

DIFFERING PERCEPTIONS OF THE PRINCIPLE OF PARENT PARTICIPATION: IMPLICATIONS FOR ASIAN FAMILIES OF CHILDREN WITH DISABILITIES

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This article discusses some of the problems associated with the transfer of special education models and concepts from developed to developing countries, with specific reference to the concept of parent participation. It describes the Western interpretation and the underlying values of the concept, and analyzes the implication of this culturally-specific understanding for Asian families of children with disabilities. I use the Western concept as a point of reference because it provides a framework to better explain and understand non-Western concepts. However, there are two caveats I would like to make before I proceed. One is that when making these comparisons, I do not wish to imply that one way is superior to another, but merely to identify the differences and increase awareness of these differences. Another is that most Western concepts emerge from Western rationalism. As a result, because alternative perspectives are often the opposite of the Western ones, sometimes they can be misunderstood as being irrational. We need to understand that people behave in certain ways that are rational to them. Merely because the behavior is different does not make it irrational.

If we identify the values and taken-for-granted beliefs that are imbedded in special education and rehabilitation policy and practice in Western countries, we can begin to understand why it becomes problematic when we transfer this knowledge to developing countries where other values may prevail and are taken for granted. The three predominant values that are imbedded in the Western concepts of parent participation in special education policy are equity, choice, and individualism.

EQUITY

Equity is a cornerstone Western value. It is the basis on which disability rights movements and the essential premise of special education – the belief that all children, including children with disabilities, have the same right to an education – have emerged. For instance, special education itself is an equity measure. The value of equity is also imbedded in the principle of normalization: the intention is to provide the same opportunities and quality of life outcomes that are available to non-disabled people to a person with disabilities. So too with the principle of parent participation. In the U.S., for instance, special education law entitles parents of children with disabilities to certain rights: they have the right to participate in the decision-making about their child's education, to be informed of any changes in placement, and should they disagree with a decision, under procedural due process, they have the right to protest. On the assumption that parents have knowledge about their child as important as the professionals' knowledge, this principle provides parents with opportunities to partner with professionals.

Problems arise when this equity-based principle is imported into developing countries where there may be no expectation of parent-professional equality. Many Asian families may believe instead in the fundamental tenet of "the value-inequality of human beings, by reason of birth, caste, skin pigmentation, economic and social status" (Miles 1981: 7). For instance, Wong (1989) notes that, among some Chinese families, people are assumed to have different capacities owing to different backgrounds (such as education) and characteristics (such as age); it is therefore accepted that some people should dominate over others because of their status. Similarly, among many Indian (Mohan 1992) and Korean (Song-Kim 1992) families, since social roles and duties are ascribed, the status of various family members is also predetermined in terms of a hierarchical order. Thus, elders have high status, men have higher status than women, and children assert their authority according to birth order. Indeed as Schweder, Mahapatra and Miller (1990) note, to many Hindu families, "the justice of received differences and inequalities, ... (the) asymmetrical interdependencies in nature (for example, parent-child) and the vulnerabilities and differential rationalities of social actors (are) universal truths" (p. 160). To prevent the abuse of power in hierarchical structures, there is the expectation that those in more privileged positions will recognize their obligations towards the less privileged, a sort of *noblesse oblige* also known as *dharma* or duty in India (Fishlock, 1983; Kalyanpur, 1996) or *li* or rules of propriety in

China (Wong 1989; Chung 1992). By the same standard, professionals, by virtue of their higher status, have a similar duty towards protecting and ensuring their clients' well-being. This understanding conflicts dramatically with the idea of individual responsibility that places the onus for partnership on parents.

The rigidly hierarchical societies in many Asian countries preclude the possibility of partnerships on an equal basis; indeed, both parents and professionals are culturally conditioned to maintain a differential status in favor of professionals. In my own research with low-income families of children with disabilities in India, I found this to be a significant issue (Kalyanpur 1994). The professionals at the school the children with disabilities attended wanted to include parents because they had heard from the West of the concept of parent participation. At the same time, however, they lacked the cultural basis for establishing equitable relationships and did not perceive the parents as equal partners. The resultant *parent participation* consisted primarily of workshops conducted by the professionals, who determined the topics, and interspersed themselves among the parents to *keep them from chattering to each other*. The parents continued in their role as recipients of information and their opinion on their child or the services was never sought.

The taken-for-granted premise of equality imbedded in the concept of parent participation in the West was lost in the transfer to a country where the milieu lacked any emphasis on rights and equality. Since parent participation in the education decision-making process is a desirable outcome because parents' needs are better met and children are better served, we must identify the values that do prevail in the importing culture and use these values as a frame of reference to create a more equitable level of parent involvement. For instance, in India, a prevailing culture of duties or *dharma* provides a more meaningful metaphor in which to couch the idea: by presenting the concept of parent participation to Indian professionals in terms of professional responsibility or duty to parents, it is more likely that collaborative, if not equitable, relationships will develop, where parental input into the decision-making is sought (Kalyanpur 1996).

CHOICE

Choice is another cornerstone value imbedded in the principle of parent participation. For instance, in many developed countries like the U.S. and Germany, parents may choose to participate in the decision-making process for their child's education and placement and decide whether they would like their child to attend a full inclusion or a separate school. This emphasis on parental choice emerges from the high regard placed on the value within society, and the belief that people must be allowed to have choices when selecting their lifestyle, career, life partner, place of residence, etc. This belief also underpins the concept of self-determination for people with disabilities, whereby they may have opportunities to make choices similar to those available to non-disabled people. Indeed, so highly regarded is the value of choice that equity-based legislation seeks to ensure that individuals who possess a trait – an *immutable characteristic* – which could reduce their chances for making choices toward the pursuit of happiness will not be denied these opportunities. However, if we transfer the concepts of parental choice or self-determination to a culture where there is no context for choice, the situation becomes problematic. For instance, in many Asian countries, families may not regard the value of individual choice as highly, and may severely proscribe personal choices on many aspects (Chung 1992; Mohan 1992). Some societies do not allow individuals a choice in the matter of religion (Ross-Sheriff 1992), while some families continue to restrict their adolescent children in the number of choices they may make about making friends, choosing an occupation, and selecting a life partner (Mohan 1992). By the same token, a trait, such as gender, that in one culture may be perceived as an immutable characteristic justifying equity-based legislation, may in another culture be interpreted as justifying specific acts of discrimination. For instance, among some Indian (Mohan 1992), Muslim (Ross-Sheriff 1992) and Chinese (Chung 1992) families, the belief that a woman need not work outside the home or have a career often precludes girls from receiving an education or pursuing any academic goals more ambitious than an elementary schooling.

In cultures where personal choice is not a highly regarded value, parents do not expect to have choices about services; nor would they expect that their child with disabilities learn or be allowed to make choices on matters that even their non-disabled children would not make. Further, parents would not assume they or their children had the right to demand such choices. In India, for instance, this is one of the

reasons for the lack of grassroots support for a disability rights movement.

INDIVIDUALISM

The high value placed on the right to freedom of choice in Western countries is related to the emphasis on the individual and the belief that the individual, not society, comes first. This individualistic belief provides the underpinning for the idea that all citizens have rights that are protected under the law. In many Western countries, parents of children with disabilities have rights specific to their child's education. Implicit in this is the idea that people are responsible for ensuring their own protection, from which the principle of due process or the right to protest emerges. Due process is a process of dispute resolution that involves formal legal mechanisms; the process can be initiated by ordinary citizens and is not imposed from the top down (Turnbull/Turnbull 1998). Friedman (1996) has argued that the tendency to sue is a structural and cultural feature of American society that emerges from modern individualism; as he states, "it would be hard to imagine much litigation among people who truly believe that it is wrong to make a fuss, or who value harmony and compromise above most other values" (Friedman 1996: 58).

Similarly, the concept of an individualized education required by law in many Western countries provides a focus on the individual. Since the purpose of education is to provide students with the skills they would need to acquire a job and become independent, productive adults (Margolis 1992), the underlying assumption in this principle of individualization is that a meaningful education for children with disabilities is one that maximizes their potential towards the ultimate goal of independence: open, competitive employment (Powers/Singer/Sowers: 1996). Such a high value is placed on individuals becoming self-reliant and responsible for making their own life choices, that these outcomes are a major part of most special education and rehabilitation plans for people with disabilities. However, these concepts of individualism may be antithetical to the beliefs of many Asian families with children with disabilities, which may lead to some dissonance when planning an appropriate education. For one, some families may traditionally subscribe to a concept of self where individual identity cannot be separated from the group, believing that, indeed, it is a product of the group (Bra-

dy/Anderson 1983; Ross-Sheriff 1992; Wong 1989). Since individual needs are subservient to those of the community, a “culture of duties” (Chung 1992) prevails where individuals have ascribed social responsibilities (Schweder/Mahapatra/Miller 1990). For instance, Wong (1989) notes that the values of participatory democracy and individual rights conflict with traditional Chinese values of propriety and individual duties:

The Chinese conception of the individual, in contrast to the Kantian tradition, is not one of an abstract entity. Here, roles and statuses determine one’s dignity; differences in abilities are believed to be relevant in evaluating one’s worth; one’s behaviors are very much constrained by social identity and the related obligations it imposes. As such, it is not difficult to understand why the Western conceptions of *rights* and *equality* are so foreign to the Chinese. (p. 97)

In such a context, families may be both unfamiliar and uncomfortable with the prevailing *culture of rights* on which the concept of parent participation is based. Studies indicate that families that have recently immigrated to the West from countries where schooling was not the norm for children are most likely to be unaware of their child’s right to education, particularly in cases where the child has a disability, or of their right to protest if their child’s rights are violated (Dentler/Hafner 1997). Further, even after having been made aware of their rights, they may be unable to assume the level of assertiveness needed for claiming them. For instance, the organizer of a support group of immigrant Vietnamese families of children with disabilities in the U.S. described a problem he faced in helping the families access services:

People are afraid of asking for favors ... I try to show them, to explain to them that they have the right to ask for the services and they are not asking for a favor. (N. Chu, personal communication, April 9, 1997)

CONCLUSION

This article analyzed how the values of equity, choice and individualism subtly frame the Western interpretation of the principle of parent participation in special education. When this culturally-specific concept is transferred to other cultures, families of children with disabilities are placed at a disadvantage. In a climate of value-inequity, parents may

persist in deferring to professionals as figures of authority. In a context that lacks choices, parents may unquestioningly accept the service options given them and circumscribe their children's life choices. In a culture of duties, parents may not demand their rights or advocate for their child, gratefully believing instead that any service their child receives is a *favor*. By the same token, professionals may not seek parents' input about their child's education nor attempt to develop collaborative relationships. As a result, the benefits of services may be considerably lessened, adversely affecting both parents and children with disabilities.

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