MEANINGS OF DISABILITY FOR CULTURALLY DIVERSE AND IMMIGRANT FAMILIES OF CHILDREN WITH DISABILITIES

Maya Kalyanpur

THE MEANING OF CULTURE FOR IMMIGRANT FAMILIES OF CHILDREN WITH DISABILITIES

Special education is a product of its culture. First, as microcosms of the macro-culture (Tyack/Hansot 1982), schools share the same values of individual rights, equality, personal choice, hard work, and social mobility that are highly regarded within the dominant American culture (Spindler/Spindler 1990). Special education, an equity measure for students with disabilities who might otherwise be at risk of academic failure, is an aspect of this microcosm of regular education. Further, it adheres to the same epistemology of Western rationalism and scientific objectivity as regular education. As the U.S. rapidly becomes the most multicultural society in the world, it is important for professionals to examine these embedded beliefs in special education. This paper attempts to deconstruct the value base on which professional knowledge in American special education is built to advocate for a level of cultural awareness that can radically alter the ethnocentricity with which we usually approach families and communities which diverge significantly from the culture of special education. It identifies the implicit assumptions of the dominant paradigm of special education epistemology, the medical model, and analyzes the implications of these assumptions for families from contrasting traditions.

CULTURAL UNDERPINNINGS OF SPECIAL EDUCATION EPISTEMOLOGY

The paradigm that has dominated professional knowledge in special education is the clinical perspective, or the medical model (Mercer 1973). This perspective of deviance contains two contrasting theories of normalcy: The pathological model defines abnormality according to the presence of observable biological symptoms, and implies that abnormality is an unhealthy state that requires alleviation or *fixing*. The statistical model defines abnormality according to the extent to which an individual varies from the average of a population on a particular attribute. The clinical perspective of disability yields four implicit assumptions: disability is a physical phenomenon; disability is a type of chronic illness; disability is individually owned; and, disability is a condition that requires *fixing* (Bogdan/Knoll 1995; Skrtic 1995; Mercer 1973). This section examines each of these assumptions and their implications for families from contrasting traditions.

Disability as a Physical Phenomenon

According to the field of medicine, a disability is assumed to have a biological etiology and an identifiable set of symptoms that constitute that disability; in turn, any individual who exhibits a minimum number of symptoms characteristic of a particular syndrome is assumed to have that specific disability. The medical model in special education assumes that characteristics specific to some students account for their need for specialized instruction. For instance, the official definition of learning disability views learning difficulties as intrinsic to the child by explicitly excluding environmental, cultural, or economic effects from the definition (IDEA 1997).

Disability as a Chronic Illness

The Western rationalist dichotomy between spirit and body informs the medical model's focus on the corporal aspect of being and imputes all etiologies of disability to biological dysfunction (Zola 1986). Further, should an individual have a disability that will prevail throughout his or her lifetime, the condition is perceived to be chronic. Western time is both linear and abstract. In contemporary Western societies, time is a finite, measurable resource. In finite clock or calendar time, disabilities are perceived to be the results of events that have occurred in individuals' present lifetime. Since death provides the end to this finite life, by definition, a lifelong condition, such as a disability, is one that persists through an individual's lifetime. Special education and rehabilitation policy is based on this understanding that a single lifetime is all the clock time individuals have to maximize their potential. Further, in clock time, the future is a dimension that occurs within the present lifetime – a belief that forms the underpinning to the legal requirement of transition planning.

Disability as an Individual Phenomenon

In mainstream American culture, a medicalized explanation of disability is generally seen as mitigating stigma, since the condition is viewed as an accident of nature, an event beyond our control for which no-one can be blamed. Further, it locates the problem within the individual rather than the family, unless there is clear evidence of genetic etiology, such as with fetal alcohol syndrome. Monks and Frankenberg (1995) suggest that this focus emerges from the notion of personhood in Western industrialized societies wherein "the location of individuality in consciousness has been associated with an emphasis on rationality, responsibility, and the continuity of a self that exists independently of both the sociocultural environment and bodily changes" (ibid.: 107). Thus, special education attributes a child's failure in school to some flaw within him or her – most notably, an insufficient IQ – rather than inadequacy on the part of the educational institution (Bogdan/Knoll 1995).

Fixing the Disability

Special education and rehabilitation are based on the premise that disability is a problem that needs to be and can be *fixed*. Further, since it is assumed that the disability is intrinsic to the child, interventions are geared exclusively towards remedying this condition within the child, ignoring the impact of environment (Bogdan/Knoll 1995). Two cornerstone tenets of special education, normalization and behavior modification, emerge from these assumptions. The understanding is that individuals with disabilities can be *normalized* if provided with the repertoire of settings and activities that typical nondisabled peers would have access to, and, through a process of behavior modification, taught the skills for successful participation, however partial, as well. In other words, given the opportunities to attain the same outcomes of life as their nondisabled peers, individuals with disabilities will have socially valued roles.

CONTRASTING TRADITIONS OF THE MEANINGS OF DISABILITY

Many cultures lack the level of abstraction and belief in the immutability of science that characterize Western cultures (Hall 1976), which contributes to an alternative perspective of disability, the social systems, or the community perspective (Mercer 1973; Edwards 1997) where "the meaning of impairment must be understood in terms of cosmology and values and purposes of social life" (Whyte/Ingstad 1995: 10). In this context, disability has no inherent meaning but is defined by any given community's understanding of people's roles, and the degree to which one is able to fulfil the tasks of membership determines the degree of one's physical ability or disability (Edwards 1997; Talle 1995). For instance, while certain descriptors, such No-Eyes in many American Indian tribes (Locust 1988) or *dhegoole* for without ears in Somalia (Helander 1995), imply a set of conditions, the image intended by the term varies from usage to usage, informed by the context (Edwards 1997; Talle 1995) and is not meant to signify the individual as being a member of a category of *disabled people* (Chan 1986; Helander 1995; Locust 1988). Further, the value attached to a specific condition varies among families, in terms of whether it is perceived as disabling and/or stigmatized. For instance, among many Hmong families, epilepsy is neither a disability nor stigmatized, but an illness of "some distinction ... , and a sign that the person has been chosen to be the host of a healing spirit" (ibid.: 21), a position of high social status (Fadiman 1997).

In this section, we examine four assumptions made by the social systems perspective that contrast with those of the medical model. These assumptions are: disability is a spiritual phenomenon, disability is a group phenomenon, disability is a time-limited phenomenon, and disability must be accepted. In noting that the assumptions of the social systems model contrast with those of the positivistic medical model, we mean that they emerge from a set of values that is often diametrically opposite to those imbedded in Western rationalist thought, and not that they are irrational.

Disability as a Spiritual Phenomenon

Adherents of the social systems perspective do not necessarily rule out the possibility of a physical etiology to a disability; the difference is that they may also ascribe spiritual or sociocultural causes (Danseco 1997; Serpell/Mariga/Harvey 1993). For example, while many Hmong (Meyers 1992; Fadiman 1997), American Indian (Locust 1988), and Punan Bah (Nicolaisen 1995) families impute to illness a natural cause, such as old age or eating unsuitable food, the most common cause of illness is soul loss, or *ghost sickness* (Locust 1988: 321). In Fadiman's study (1997) of a Hmong family whose daughter developed epilepsy, the parents attributed the condition, which they referred to as the sickness in which "the spirit catches you and you fall down", to soul loss caused by fright. Similarly, the Mexican-American families in Mardiros' study (1989) attributed their child's disability to both biomedical causes, such as chronic health problems during pregnancy or pollution, and to sociocultural beliefs such as marital difficulties and divine punishment for parental transgressions.

The 'evil eye', curses, and other metaphors of spiritual malevolence are also seen as common causes for sickness and disability among many Maasai (Talle 1995), Hmong (Fadiman 1997), Jewish-Oriental (Stahl 1991), American Indian (Locust 1988), Latin American (Groce/Zola 1993), and Hubeer families (Helander 1995). These spiritual concepts have a distinct social component and are believed to have been triggered by some neglected duty or obligation of the victim. In the case where the victim is a child, the cause may be envy from those less fortunate (Helander 1995; Devlieger 1995). As a result, many deem it a bad omen to express admiration for anything good, like a large and healthy family (Talle 1995; Fadiman 1997). This belief in the concept of the 'evil eye' impacts on the families' responses to illness and disability, including beliefs about causes and treatments sought. For example, some Maasai families distinguish between congenital anomalies which are seen to be caused by a divine curse, an act of God, and acquired disabilities, which are caused by sorcery, a human act, in response to a social transgression; whereas nothing can be done about the former, the latter condition might be ameliorated through the services of a shaman and/or by righting the wrong (Talle 1995).

Another spiritual explanation for a disability is that it is direct evidence of a transgression in a previous life of either the parents or the child, a belief strongly held among many Southeast Asian (Danseco 1997; Chan 1986) and Indian (Groce/Zola 1993) families who believe in re-incarnation. To many Mexican American (Smart/Smart 1991), African American (Rogers-Dulan/Blacher 1995) and Tswana families (Ingstad 1995) their child with disabilities is a gift from god. Among many Songye (Devlieger 1995) and Hmong (*Hmong family* 1991) families, a child who is born with certain characteristics will sometimes be considered to be an ancestor who has come back into the family, that is, the child is said to be born with "the spirit of the ancestor" (Devlieger 1995). For example, in the case of a child born with a club-foot, the Songye interpretation was that the ancestor was not well buried, too small a coffin causing the feet to be squashed (Devlieger 1995: 101-102), while the Hmong interpretation was that the ancestor had been wounded in the foot in a battle (*Hmong family* 1991).

Disability as a Time-Limited Phenomenon

Beliefs about the causes of disability can affect families' perspective on whether a condition is chronic. Among many non-Western cultures, time is cyclical and, therefore, infinite (Fadiman 1997; Locust 1988; Meyers 1992; *Hmong family* 1991). The past, then, is not necessarily that period of time that occurs between an individual's birth to the present moment, as might be understood in most Western cultures, but also the preceding period which includes previous lives (Fadiman 1997). Similarly, the future need not be the period between the present and the moment of death, but can include the period following the death of the corporal body, where the spirit will go on to inhabit yet another body (Locust 1988). Those who see a spiritual explanation for the disability, such as soul loss, view the child's condition as temporary, with the hope that either the soul will be recalled (Fadiman 1997) or the child outgrow the problem (Smith/Ryan 1987). Danseco (1997) notes that among families who believe in reincarnation, "disability is perceived as a temporary condition when viewed along several possible lives" (ibid.: 44), the disability itself seen as the result of an event in a previous life. This notion of cyclical, infinite time makes future planning an exercise in futility. Further, to plan for the future is to assume a certain life expectancy that may be inappropriate, especially for an individual with a disability (Whyte/Ingstad 1995), or appear as if one were unappreciative of the present (Locust 1988; Cunningham/Cunningham/O'Connell 1988).

Disability as a Group Phenomenon

A tacit understanding in all these nonphysical explanations of the causes of a disability is that the child is not solely responsible for its occurrence, but that the entire family is implicated. For instance, many American Indian tribes believe that while a spirit may choose to inhabit the body of a handicapped person for some purpose that the spirit and the Supreme Creator have determined, the causes of a body's being handicapped, and consequently the blame lie with the parents (Locust 1988). Similarly, many Maasai families believe that, although the supernatural punishment for an ancestor's sins, such as dereliction of duty towards one's parents, comes in the form of the disabled child, the child itself cannot be blamed for it (Talle 1995). Many Tswana families refer to a child with disabilities as *mopakwane*, a condition believed to be caused by breaking taboos against sexual intercourse during confinement, a label that stigmatized the parents, not the child. Again, among many Songye families, disability is made a relational problem between human beings and the occurrence of disability in the family the starting point for an inquiry into the relations of the family; the assumption is that "the problem of disability is not a problem of the individual but rather a problem of the family" (Devlieger 1995: 100-101).

However, there are positive and negative implications for this perspective of group responsibility. On one hand, the stigma attached to a condition affects the entire family. On the other, the stigma is mitigated by a holistic view that interprets disability and illness in terms of family rather than individual traits (Harry/Kalyanpur 1994; Kalyanpur/Rao 1991). For example, in Harry's study (1992), the Puerto Rican American parents tended to describe individual difficulties in terms of a normal range of diversity within the family pattern, allowing for a less stigmatizing interpretation of a child's slowness in reading or a quick temper as being *just like his aunt*, or *just like her father*. Similarly, many Asian families often interpret their child's school-based difficulties as *laziness*, oppositional behavior, or indications that they may not have trained their children adequately (Chan 1986). Another positive aspect of group responsibility is the collectivistic support that becomes available to the family. For example, Locust (1988) notes that:

> (Native) Indians believe that an individual's spiritual illness can affect the group (family and friends), and thus group efforts are required to return all members of the group to wellness. As a result, students who are not ill may be absent from school in order to assist a sick relative in returning to wellness. Although this group effort is of vital importance to tribal, clan, and family members, it often becomes a point of antagonism between group membership and school officials, resulting in discriminating actions by school authorities. (ibid.: 319)

ACCEPTING THE DISABILITY

A family's perceptions of the cause of disability impacts greatly on whether they will seek help, and the types of interventions they seek (Danseco 1997). Reasons for accepting the disability are many. For instance, a study of familial attitudes in Africa (Serpell/Mariga/Harvey 1993) found that families who attributed a condition to witchcraft, an act of god, or natural causes were likely to seek help while those who linked the condition to family ancestors tended to accept it without seeking external help. Similarly, among many Maasai families, a disabled child is a fact of life which must be accepted, and statements like "we met him just like that" (referring to a child who was born disabled) convey the message that the child's impairment is an act of god that is beyond human comprehension and ability to cure (Talle 1995: 62). Again, the belief among many Hmong families that the body must be whole to reincarnate as a whole being compels them to reject invasive medical procedures like surgery, prostheses, dental fillings, and autopsies (Meyer 1992; Fadiman 1997). The belief among many Hubeer families that individual deviance is given "cosmological sanction and religious legitimation by the astrological system" facilitates a fatalistic acceptance of the disability (Helander 1995: 75). It is important to note, however, that most families do seek intervention, the type of service often depending upon what is perceived to be the cause of the disability. For instance, in their study of African families (Serpell/Mariga/Harvey 1993), the authors note that families who attributed a condition to an act of god were more likely to seek help from a modern medical facility, while those who believed that witchcraft was involved were as likely to visit traditional practitioners as a medical facility. Similarly, the Hmong family in Fadiman's study (1997) treated their epileptic daughter with the anticonvulsants prescribed by American doctors and a soul calling ceremony to retrieve the soul that was performed by a traditional health care practitioner, a shaman. Among Songye families who believe that disability is a response to disharmony in the relationships among family members, the father of the child with the disability may ask his wife to redistribute her bridewealth among the members of the family towards restoring harmony (Devlieger 1995). Helander (1995) notes that many Hubeer families as a measure might initially seek different medicines or healing techniques, both traditional and modern, but the few, if any, results and the cumulative costs of health care combine to fuel feelings of despair and resignation, at which point the terms *naafo* or *boos* are used to describe the person to imply that nothing more can be done.

However, whether families choose to do nothing or seek help, their actions are grounded in an acceptance of the disability. Indeed, among many groups, there is little awareness of the potential for rehabilitating, finding roles, or developing adapted life-styles for adults with disabilities (Helander 1995) and the notion that a child with disabilities can be helped by early intervention or stimulation may not be part of common knowledge, or, in the case of many developing countries, even the standard knowledge base of medical and educational professionals (Groce/Zola 1993; Kysela/Marfo 1984). One factor that accounts for this level of acceptance is the belief in fate or *karma* (Danseco 1997), enhanced when the cause of the disability is perceived to be divine retribution for one's sins. This fatalism has been instrumental in some Christian Scientist families choosing not to seek medical treatment for a child with a life-threatening illness (Fadiman 1997). Another factor is the belief in value-inequality which, by assuming that every individual has his or her own niche within a social hierarchy with its ascribed roles and status, runs counter to the concept of maximization of potential. Attempting to change this status quo by seeking treatment or interventions would be considered tantamount to destroying the existing social equilibrium and harmony, an act that would affect the entire community (*Hmong family* 1991).

CONCLUSION

Western professional epistemology is based on the assumption that scientific knowledge is objective and therefore universally applicable; this assumption has contributed to the medical model predominating in special education policy and practice. Professional unawareness of the assumptions inherent in the medical model, that disability is physical, chronic, individually owned, and can be fixed, has significant implications for families who may believe, on the other hand, that disability has spiritual causes, is temporary, group-owned, and must be accepted. Believing that disability is a physical phenomenon, professionals may not understand parents who might use the services of a shaman to recall the lost soul of the person with a disability. Believing that disability is a chronic phenomenon that will last through the lifetime of the individual, professionals may not understand parents who do not plan for the future. Believing that disability is an individual phenomenon, professionals may not understand parents who perceive the attribution of a disability to their child as a matter of shame for the whole family. Finally, believing that disability can be fixed, professionals may not understand parents who will not seek any treatment or intervention for the condition.

REFERENCES

Bogdan, R./Knoll, J. (1995): “The sociology of disability”. In: E.L. Meyen/T.M. Skrtic (eds.), *Special education and student disability, an introduction: Traditional, emerging, and alternative perspectives*, 4th ed., Denver/CO: Love, pp. 609–674.

Chan, S. (1986): "Parents of exceptional Asian children". In: M.K. Kitano/P.C. Chinn (eds.), *Exceptional Asian children and youth,* VA: Council for Exceptional Children: Reston, pp. 36–53.

Cunningham, K./O'Connell, J.C. (1986): "Impact of differing cultural perceptions on special education service delivery". *Rural Special Education Quarterly* 8, pp. 2–8.

Danseco, E.R. (1997): "Parental beliefs on childhood disability: Insights on culture, child development, and intervention". *International Journal of Disability, Development, and Education* 44/1, pp. 41–52.

Devlieger, P. (1995): "Why disabled? The cultural understanding of physical disability in an African society". In: B. Ingstad/S.R. Whyte (eds.), *Disability and culture,* Berkeley: University of California Press, pp. 94–106.

Edwards, M.L. (1997): "Constructions of physical disability in the ancient Greek world: The community concept". In: D.T. Mitchell/S.L. Snyder (eds.), *The body and physical difference: Discourses of disability,* Ann Arbor: University of Michigan Press, pp. 35–50.

Fadiman, A. (1997): *The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures,* New York: Farrar, Straus, & Giroux.

Groce, N.E./Zola, I.K. (1993): "Multiculturalism, chronic illness, and disability". *Pediatrics* 91, pp. 1048–1055.

Hall, E.T. (1976): *Beyond culture,* Garden City/NY: Anchor Press, Doubleday.

Harry, B./Kalyanpur, M. (1994): "Cultural underpinnings of special education: Implications for professional interactions with culturally diverse families". *Disability and Society* 9/2, pp. 145–165.

Helander, B. (1995): "Disability as incurable illness: Health, process, and personhood in southern Somalia". In B. Ingstad/S.R. Whyte (eds.), *Disability and culture,* Berkeley: University of California Press, pp. 73–93.

Hmong family prevents surgery on son (1991, January). Omaha World Herald, p. 16.

Individuals with Disabilities Education Act. 20 U.S.C., 1400 et seq. (1997).

Ingstad, B. (1995): "Mpho ya modimo – a gift from God: Perspectives on attitudes toward disabled persons". In: B. Ingstad/S.R. Whyte (eds.), *Disability and culture,* Berkeley: University of California Press, pp. 246–266.

Kalyanpur, M./Rao, S.S. (1991): "Empowering low-income black families of handicapped children". *American Journal of Orthopsychiatry* 61, pp. 523–532.

Kysela, G.M./Marfo, K. (1984): "Early handicapping conditions: Detection and intervention in developing countries". In: J.M. Berg (ed.), *Perspectives and progress in mental retardation, 1, Social, psychological, and educational aspects,* Baltimore: University Park Press, pp. 119–130.

Locust, C. (1988): "Wounding the spirit: Discrimination and traditional American Indian belief systems". *Harvard Educational Review* 58, pp. 315–330.

Mardiros, M. (1989): "Conception of childhood disability among Mexican-American parents". *Medical Anthropology* 12, pp. 55–68.

Mercer, J. (1973): *Labeling the mentally retarded,* Berkeley: University of California Press.

Meyers, C. (1992): "Hmong children and their families: Consideration of cultural influences on assessment". *The American Journal of Occupational Therapy* 46, pp. 737–744.

Monks, J./Frankenberg, R. (1995): "Being ill and being me: self, body, and time in multiple sclerosis narratives". In: B. Ingstad/S.R. Whyte (eds.), *Disability and culture,* Berkeley: University of California Press, pp. 107–136.

Nicolaisen, I. (1995): "Persons and nonpersons: Disability and personhood among the Punan Bah of central Borneo". In: B. Ingstad/S.R. Whyte (eds.): *Disability and culture,* Berkeley: University of California Press, pp. 38–55.

Rogers-Dulan, J./Blacher, J. (1995): "African American families, religion, and disability: A conceptual framework". *Mental Retardation* 33, pp. 226–238.

Serpell, R./Mariga, K./Harvey, K. (1993): "Mental retardation in African countries: Conceptualization, services, and research". *International Review of Research in Mental Retardation* 19, pp. 1–39.

Skrtic, T.M. (1995): "The crisis in professional knowledge". In: E.L. Meyen/T.M. Skrtic (eds.), *Special education and student disability, an introduction: Traditional, emerging, and alternative perspectives,* 4th ed., Denver/CO: Love, pp. 567–608.

Smart, J.F./Smart, D.W. (1991): "Acceptance of disability and the Mexican American culture". *Rehabilitation Counseling Bulletin* 34, pp. 357–367.

Smith, M.J./Ryan, A.S. (1987): "Chinese-American families of children with developmental disabilities: An exploratory study of reactions to service providers". *Mental Retardation* 25, pp. 345–350.

Spindler, F./Spindler, L. (1990): *The American cultural dialogue and its transmission,* London: Falmer Press.

Stahl, A. (1991): "Beliefs of Jewish-Oriental mothers regarding children who are mentally retarded". *Education and Training in Mental Retardation*, pp. 361–369.

Talle, A. (1995): "A child is a child: Disability and equality among the Kenya Maasai". In: B. Ingstad/S.R. Whyte (eds.), *Disability and culture,* Berkeley: University of California Press, pp. 56–72.

Tyack, D.B./Hansot, E. (1982): *Managers of virtue: Public school leadership in America, 1820–1980,* New York: Basic Books.

Whyte, S.R./Ingstad, B. (1995): "Disability and culture: An overview". In: B. Ingstad/S.R. Whyte (eds.), *Disability and culture,* Berkeley: University of California Press: pp. 3–35.

Zola, I.K. (1986): "The medicalization of American society". In: P. Conrad/R. Kern (eds.), *The sociology of health and illness: Critical perspectives,* 2nd ed., New York: St. Martin's Press, pp. 378–394.