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Kathryn M. Loukas
University of New England, kloukas@une.edu

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The Evolution of Language and Perception of Disability in Occupational Therapy

Kathryn M. Loukas, MS, OTR/L, FAOTA

How do occupational therapy practitioners refer to the persons they serve, and how do these terms reflect our perception of disability as a profession? In the hospital or medical model, we call these persons *patients;* in the community we referred to them as *clients*; in the marketplace, they may be called *consumers*. Children serviced through the schools often are called *students,* and persons in long-term care may be called *residents*. However, most of the individuals we serve carry a diagnostic label that makes them eligible for services and defines the work of therapy (Centers for Disease Control and Prevention [CDC], 2007; Shepard & Jensen, 2002). *Impairment* refers to the result of pathology, such as a physical, mental, or psychiatric condition. *Disability* refers to functional limitations as a result of disease or impairment, such as in ambulation or self-care activities. *Handicap* is the inability to participate in a life activity, such as work, recreation, and community involvement, because of external or internal barriers (CDC, 2007; Shepard & Jensen, 2002).

These terms, or "labels," although currently necessary for eligibility and reimbursement of therapy programs, can be limiting and destructive to one's self-concept as a human being. With that understanding, how should occupational therapy practitioners address persons within our service? What terms are acceptable, respectful, and honorable and enhance our clientele's self-image? Through the use of historical inquiry, this article explores the evolution of language in the occupational therapy profession.

Historical Perspective

In the early 1900s the term *invalid* was often used to describe persons with disabilities. Susan Tracy, a nurse and founder of occupational therapy, wrote a book that used the term *invalid occupations* (Tracy, 1912). At the turn of the century, a new perspective of disability emerged with the creation of the first institutions, often referred to as *hospital-schools* (Byron, 2001, p. 133), and led to the first programs in vocational training of *cripples* and the approach to their care known as *rehabilitation* (Byron, 2001, p. 133). The term *cripple* primarily was used for persons with mobility impairments, such as polio, but also was correlated with dependency (Byron, 2001).

From this early perspective, the role of rehabilitation emerged with the intention to decrease dependency and assist acceptance of persons with impairments in society. As the profession of occupational therapy further developed, scholars such as Yerxa (1966/2005) urged authentic occupational therapy to assist the *patient* to confront his or her disability, and Fiorentino (1974/2005) referred to both the habilitation and the rehabilitation of the *physically handicapped child.* Images of persons with disabilities ranged from the "freak shows" of the early 1900s, which used medical conditions to exploit individuals with unique physical characteristics, to the poster children of the March of Dimes (Garland-Thomson, 2002). The poster children concept alluded to the child who overcame his or her disabilities by rising from crutches or wheelchairs, which was firmly set in the medical model of *cure* and the importance of *overcoming* disability. Finally, sensationalism and awe was associated with persons with disabilities who overcame huge obstacles, such as Helen Keller, and later those who scaled mountains and conquered physical or societal barriers, such as Erik Weihenmeyer, the blind man who climbed Mount Everest. Garland-Thompson (2002) used the term *extraordinary bodies* for persons who have "monstrosity, mutilation, deformation, crippledness, or physical disability" (p. 34). Occupational therapy functioned within the rehabilitation systems and the hospital-schools of those times until institutionalization and the medical model were questioned in the 1960s and 1970s (Baum, 1980; Finn, 1971/2005; West, 1968/2005).

Around the 1980s and 1990s the perspective evolved toward enlightenment, deinstitutionalization, and sweeping legislation for persons with disabilities as the Americans with Disabilities Act of 1990 (Public Law 101-336) and the Individuals with Disabilities Education Act of 1990 (Public Law 101-476) demanded more inclusion (American Occupational Therapy Association [AOTA], 1999). The independent living movement brought forth the term *disabled* and, later, *people first* terminology (Shapiro, 1993). Shapiro (1993) challenged the past images of "Tiny Tim and Supercrips" (p. 12) and advocated that persons with disabilities wanted "no pity" (p. 12) from society or rehabilitation specialists. Joseph Shapiro and Ed Roberts led the movement away from charity and dependency that had been associated with disability and toward independent living (Grady, 1995). In occupational therapy, special interest sections promoted positive language and attitudes in occupational therapy (Loukas, 1994), and the term *mental health* versus *psychiatric illness* was used in occupational therapy literature. Leaders in occupational therapy in the 1990s were at the helm of this transformation, as occupational therapists advocated for inclusion (Grady, 1995), occupation in real-life contexts (Clark, 1993), purpose and meaning (Trombly, 1995), and disability identity (Christiansen, 1999; Kielhofner, 2002).

Today, occupational therapy has entered the realm of disability studies (Kielhofner, 2005), identity (Christiansen, 1999; Kielhofner, 2002), and "engagement in occupation to support participation in context" (AOTA, 2002, p. 611). Christiansen (1999) described *identity* as a composite of the self that includes roles, relationships, values, self-concept, and personal goals, and Kielhofner (2002) built on this by describing *occupational identity* as "a composite sense of who one

is and wishes to become as an occupational being generated from one's history of occupational participation" (p. 119). The capacity to do something that has meaning creates occupation and identity. These emerging concepts are important to the culture created and the language used in occupational therapy practice.

The ideology of *disability studies* seeks to integrate the perspective and responses of persons with disability into the practice of rehabilitation professionals (Kielhofner, 2005). The discipline of disability studies asserts that disability is not something to be *fixed* and that implementation of the medical model to *overcome* disability is no longer the ultimate goal (Kielhofner, 2005). In this perspective, Yerxa's (1966/2005) authentic occupational therapy is again important to philosophy and practice as occupational therapy practitioners seek to facilitate participation in the occupations of life and establish positive individual identity within the ability set of each person served.

Language Related to Issues of Power

Ruth Brunyate (1957/2005) stated, "An occupational therapist is, after all, merely a tool through which the doctor treats his patient" (p. 27). This statement is indicative of the profession of occupational therapy, which lacked empowerment itself, thus hindering the ability to empower others. During the 1950s and early 1960s, persons with developmental disabilities were segregated by the societal perception that *disabled people* required institutionalization and needed to be removed from the community (Byron, 2001).

Medical patriarchy was practiced in the United States until questioned by social reformers who shifted power through their advocacy of patient rights and collaborative relationships with health professionals (Fletcher, Spencer, & Lombardo, 2005). The context of life for persons with disabilities began to shift from the confines of institutions and patriarchal medical models to natural environments. Dependency was challenged by Yerxa (1966/2005) and others who asserted that client choice, perception, and self-direction were of greatest importance in the therapeutic context. Frank (2000) described dependence as correlated with "powerlessness, manipulation, coercion, and playing on others' feelings of pity, guilt and shame" (p. 39).

Policy and Power

The entitlement system of the U.S. government fed into the concept of dependency of persons with disabilities (Frank, 2000; Shapiro, 1993). In contrast, the independent living movement of the 1990s empowered these persons to make choices and be heard. Shapiro (1993) called it "the mosaic movement for the 1990s" (p. 11), with diversity that encompassed complex and varying opinions. Gill (1987) and Grady (1995) proposed inclusion as a means to removing barriers to power, resulting in more alternatives and choices in the lives of persons with disabilities.

With more equalized power, the language of disability evolved as well. Individuals began to be described as *living with* versus *suffering from* a particular condition; *wheeled mobility* replaced the minimizing term *confined to a wheelchair;* persons began *living with* conditions versus *dying from* chronic disease; and the term *survivor* replaced *victim* when referring to persons with an acquired disability. *Mental health challenges* replaced the negative term of *insanity,* and persons with *intellectual challenges* were no longer identified as a *moron* or an *idiot* (Byron, 2001). Occupational therapy moved toward occupation-based empowerment models such as the Model of Human Occupation (Kielhofner, 2002, 2005, 2007) and the Canadian Model of Occupational Performance (Canadian Association of Occupational Therapists, 1991) to replace the disablement model.

Movement Toward Community Participation

As early as 1967, Wilma West (1968/2005) advocated that occupational therapists move from "therapist to health agent" (p. 149), and she put forward the idea that occupational therapy should be practiced in "many other settings than the hospital" (p. 149). Finn (1971/2005), rising from the social activism of the 1960s, advocated for social change and prevention programs in occupational therapy practice. Baum (1980) first introduced the concept of the client as a *consumer* of occupational therapy services, which turned the tables on the power relationship in the medical model toward client-centered care. Occupational therapy became increasingly autonomous as community-based practice began to flourish and clinical reasoning became important to the independent practitioner (Rogers, 1983).

Gilfoyle (1984) recognized the decline of occupational therapy's allegiance to the medical model and acknowledged the slow decrease of patriarchy in our profession. Our client-centered attitudes and collaborative relationships with clients permeated the literature as life stories and occupational science came to the forefront (Clark, 1993; Fine, 1991; Frank, 2000). Christiansen (1999) proposed that identity is shaped by relationships with others, and consequently, occupational therapy's relationship with the patriarchal medical model was replaced by empowerment, choice, and collaborative relationships with clients and families.

Feminism as an Inclusive Perspective

Transformation of our profession, as well as a much broader cultural emergence, required the "renaissance of the feminist movement" (Gilfoyle, 1984, p. 575). In a special issue of the *American Journal of Occupational Therapy* devoted to feminism as an inclusive perspective, Hamlin, Froehlich, Loukas, and MacRae (1992) declared the feminist perspective as "a dynamic, evolving ideology" that developed from a focus on women's issues and inequality to encompass "an inclusive model for all people" (p. 967). Frank (1992) opened the issue with the history of feminist thought in occupational therapy and acknowledged that gender segregation was a force in our profession. Miller (1992) asserted "occupational therapy has more in common philosophically with feminism and holistic health than it does with medicine" (p. 1013). Froehlich (1992) advocated for pride and visibility for our clients with disabilities and our work as occupational therapists.

Royeen (2003) brought feminist thought to her "chaotic occupational therapy" (p. 609) Eleanor Clarke Slagle lecture through "herstory, or the pattern that connects" (p. 610). Feminism is an interwoven tapestry of perspective that values relationship, interconnectedness, holism, and nonlinear dynamic perspectives. Royeen

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(2005) directed a "pink-collar call for feminist development in occupational therapy" (p. 810) and the reexamination of our history, present, and future from a humanistic, feminist perspective, as described by Hamlin et al. (1992).

Future Transformation

Scholars of the discipline of disability studies assert that occupational therapy must continue its evolution toward positive, productive language and perceptions of disability by further engaging and empowering persons with disabilities to greater participation and influence in society (Kielhofner, 2005). AOTA's Centennial Vision facilitates this transformation by envisioning occupational therapy as a "powerful, widely recognized, science-driven, and evidence-based profession" that is "globally connected" and "[meets] society's occupational needs" (AOTA, 2007, p. 613). The language of empowerment and inclusion is key to achieving this vision. As technology opens new doors, occupational therapists must collaborate with clients, families, community leaders, and legislators to facilitate full life participation of persons with disabilities. Dependency leads to powerlessness, coercion, and manipulation on personal, professional, and policy levels. Language, if used intentionally and compassionately, can be a positive and powerful tool to open borders, engage in person-centered practice, and build inclusive community in occupational therapy.

Conclusion

Occupational therapy, as a client-centered, dynamic, and emerging allied health profession, has struggled with identity, language, concepts, and attitudes in its quest for enlightenment. The use of language to describe occupational therapy clientele has evolved from a medical model of disablement and patriarchy to a client-centered model that is positive, inclusive, empowering, and collaborative. Occupational therapy practitioners were once "crippled" by adherence to biomedical practices and contexts that confined clients. Through emergent language, concepts, attitudes, and holistic models, occupational therapy and persons with disabilities are transforming to embrace the empowerment of full occupational participation in all contexts of life. ■

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Kathryn M. Loukas, *MS, OTR/L, FAOTA, is Associate Clinical Professor, Department of Occupational Therapy, University of New England, 11 Hills Beach Road, Biddeford, Maine 04062; kloukas@une.edu.*

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