society. Later, parent organizations would emerge as independent, social change groups.

The 1970s saw adoption of Section 504 of the Rehabilitation Act (Public Law 93–112) prohibiting discrimination on the basis of disability. But Section 504 was not implemented for nearly 5 years after its adoption and was implemented only after a group led by Roberts and others staged a sit-in at the Department of Health, Education and Welfare office in San Francisco. Besides succeeding in obtaining regulations for Section 504, the event in San Francisco created an awareness that linked groups of adults around the country in a civil rights movement. Also in the 1970s, Public Law 94–142 was adopted as the Education for All Handicapped Children Act (1975), mandating public education in the least restrictive environment for children with disabilities who were 5 years of age and older.

In the 1980s, support was provided for that act through the establishment of statewide parent information and advocacy centers in every state. The legislation was expanded to include infants and toddlers with passage of the Education for All Handicapped Children Act Amendments of 1986 (Public Law 99–457). With this expanded legislation for education came the components of family-centered care, or respect for a family's central role as decision maker for a child, or support for an adult, which is now considered best practice across the life span. Public Law 94–142 and Public Law 99–457 were combined and expanded in reauthorization as the Individuals With Disabilities Education Act of 1990 (IDEA) (Public Law 101–476). Meanwhile, the Technology-Related Assistance for Individuals With Disabilities Act (Public Law 100–407) (1988) began the process of changing policy and availability of assistive technology for persons with disabilities in all states. The legislative decade of the 1980s culminated with the Americans With Disabilities Act of 1990 (ADA) (Public Law 101–336). ADA encompasses ideology from all previous legislation by ensuring that the barriers to inclusion be

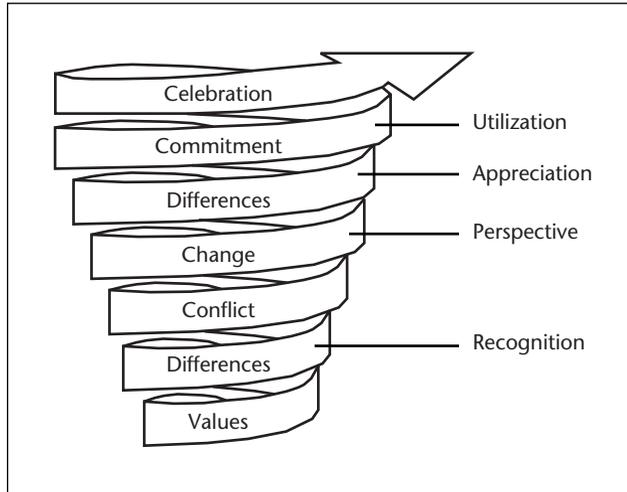
eliminated for persons with disabilities. Although far-reaching disability rights legislation was officially adopted in the 1980s, we are still struggling with implementation of all the laws in the 1990s.

The disability rights movement and legislation has focused primarily on removing physical and legal barriers to inclusion. Legislative mandates serve the purpose of forcing inclusion. The spirit of inclusion only comes with attitude change supported by community preparation and relationship building. In a midwestern city, 9-year-old Amy, who has cerebral palsy, visited Santa Claus last year and had only one wish for Christmas—just one day in school when the kids did not tease her about her cerebral palsy. Clearly, Amy was present in school with her typical peers, and being there is a start. But she is not truly included since a community that accepts her for who she is has not been created. She needed a school community that gave her a sense of familiarity, caring, and belonging. She needed relationships that she could depend upon for support (“Disabled Girl Asks Santa,” 1993). In another city, 14-year-old Kevin, who has Down’s syndrome, has been with typical peers from the beginning of his school career. His inclusion has focused on preparation and relationship building that included Kevin along with the teachers and children in the building. When asked what it would be like if he was not included in typical school, he replied that he’d feel sad. “I like to be in school with my friends—I learn from them and they learn from me” (Kevin, personal communication, February 1993).

Inclusion is about relationships. Judith Snow, a consumer advocate in Canada, has said that the only real disability is having no relationships (personal communication, January 1994). Inclusion means participation. Inclusion in school is only the prelude to inclusion in life. Participation may require support not only in the traditional sense of personal assistance and adaptations, but also in terms of preparing the persons in the community to welcome differences into their community and help develop natural support systems. *A challenge for occupational therapy is development of programs that prepare persons and their families for life in the community while working to prepare the community and persons in it to welcome the gifts of diversity.* If we espouse the interactive model of disability, we can affect the arrangements between the individual and society and make unique contributions to the interactive model of change. We can assist with remediation of the person’s physical or psychological problem to the extent that the manifestations of the problem can be changed. We can participate in modification of the person’s environment so that it can accommodate the needs. We can assist with building community with the person or family in order to create a place for belonging that includes both the formal and informal sources of support. We can continue to promote inclusion as a value through our sociopolitical systems.

Building inclusive community sometimes requires change in value-based practices. The spiral (see Figure 42.3) serves as a model to illustrate that when we recognize differences in values, we may experience conflicts within ourselves or with others. If we cannot move beyond the downward spiral between values and differences, we will not be able to move beyond conflict. But if we move upward to change our perspective to one of appreciating differences, we can make a commitment to using differences in ways that productively build community. The spiral begins with a small, defined center focusing on personal values

about differences. These values were established with past experience. As the spiral moves upward and widens, new experiences are included. The person uses past experience to respond to new situations. The response may be use of past behavior or of a new behavior that will modify old behaviors. For example, Bobbie wants to live alone in an apartment, but he cannot tie his shoes, button his shirt, prepare meals very well, or use the telephone to summon help. If your values about independence mean a



**Figure 42.3. Celebrating diversity: Individual and society.**

person can only choose between doing everything alone or living in a segregated community, then Bobbie's proposal is different, causes conflict, and probably elicits a negative response. If you stay in a downward spiral of conflict between values and differences, you will continue to respond negatively to full inclusion for persons who cannot perform all tasks independently. But if you take an interactive view of disability, your perspective changes. You appreciate that Bobbie's disability resides in the community that cannot accommodate his differences. A change in perspective leads to modification of old behavior by new responses. A commitment to using rather than rejecting differences creates new possibilities for removing the barriers to inclusion. *The challenge for individual occupational therapists and the profession is making a commitment to inclusion in community for all persons with disabilities and chronic health problems.* The following values are proposed for occupational therapy:

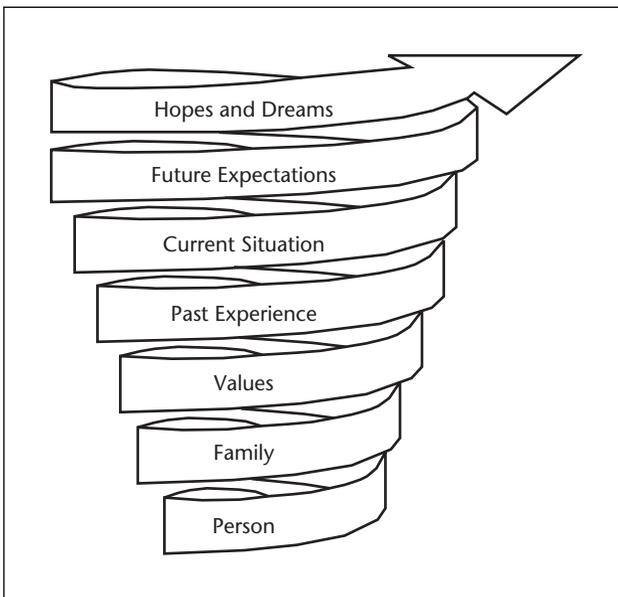
- Every person has a right to be an integrated member of a community of choice.
- Every person has a right to active participation in decision making for self and family.
- Every person has a right to information and options as part of decision making.
- Every person has a right to choice of services delivered in natural environments in order to maximize success in occupational roles.

## The Nature of Adaptation and Environment

To explore means for occupational therapists to meet the challenges of building inclusive community, I would like to turn to the spatiotemporal adaptation theory developed with my colleague Elnora Gilfoyle. The theory was developed when we were both involved in pediatric practice and education. During those years, pediatric occupational therapy and other disciplines focused knowledge development and research on typical child development as a means for designing programs for children who were not developing typically. Although the spatiotemporal adaptation theory articulated the importance of interaction between the child

and the environment, it emphasized ways in which therapists could influence the child's development rather than ways in which the environment could be prepared to accommodate the child's function. In light of the shift from medical to interactive approach to disability, it seems appropriate to reexamine the categories of the theory, especially the environmental category of the model. The original categories in the theory included *movement, environment, adaptation, and spiraling continuum of development* (Gilfoyle et al., 1990).

In the theory, both development in children and ongoing functioning of adults is seen as a transactional process between a person and the environment; for example, movement provides a means for action and the environment presents a reason to act. The person influences and is influenced by the environment through a process of adaptation. According to Kegan, "adaptation is not just a process of coping or adjusting to events (of the environment) as they are, but an active process of increasingly organizing the relationship of self to the environment" (1982, p. 113). The relationship is transactional because persons organize themselves around events of the environment while simultaneously organizing environmental events to meet their needs (Yerxa, 1992). Adaptation as a category of the theory is viewed as an ongoing process of change in behavior. The spiral again provides the model for the adaptation process (see Figure 42.4). Throughout the life span, a person uses past experience, including values established in early life, to adapt to current situations and prepare for future adaptations. Through adaptation, more complex behaviors evolve to respond to more extensive demands from the environment. If the demands of the current or future situations exceed the ability to adapt, the person may recall past behavior to respond until environmental events can be reorganized to elicit a higher level response. With adaptation as a process for organizing one's self and environment, interaction between person and environment sets up a system of relationships.

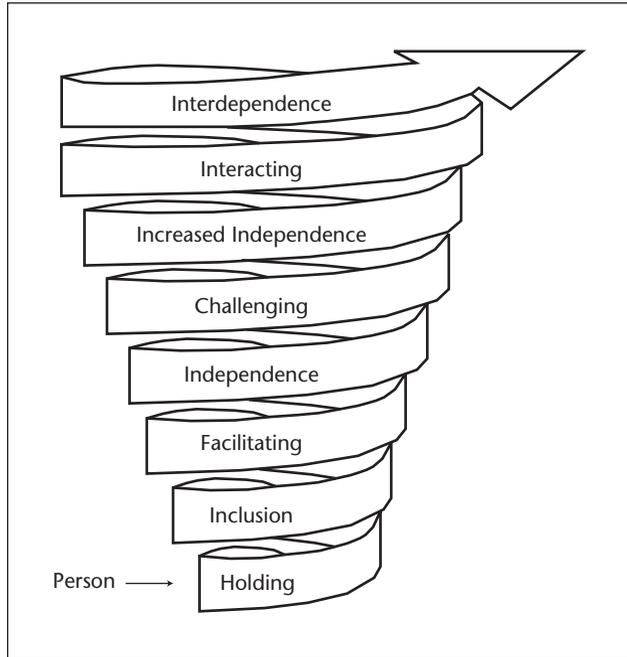


**Figure 42.4.** The person in life span.

Environment as a category in the adaptation theory is all-inclusive. Environment represents the complete setting or surrounding in which a person lives, including self, other persons, objects, space, and relationships between all components in the environment (see Figure 42.2). According to Winnicott, a "good enough" (1965, p. 67) environment meets and challenges a person's need to grow and develop by adapting to stimulation from continually changing situations. Yerxa (1994) noted that persons need just the right challenge to make an adaptive response. Daloz said that

how readily we grow—indeed whether we grow at all—has a great deal to do with the nature of the world in which we transact our lives' business. To understand human development, we must understand the environment's part, how it confirms us, contradicts us and provides continuity. (1986, p. 68)

Environment–person relationships (see Figure 42.5) are conceptualized on a spiraling continuum from a *holding environment*, which promotes inclusion, to a *facilitating environment*, which promotes independence, to a *challenging environment*, which increases independence, to an *interactive environment*, which fosters interdependence.



**Figure 42.5. Environment–person relationships.**

The holding environment begins in infancy and provides support through physical and psychological holding. Winnicott (1965) maintained that the holding environment is the context in which early development takes place. The infant experience can influence a lifetime. Kegan referred to holding as the “culture of embeddedness” (1982, p. 115), which means an environment that is for growth as well as for accumulating history and mythology. In the holding environment, the infant begins to acquire a culture based on values and traditions communicated during this phase. According to Kegan, there is no single holding environment in early life, but a succession of holding environments, a life history of embeddedness. Holding environments are psychosocial environments that hold us and let go of us. If the infant’s experience is satisfactory, it becomes a reference point whenever holding or support is needed later in life. The holding environment promotes a sense of inclusion or belonging, which usually precedes movement away from sources of support and is vital for all persons’ development of independence.

The facilitating environment motivates a person to move beyond a familiar setting and on to new challenges and independence. It provides just enough support for moving, literally or figuratively, into new situations.

The challenging environment focuses on separating the person from embeddedness in order to develop and test potential. Just the right amount of challenge is needed if the person is to make an adaptive response to the situation. Increased independence evolves from successful adaptation to challenges.

Finally, the interactive environment promotes interplay between person and environment by combining a sense of self with an appreciation for relationships with others.

Interactive environment supports interdependence. Winnicott stated that independence is never absolute. The healthy person does not become isolated, but relates to the environment in such a way that person and environment can be considered interdependent. The different functions of environment and the spiraling sequence of relating to environment can be useful for helping persons identify the environment they need to seek or create for their own health and well-being.

The role of the therapist is construction of Winnicott's "good enough" environment (1965), depending on the person's adaptation needs (Letts et al., 1994). A new parent of a child with significant health problems may need a supportive holding environment to learn the special care that will be given at home. A teenager with a spinal cord injury may seek a facilitating environment when he decides to go to college. He may begin assembling the sources for assistance and adaptations he will need to live independently as well as the advocacy skills he will need to act on his own behalf. A woman recovering from a head injury may have regained considerable function in a rehabilitation setting, but may be fearful of being back in her community. She will need challenge to regain her independence, but with enough support and facilitation to ensure progressively successful adaptation. She may want to reconstruct the life she led before the accident, or she may construct a new community and need resources for her new life. An infant may literally require a supportive environment to learn sensorimotor skills or speech or to focus on learning through play. For all of us, gaining and maintaining a balanced interaction between self and environment is a work in progress. We often need to challenge ourselves if we wish to move ahead. Or we seek facilitation for new situations, or support in difficult times. A challenge for occupational therapy practitioners is development of skill in analyzing environments and helping consumers to identify the type of environmental milieu that will facilitate their adaptation process.

### **Interactive Strategies for Choice and Inclusion**

The promise of occupational therapy lies in our ability to continuously combine the mandates put forth in the early tenets of our discipline with our constantly changing practice environments. Occupational therapy emerged from both community and medical models of practice, although our philosophy is more related to what we know as the community-based model because occupations are practiced in community settings. For decades we tended to practice more in institutions or specialized settings, usually trying to simulate real-life settings to prepare persons to live in their community. Some of our more visionary colleagues set the course toward a future that focused on community consultation models of service delivery. The founders and leaders in our profession have fostered the importance of providing services in a person's own setting and according to the person's own choices and priorities for gaining or regaining specific skills for living. Our philosophy from the beginning of our profession has included the value of choice, relevance, and active participation through engagement in meaningful occupations. Occupation provides a context for organizing one's self and one's environment, thus promoting the transactional process of adaptation within a community setting (Engelhardt, 1977; Gilfoyle et al., 1990; Grady, 1992; Meyer, 1922; Schwartz,

1992; Yerxa, 1966). Therapy programs are designed to prevent or remediate the effects of disability or health issues and promote independent living in the community through occupations such as self-care and daily care of others, ability to play independently or with other children, ability to learn as a child and engage in lifelong learning as an adult, ability to be engaged in meaningful work to make a living or for one's own satisfaction or both, ability to balance work and recreation, and ability to blend all occupational activity with rest. Although models for community service delivery have been promoted from within the profession, external mandates for change have also influenced expansion of our practice environments. The voices heard from our consumers, our colleagues, legislation at state and national levels, and rapidly changing payment systems direct us toward service delivery that focuses on consumers' priorities for goals and naturally occurring venues for activities. The new directions in practice allow us to combine our past experience and founders' mandates with the current realities of practice in ways that lead us to realize the future hopes and dreams of our consumers, ourselves as individuals, and the profession as a whole.

To build collaborative models of consumer-driven, community-based practice, we need to focus on a communication process that helps us understand other persons' unique culture and priorities for life occupations as well as meaning associated with past experiences, current situations, and hopes for the future. Recent developments in the field support a focus on communication that enhances a shift from medically focused to interactive models of practice in which the therapist serves as an agent of remedy to affect the arrangements between the individual and society. The use of narrative for storytelling has increased our understanding of a person's past and present experience. Reflective practice and clinical reasoning support our ability to gain insight into the interactive roles that can unfold between a therapist and a person seeking services. Ethnographic approaches to research have in general heightened our knowledge of persons living in their own environments (Clark, 1993; Mattingly & Fleming, 1994; Schön, 1983; Yerxa, 1994).

Therapist–consumer collaborative practice models mean that communication among the therapist, the person seeking services, the family members, and the close community members is critical. From the beginning, it is the relationships we build that are critical to our ability to collaborate effectively. Listening, talking, reflecting, informing, and demonstrating are all part of the ways we establish relationships. Human beings are uniquely constituted for giving and receiving information, making and sharing meaning. We have the capacity to use intrapersonal communication skills to explore the meaning of our own values and experiences, and interpersonal communication skills to link with another person's values and experiences. *Intrapersonal communication* refers to the creating, functioning, and evaluating of symbolic processes that operate within us. Such activities as thinking, reflecting, solving some problems, and talking with oneself are part of our unique intrapersonal communication system (Dance & Larson, 1972). Intrapersonal communication is active within us whenever meaning is attached to an internally or externally generated source of stimulation. Meaning associated with past events and current situations is deeply embedded in the intrapersonal system of both the persons seeking services and the service provider. Interpersonal communication serves to link us through verbal and nonverbal expression so that we can more

explicitly share information and meaning. Through interpersonal communication, we can tell our stories; explore the meaning of relationships, events, and circumstances; reflect on similarities, differences, strengths, and challenges; and develop plans for working together toward future goals. Kegan said, “If you want to understand another person in some fundamental way, you must know where the person is in his or her evolution. You need to understand his or her underlying structure for making meaning” (1982, p. 113). The context in which we as therapists seek and receive the information shared by persons seeking services can enhance our communication and collaborative planning. A communication model of collaboration can be illustrated by the spiraling model of person in life span (see Figure 42.4). If we place spirals side by side and let one spiral represent the consultant therapist and the other represent a person seeking services, we can visualize the communication sequences that occur. Communication moves from intrapersonal reflection to interpersonal linking through listening and speaking (see Figure 42.6). A closer look at the circle representing past experience provides details that can be shared about the meaning embedded in values and culture of childhood, family, and personal community (see Figure 42.7). We can discuss past experiences in terms of activities and relationships with family and close friends, with personal community, and with the larger environment. Exploring the past provides insight into the values that have directed past choices and the types of environments that the person has experienced. Discussing the current situation (see Figures 42.8 and 42.9) in the same context allows the therapist to understand the extent and meaning of the change that has occurred in the person’s life as well as the priorities and types of environments that need to be foremost in planning together. The persons can glean considerable information about the ther-

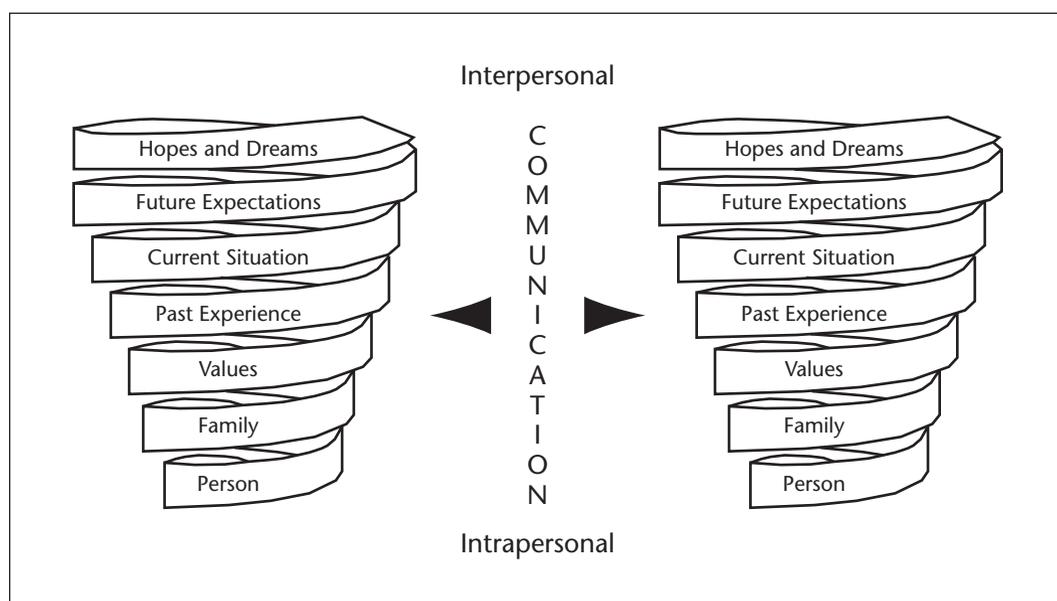


Figure 42.6. Linking past experiences.

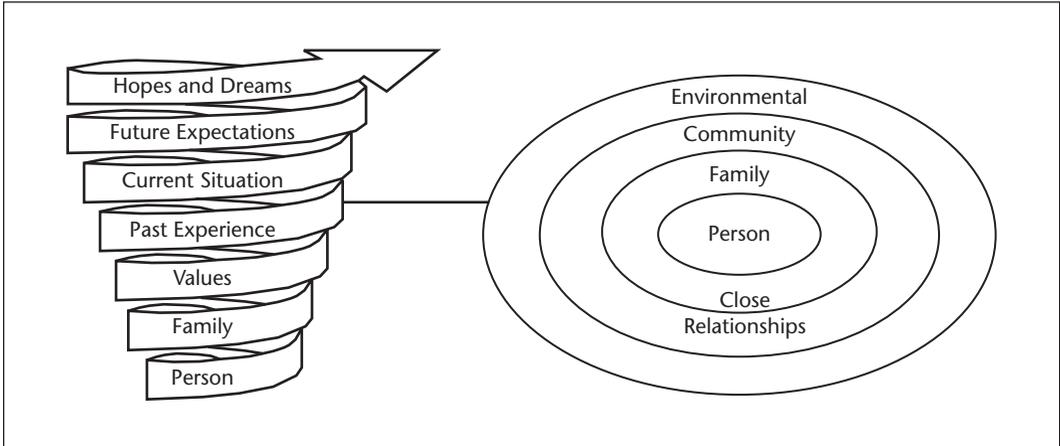


Figure 42.7. The link of past experience with personal community.

apist’s perspective on the current situation on the basis of past experience. The interpersonal linking increases understanding and promotes collaborative goal setting between person and therapist. As much as we have moved toward collaboration in family-centered and person-centered planning, we are still sometimes heard to say that we are having difficulty with a person receiving services accepting the goals we have set for their therapy. Interactive strategies mean that persons receiving services set the goals and therapists collaborate to design programs with them that will help address the goals. Information shared and the meaning it holds for both consumer and therapist provide the basis for collaboratively planning the

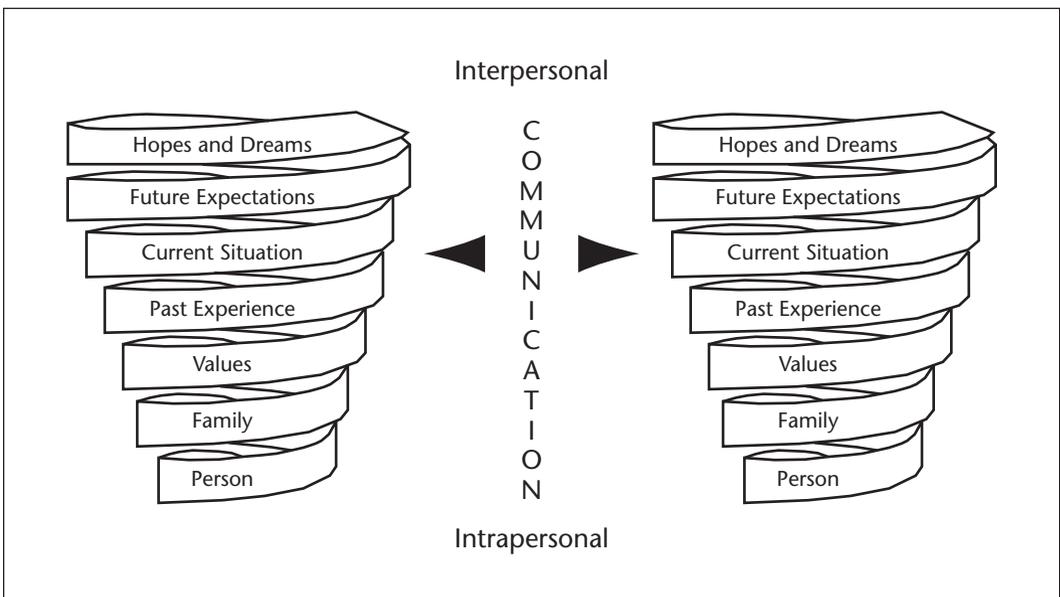


Figure 42.8. Linking current information.

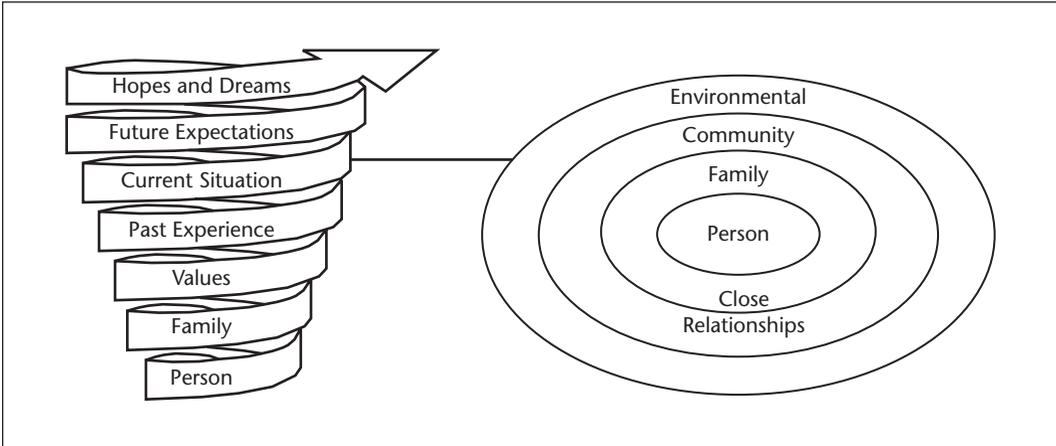


Figure 42.9. The link of current situation with personal community.

future (see Figures 42.10 and 42.11). According to Schön (1983), there is gratification and anxiety for the reflective, interactive practitioner in becoming an active participant in a process of shared inquiry. For a therapist or consumer who wishes to move from traditional to reflective communication, there is the task of reshaping expectations for the relationship. But if we are to be agents of remedy in the arrangements between a person and the environment, we need to be able to share with and receive comprehensive information from the persons who are seeking choices for inclusion in their community.

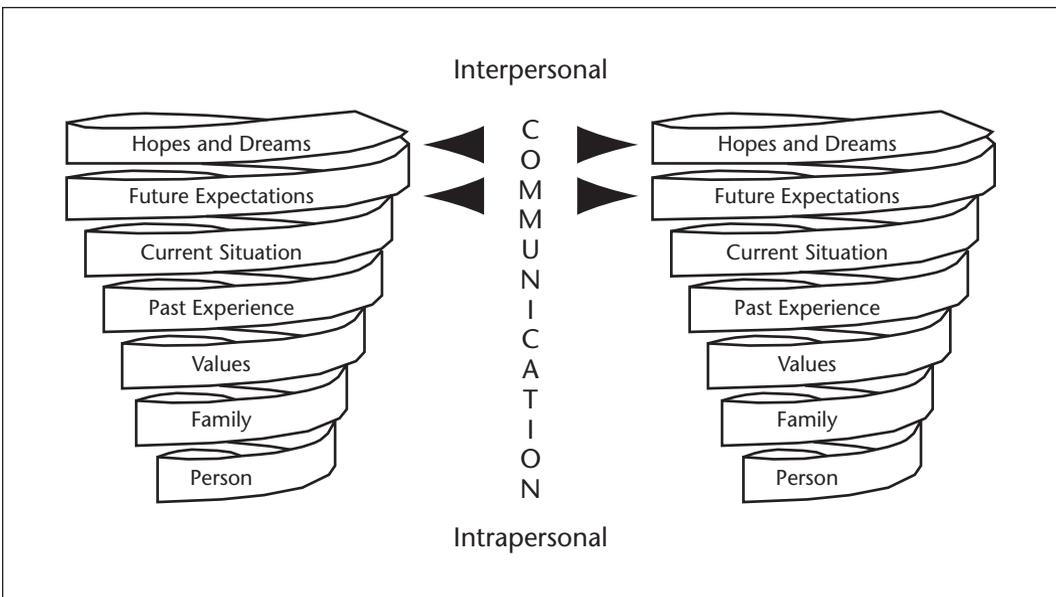
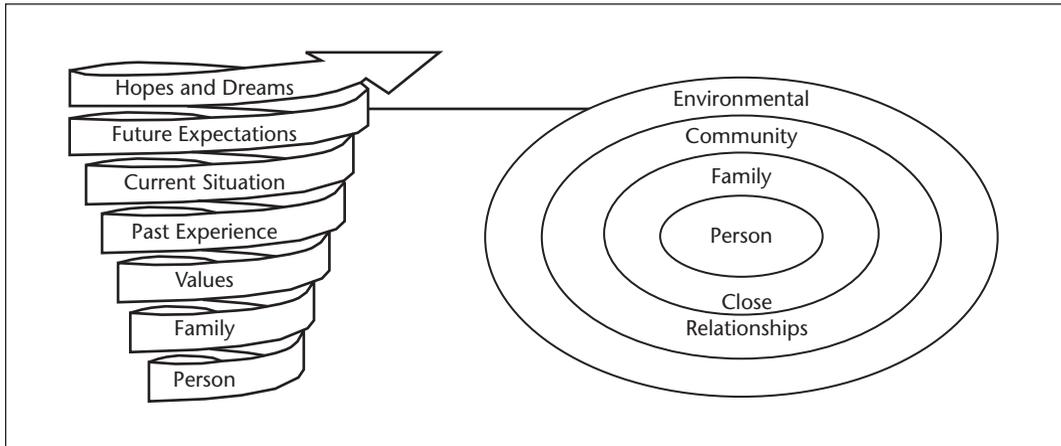


Figure 42.10. Exploring future possibilities.



**Figure 42.11. The link of hopes, dreams, and future expectations with personal community.**

## Summary

We have had an opportunity to focus on the challenges and opportunities for building inclusive community with the persons with whom we work in occupational therapy. We have gained understanding about the meaning of community and choice, reviewed current ideas about the nature of disability and mandates for inclusion, expanded ideas about environment and adaptation, considered strategies for promoting choice and inclusion, and related these concepts to the philosophy of occupational therapy. I had the extraordinary opportunity to explore my own values, past experience, current situation, and hopes for the future and I am forever changed by the experience. As Emily Brontë reflected, “I’ve dreamt in my life—dreams that have stayed with me ever after, and changed my ideas: they’ve gone through and through me, like wine through water, and altered the color of my mind” (cited in *The Quotable Woman*, 1991, p. 185). Leading the development of inclusive community is right for occupational therapy and we all have it in us to do it. The challenges before us are as follows:

1. Understanding each person’s unique community, including its culture and the context in which it was formed.
2. Resolving the conflict we have over the need for persons with disabilities to prove themselves capable before being included in typical communities of choice rather than creating opportunities for developing capabilities in the community with appropriate supports.
3. Fostering choice that reflects a person’s priorities for living and accomplishing occupational tasks, even when there are differences regarding values or perceptions of expertise.
4. Promoting the interactive model for practice, regardless of the venue of practice.
5. Increasing support for more practice venues in the community where engagement in real occupation takes place.

6. Developing programs that prepare people and their families for life in the community while working to prepare the community to welcome the gifts of diversity.
7. Making a commitment to inclusion in community for all persons.
8. Developing skill in analyzing environments and helping people identify the type of environmental milieu that will facilitate their adaptation process.

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## References

- Americans With Disabilities Act of 1990 (Public Law 101-336) 42 U.S.C. § 12101.
- Beisser, A. (1989). *Flying without wings*. New York: Doubleday.
- Brontë, E. (1991). Cited in *The quotable woman*. Philadelphia: Running Press.
- Clark, F. (1993). Occupation embedded in a real life: Interweaving occupational science and occupational therapy. 1993 Eleanor Clarke Slagle Lecture. *American Journal of Occupational Therapy*, 47, 1067-1078.
- Daloz, L. (1986). *Effective mentoring and teaching*. San Francisco: Jossey-Bass.
- Dance, F., & Larson, C. (1972). *Speech communication: Concepts and behavior*. New York: Holt, Rinehart, & Winston.
- Disabled girl asks Santa to end teasing. (1993, December 14). *The Denver Post*, p. 1.
- Education for All Handicapped Children Act of 1975 (Public Law 94-142).
- Education of the Handicapped Act Amendments of 1986 (Public Law 99-457).
- Engelhardt, H. (1977). Defining occupational therapy: The meaning of therapy and the virtues of occupation. *American Journal of Occupational Therapy*, 31, 666-672.
- Gilfoyle, E., Grady, A., & Moore, J. (1990). *Children adapt* (2nd ed.). Thorofare, NJ: Slack.
- Gill, C. (1987). A new social perspective on disability and its implication for rehabilitation. *Occupational Therapy in Health Care*, 7, 1.
- Grady, A. (1992). Nationally Speaking—Occupation as vision. *American Journal of Occupational Therapy*, 46, 1062-1065.
- Groce, N. (1985). *Everyone here spoke sign language: Hereditary deafness on Martha's Vineyard*. Cambridge, MA: Harvard University Press.
- Individuals With Disabilities Education Act of 1990. (Public Law 101-476).

- Kegan, R. (1982). *The evolving self*. Cambridge, MA: Harvard University Press.
- Kunc, N. (1994). *The other side of therapy*. Port Alberni, BC: Axis Consultation and Training.
- Letts, L., Law, M., Rigby, P., Cooper, B., Stewart, D., & Strong, S. (1994). Person–environment assessments in occupational therapy. *American Journal of Occupational Therapy*, 48, 608–618.
- Mattingly, C., & Fleming, M. (1994). *Clinical reasoning: Forms of inquiry in a therapeutic practice*. Philadelphia: F. A. Davis.
- Meyer, A. (1922). The philosophy of occupation therapy. *Archives of Occupational Therapy*, 1, 1.
- McLaughlin, C., & Davidson, G. (1985). *Builders of the dawn*. Summertown, TN: Book Publishing.
- McWilliams, P. (1994). *Do it again!* Los Angeles: Prelude.
- Patterson, A. (1992). *Rock art symbols of the greater Southwest*. Boulder, CO: Johnson.
- Patterson-Rudolph, C. (1993). *Petroglyphs and Pueblo myths of the Rio Grande* (2nd ed.). Albuquerque, NM: Avanyu.
- Rehabilitation Act of 1973 (Public Law 93–112), 29 U.S.C. § 794.
- Schön, D. (1983). *The reflective practitioner*. New York: Basic.
- Schwartz, K. (1992). Occupational therapy and education: A shared vision. *American Journal of Occupational Therapy*, 46, 12–18.
- Shapiro, J. (1993). *No pity*. New York: Times.
- Shelton, T., & Stepanek, J. (1994). *Family-centered care for children needing specialized health and developmental services*. Bethesda, MD: Association for the Care of Children's Health.
- Technology-Related Assistance for Individuals With Disabilities Act (Public Law 100-407) (1988).
- Winnicott, D. (1965). *The maturational processes and the facilitating environment*. New York: International Universities Press.
- Yankelovitch, D. (1981). *New rules*. New York: Random House.
- Yerxa, E. (1966). 1966 Eleanor Clarke Slagle Lecture—Authentic occupational therapy. *American Journal of Occupational Therapy*, 21, 1–9.
- Yerxa, E. (1992). Some implications of occupational therapy's history for its epistemology, values, and relation to medicine. *American Journal of Occupational Therapy*, 46, 79–83.
- Yerxa, E. (1994). Dreams, dilemmas, and decisions for occupational therapy practice in a new millennium: An American perspective. *American Journal of Occupational Therapy*, 48, 586–589.