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Cultural Effects of Disability on Siblings of Persons with Intellectual and Developmental Disabilities: from the Perspective of Cultural Psychology

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Cultural effects of disability on siblings of persons with intellectual and developmental disabilities: from the perspective of cultural psychology

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When researching disability, in this case, by examining the problems faced by siblings of persons with intellectual and developmental disabilities, it is essential to present disability as a social obstacle. In approaching this problem, one must be careful not to distinguish the characteristics of a society and the characteristics of siblings of persons with intellectual and developmental disabilities as separate attributes entirely explainable through deduction. Rather, we must redefine this relationship as different facets of a single complex; it is the conceptualization of an individual's various psychological processes as one part, one phase, of the socio-cultural system. From this cultural viewpoint, we delve into the social obstacle of disability.

Keywords: culture; cultural models of the self; social relations; disability; siblings of persons with intellectual and developmental disabilities

1. Introduction

Numerous studies have looked at siblings of persons with intellectual and developmental disabilities[1] from the perspective of family system theory (e.g. Abramvoitch, Corter, & Pepler, 1980, 1986; Kreppner, Paulsen & Schuetze, 1982; Lamb, 1987a, 1987b; Stoneman, Brody, Davis & Crapps, 1987; Kyobayashi & Ida, 1990; Mihara, 1993; Nishimura & Hara, 1996a; Dunn, 2005). Several obstacles are faced in bringing the experiences of siblings of persons with IDDs into focus (Hirakawa, 1986; Schunterman, 2007), and siblings of persons with IDDs or sicknesses respond with considerable variability: some siblings benefit from their experiences, others remain unaffected, and some are worse off (McHale & Gamble, 1989; Meyer & Vadasy, 2000). Recent approaches have added other qualifications such as peer relationships and sibling support (Meyer & Vadasy, 1994; Fujii, 2006; Nishimura, 2006), but the position of the siblings remains largely unchanged. We cannot be reasonably satisfied just to offer support for the siblings of persons with IDDs. A deeper analysis into the underlying problems is essential. Recent work from a cultural perspective suggests that the situation will not improve by simply providing support as a preventive measure.

Problems facing the siblings of persons with IDDs do not exist in a vacuum. Rather,

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the very nature of the public sphere contributes to the formation of these problems, or at the very least, acts as a significant element in its construction. Thus, any resolution to these problems must take this state into careful consideration. The purpose of this article is to delve into the experiences of siblings of persons with IDDs from the viewpoint of cultural psychology. Using this approach, it might seem that this discussion is natural and does not require clarification, but we hope to reveal what often goes unseen and to explain in detail certain social aspects related to the issue.

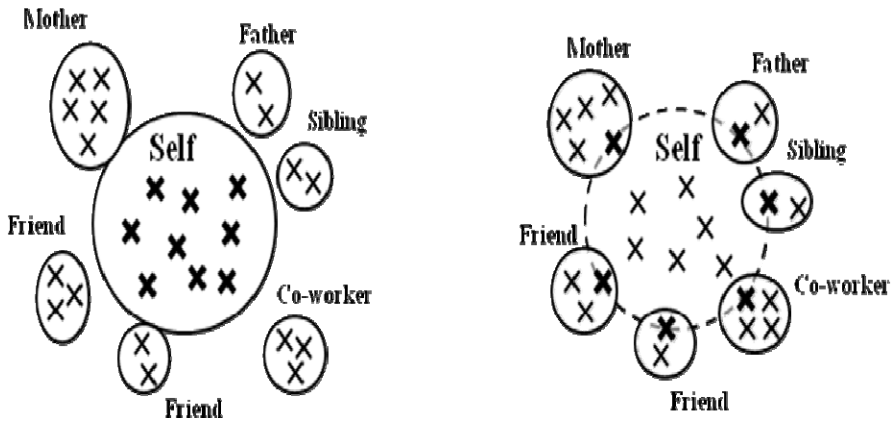
2. The cultural construals of the self: independent and interdependent models of being.

In cultural psychology, a concept known as the cultural construals of the self, which focuses on the cultural differences in one's makeup from the perspective of self schemata[2], was recently developed. The cultural construals of the self are defined as a 'generally accepted idea about the tacitly shared dominant nature of a person historically created within a culture' (Kitayama 1998, 29). In other words, it is the centre point of mutual effect processes between culture and psychology, or the shared view of the human being and the assumptions we each make about ourselves.

The two types distinguish cultural construals of the self as independent or interdependent and the form of each individual self as independent or interdependent. Within the framework of everyday Western customs, social systems, and various other common understandings, we know that: (1) individuals are independent from their surroundings; (2) their existence is defined by internal attributes such as opinion, attitude, ability, motivation, and personality traits that are lasting and consistent; (3) the behaviours influenced by these internal attributes affect their surroundings. This independent model of the self is accepted as the norm. However, in Eastern societies, other cultural elements are seen, such as: (1) individuals are closely tied to their surroundings; (2) their existence is defined by the social relationships that result from these connections; (3) individual behaviours are influenced by these connections. This interdependent model of the self seems to be the norm in this case. Numerous cross-cultural studies have indicated that cultural models of the self are associated with analogous psychological forms and functions of the self in respective communities (Markus & Kitayama, 1991a). This is illustrated in figure 1.

The cultural models of the self that are reflected in practices on a cultural level can also be seen in behavioural tendencies on a personal level. This is because individual differences in behaviour are influenced by the relevant cultural and common practices. According to such input, certain behaviours are taken, or not taken, and individuals who behave counter to this input distance themselves from the norm. Depending on which of the two cultural models of the self is dominant, there will be a difference in the psychological processes resulting in individual behaviour (Markus & Kitayama, 1991a, 1999b).

Thus, cultural models of the self can be used as analytical models to compare the differences in individual behaviour within a country (Kurokawa, 1994; Kiuchi, 1995; Takata, Omoto & Seike¸1996). Research has also been done on how independent and interdependent self-construals are incorporated into the self-schemata and the relationships between these and social and cultural formative factors (Singelis 1994; Takata, 1994a, 1994b, 1999a, 1999b; Takata & Matsumoto, 1995; Kiuchi, 1995, 1996, 1997).



Independent model of the self Interdependent model of the self

Figure 1. Conceptual representation of cultural models of the self (Markus & Kitayama 1991a, 226).

In the literature, it is assumed that people in different cultural contexts tend to internalize and believe the respective models and psychological systems, which have cross-culturally divergent characteristics. All major attempts to measure self-construal at the individual level and then to relate individual differences in the sense of self to differences in psychological functions in other domains have been grounded in the assumption that cultural views of the self must be internalized in order for them to have any significant influence on psychological processes.

The above rationale focuses on how cognitive symbols are developed within the individual. On the other hand, Kitayama, Markus, Matsumoto & Norasakkunkit (1997), assert that the transformation of cultural models to individual psychological and interpersonal systems is mediated collectively by the way in which situational scripts are accumulated and thus available in the respective cultural context. Kitayama et al. point out that a complex of psychological and social elements should serve as the unit for analysis. Cognitive models of the self are fundamentally social, and have roots in the nature of society while also representing an element in the make-up of society. This does not deny the involvement of internalized cognitive models of the self in mediating psychological responses. In other words, it emphasizes the role of collectively constructed social situations in the analysis of culture's influence on psychological processes.

Furthermore, examinations of various cultures to see if their values and beliefs are predominantly independent or interdependent find significant overlapping among these different cultures. Judging from this research, many individuals resist the predominant values and behavioural norms of their society, regardless of country or culture. However, there is a tendency to accept these at face value. Kitayama et al. (1997) believes this complex to be a very dynamic unit.

3. Cultural participation and siblings of persons with IDDs

There are a number of factors that influence how siblings adapt to life with brothers or

sisters with IDDs. Hirakawa (1986) divides these factors into three general categories: (1) those relating to the child with a disability or sickness (name of diagnosed disability, seriousness of disability, place of residence, age); (2) those relating to the sibling (birth order, sex, number of siblings, age difference, personality, sibling's relationships); and (3) those relating to the family (size of family, social and economic status, attitude of parents toward disability, parents' ability to discuss disability with sibling, marital relationship, religion, personality, health, age). Research on siblings with brothers or sisters diagnosed with pervasive IDDs conducted in 2007 by Schuntermann shows six domains based on the assumption that there is a common range of temperament with which siblings adjust to their particular situation. The six domains are: (1) Family system theory perspective, (sibling's birth order, variations in sibling's functional roles regardless of birth order, shifts in the mother-child relationship following the arrival of a sibling, and the so-called convergence and divergence perspectives on similarities and differences among siblings within a family); (2) Parent-child interaction; (3) Sibling's relationships; (4) Sibling's intergenerational position (grandparents); (5) Sibling's social position (friends/peers); (6) Sibling's assessment of their own situation (how to give meaning to living with brothers or sisters with IDDs, or how to make the relationship as positive as possible in order to successfully adapt to a life with IDDs).

When examining the level of influence of each of the above factors, sex and birth order become very significant. Female siblings take care of their brothers or sisters with IDDs more commonly than male siblings (Abramovitch, Corter, & Pepler, 1980, 1986; Abramvoitch, Stanhope, Pepler & Corter, 1987; Lamb, 1987a, 1987b; Stoneman, Brody, Davis & Crapps, 1987; Yoshikawa, 1993; Nishimura & Hara, 1996a; Mihara, 1998). They also do more of the housework. Research shows that female siblings of persons with IDDs have fewer opportunities to plan activities outside the home, and it has been reported that sibling participation in activities outside the home is influenced by the level of the parents' education as well as family income（Stoneman, Brody, Davis & Crapps, 1987). Furthermore, the awareness of siblings of persons with IDDs may be connected to the financial situation of the father (Tachibana & Shimada, 1990). Siblings of persons with IDDs with fathers forty years of age or younger worry about such things as their brother or sister's prognosis and their father's participation in social activities like parent support groups. On the other hand, siblings of persons with IDDs with fathers over forty years of age tend to worry about their father's financial situation and the future of brothers or sisters with IDDs.

Although the theoretical framework suggested above is not intended to encompass all such factors, it does highlight one significant cluster of factors that has been relatively neglected in the contemporary literature on the topic.

According to the theoretical framework of cultural psychology, the approach taken by siblings of persons with IDDs in their effort to adapt may not simply be a psychological product of each individual. It may, in fact, be afforded and brought on through various social and cultural processes. Kitayama & Markus (2000) assume that the psychological processes that result from efforts at cultural and social adaptation are conceptualized as the intra-individual phase of the relevant cultural complex. These processes are sustained, reinforced, or corrected by individuals and the socio-cultural phase of the shared complex. These are further sustained by the appropriate tacit, active, and harmonious mechanisms of the intra-individual process. Therefore, these two phases are mutually constructed. In addition, they define the relevant elements of the

entire cultural complex.

In other words, this theoretical aspect emphasizes the role of collectively constructed social situations in an analysis of culturally influenced psychological processes. From this viewpoint, we can consider the theoretical reasons why attuning to the dominant cultural complex of a given society would affect the ability of siblings to adapt to life with brothers or sisters with IDDs.

As one theoretically clear reason, we can cite symbols. Culturally accepted forms of social relationships are called cultural complexes. Such complexes are formed through popular ideology, cultural norms, other related images, commonly accepted theories, and values of common sense (Adams & Markus, 2004). Therefore, by virtue of being part of such a cultural complex, siblings of persons with IDDs find their places in life within the wide range of meanings provided by the cultural symbolic systems. As a result, each reaffirms the self as a significant, stable, and worthwhile cultural entity.

The way in which siblings adapt to their brother or sister's IDDs, which encompasses a range of normal variability, is a psychological process resulting from an attempt at social adaptation of the appropriate cultural community. Can we not say it is the product of the conceptualization of the intra-individual phase of the cultural complex?

4. Review of empirical research

4.1 Social relations and siblings of persons with IDDs

A number of studies suggest that differences in cultural background lead to differences in how siblings of persons with IDDs adapt to their social environments.

A study by Hara & Nishimura (1998) finds that the developmental processes of siblings with brothers or sisters with IDDs differ from those who do not. With the aim of determining the process of self-awareness and social adaptability of siblings of persons with IDDs, 180 siblings with brothers or sisters with IDDs and their mothers and a 180-person control group of siblings who did not have brothers or sisters with IDDs and their mothers were given a questionnaire. The results show that the self-awareness and social adaptability of siblings of children with IDDs are in fact affected. Compared to the control group, it became clear that siblings with brothers or sisters with IDDs have a compromised cognitive ability with relation to self-awareness. Furthermore, similar, earlier research in the United States finds that one great difference between the two groups manifests itself in a combination of social and physical ways.

Comparing Japan and the United States, because Japanese people tend to place a high value on academic achievement, social and physical factors become less important. As a result of Japan's rigorous educational culture, junior high school students have less self-awareness and lower self-esteem than their U.S. counterparts. Against this backdrop, Hara & Nishimura (1998) assume that siblings of those with IDDs are more affected by the educational environment than those without brothers or sisters with IDDs, showing that self-esteem is affected by educational circumstances. Although individuals without brothers or sisters with IDDs are also affected by these circumstances, Hara & Nishimura clearly find that siblings of children with IDDs look for values in areas other than academics to maintain their self-esteem and self-respect. In one instance, they point out that these siblings mature faster.

In terms of social adaptation, the disadvantaged generally try harder than others to be socially accepted. In Japan, a culture where individuals routinely measure their worth

by comparing themselves to others, this tendency is generally strong, and the same can be said for siblings of those with IDDs. However, research shows that the drive toward social acceptance is stronger among those without brothers or sisters with IDDs. Nevertheless, what is important is that siblings of persons with IDDs show no significant differences in social adaptation.

In order for siblings to accept the disabilities of their brothers or sisters they must endure more psychological stress than they normally would. However, these psychological stresses are not all disadvantageous or negative. By overcoming these issues, such individuals can develop into fuller, richer human beings (Goto, Suzuki, Sato, Murakami, Mizuno, & Kojima, 1982). The process of overcoming these psychological issues is called resilience.[3] Shunterman (2007) also discusses the resilience of siblings of persons with IDDs and points out that peer social functioning, which siblings of children with IDDs have problems with, has been ignored in the many studies pertaining to such siblings. Peer relationships undergo remarkable transformations as the experience of siblings of children with IDDs changes in their social adaptation. Since positive peer relationships promote resilience, this can help protect such siblings, but negative ones, of course, can be detrimental.

In addition, Shunterman (2007) indicates an interesting finding in the complexity of interplay in sibling peer relationships. Siblings who have negative relationships with their brothers or sisters with IDDs may seek out compensatory relationships with their friends. Such friendships have been explored in similar studies. Tsuboi, Sato, Otsuki, & Okamoto (1988) give the example of 6th and 7th grade siblings with brothers or sisters with IDDs who develop psychological problems such as tics or impulsiveness. These siblings took good care of their brothers and sisters with IDDs when in elementary school but started to lose patience with them after entering middle school. They also document siblings who start hiding the existence of brothers or sisters with IDDs.

Although siblings of persons with IDDs have themselves no impairments, they become sensitive to social prejudice and discrimination and these feelings become socialized. According to Goffman (1963), there is an important difference in the level of stigma depending on whether the disability is readily and visually apparent or it can be easily perceived or not. The latter case can be divided into two categories: welfare workers who come into contact with persons with disabilities on a professional level and family members who have a socially structured relationship with persons with disabilities. As a defence mechanism, people generally turn to self-enhancement when dealing with a loss. However, this is quite difficult for families looking after persons with disabilities. In addition, these families tend to be avoided not only by strangers but also by those close to them. In addition, although the stigma does not influence the attitudes of close friends who accept the family with members with disabilities, it does have an impact on family responsibilities.

In other words, stigma is placed on the siblings of those with IDDs, and, as a result, they find self-enhancement to be difficult. As self-enhancement is closely related to self-esteem, it then becomes necessary to think about how self-esteem can be raised.

4.2 Self-enhancement and self-criticism

According to cultural psychology, self-esteem differs according to culture. Influencing behaviours are more culturally accepted in independent cultures (North America) than in interdependent cultures (Japan), and the effects of acts of influence on self-esteem

may be more conspicuous in North America than in Japan. Another relevant aspect of self-esteem concerns the sense of connectedness to others in interdependent cultures (Japan). Adjustment is an expression of one's commitment to a relationship and the value one attaches to it, and individuals are thought to feel more connected when they engage in acts of adjustment. Moreover, because adjustment is more culturally accepted in Japan than in North America, the effects of adjustment on the perceived connectedness of the self are predictably greater in Japan than in North America (Heine, Lehman, Markus, & Kitayama, 1999).

Kitayama & Markus (2000) contend that there are three main characteristics of the cultural models of the self and social relations.

In the case of the independent model of the self and social relation, first is the notion of prosocial interpersonal influence, which acts as the adhesive in a relationship. The individuals involved in this relationship are expected to exert beneficial, prosocial influences on the other parties; common scenarios include showing admiration and offering verbal encouragement for other individuals. Second, within this scheme, individuals who take part in the relationship are believed to possess high self-esteem and attractive, positive attributes, and are willing to voice similar positive characteristics toward others. Third, the prosocial influences that are believed to connect people and the high self-esteem of these people are interdependent. That is, each exists and functions as a result of the other. This is illustrated in figure 2.

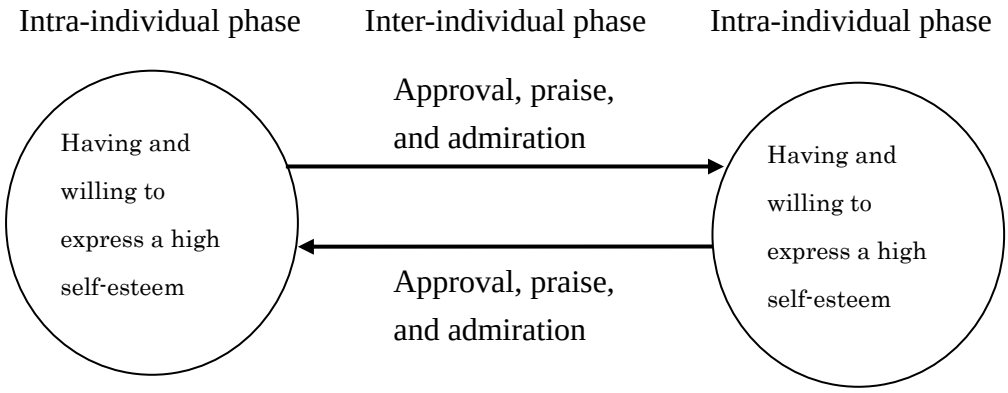


Figure 2. Cultural complex of self-esteem and mutually approving relationship common in European and America (Kitayama & Markus 2000, 119).

The features of the interdependent model of the self and social relations are quite different. First, the notion of interpersonal adjustment acts as the adhesive of the relationship. This requires that individuals in a relationship view things from the other's viewpoint, empathize, and then act appropriately, often nobly, for the other's benefit. In such situations one must often provide support or aid to the other. Second, people in interdependent relationships are said to suffer from being somehow subpar, and participants have a negative self-image because of these perceived shortcomings. Third, the behavioural adjustments born of sympathy and empathy that are supposed to connect people and the negative self-image of those who need to connect with others are mutually interdependent. This is illustrated in figure 3.

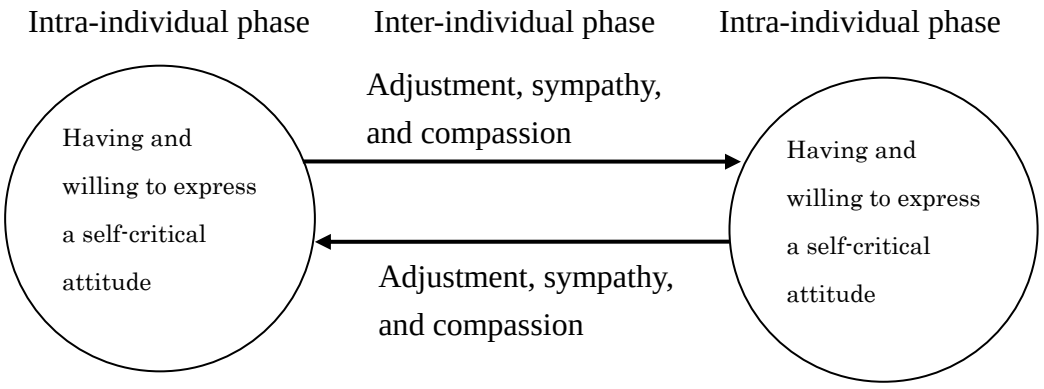


Figure 3. Cultural complex of self-criticism and mutually sympathetic relationship common in East Asia (Kitayama & Markus 2000, 119).

Although self-enhancement is important in the independent cultural context of North America, it is nonetheless difficult to achieve. However, in the interdependent cultural context of Japan, self-criticism, failure, and suffering all come into play in the search for personal adjustment. Therefore, both siblings of persons with IDDs in Europe and America and those in East Asia may have trouble raising self-esteem within their respective structures.

In her research, Minoura (1984, 2003) studied the intercultural experiences of children, specifically how Japanese children who accompanied their parents to the United States adapted to American culture. She finds that cultural meaning is comprised of 'cognition, motivation, and emotion along with the psychological processes of cognition, emotion, and behaviour' (Minoura, 2003, pp.279-280). The cultural models of the self as independent and interdependent are embedded in self-schemata (Takata, 1993, 2002, 2007). Depending on which of the two is dominant, deviations appear in psychological processes, which results in personal differences. In other words, even among siblings of persons with IDDs from the same country, depending on how cultural models of the self are incorporated into self-schemata, differences will appear in how individuals attain self-esteem.

The transmission of cultural meaning requires interpersonal interaction in the formative years between the ages of 9 and 15 (Minoura, 1984, 2003). During adolescence, siblings learn how they should treat their brothers or sisters with IDDs as members of the family, and further come to understand their own position within the family. Adolescence is also the period when there is a tendency for problems to appear (Nishimura & Hara, 1996b). According to Goto, Suzuki, Sato, Murakami, Mizuno & Kojima (1982), siblings of children with IDDs from the age of three can perceive that their brothers or sisters are not 'normal'. From the ages of three to six, they may show mixed feelings about the situation, and these ambivalent feelings are then influenced by the attitudes of their parents and/or other adults. As siblings of persons with IDDs enter school, this process continues.

In summary, siblings attitude toward brother or sister with IDDs is recognized as a central aspect of the self, and furthermore it characterizes the self-relevant

psychological tendencies or processes of the people who engage in these divergent cultural worlds.

It is this interpersonal consequence of cultural adaptation that contributes significantly to the normal variability in the adaptive styles of siblings of persons with IDDs. The theoretical perspective of cultural psychology assumes that the self and the social relations of a given community are mutually constitutive and that maintaining a sense of self amounts to being a part of attendant social relations. What is considered good and what is considered bad requires an attunement between the self and the social relations that are organized and maintained by the cultural practices and meaning of a community. As a result, discord felt by siblings of persons with IDDs and other problems arise because they cannot easily find their proper position in relation to their place in the community and in regards to their brothers or sisters with IDDs.

5. Conclusion and future directions

For some time, research on siblings of persons with IDDs has been concerned exclusively with negative emotional states such as frustration, stress, burnout, anxiety, shame, and guilt. The focus has been put on siblings of persons with IDDs who are placed in a stressful environment and trying to adapt to their brothers or sisters with IDDs as a family unit. Most studies on sibling relationships are devised with the intent of improving sibling relationships. Therefore, while investigating various factors, researchers have concentrated on helping siblings of persons with IDDs transform any negative feelings they might have toward their brothers or sisters with IDDs into positive ones.

However, the mind is a social entity. If we assume that all attributes of the mind are grounded in the nature of society, there is no good reason to conclude that one set of relationships is good and that another is bad. To interpret differences and variations in the nature of these relationships within the framework of ‘evolution’ entails difficulties. How siblings adapt to their brothers or sisters with IDDs is a psychological process resulting from social adaptation to the relevant cultural community, and it results from the conceptualisation of the intra-individual phase of the relevant cultural complex. In other words, it is necessary to understand how siblings adapt to their brothers’ and sisters’ IDDs by systematically researching cultural norms and related psychological tendencies.

The cultural psychological approach assumes from the outset that situations may be different from what is typical. Details previously thought to be insignificant become noteworthy and social aspects receive more focus in this type of research. Applying this method to research on sickness and disability will lead to further studies on how disability is influenced by cultural relationships.

More often than not, the experience of siblings of persons with IDDs is marginalized in the research of problems stemming from disability. But the cultural psychology grounded approach to disability and role of siblings of persons with IDDs can nicely supplement earlier research on siblings of persons with IDDs. This will produce a fuller account of human emotional experience and its socio-cultural and individual dynamics. The cultural perspective offers a number of useful directions for future research in this area.

First, it should be recognized that problems of siblings of persons with IDDs are conceptualised as a tuning between an individual and his or her socio-cultural context.

This should be taken more seriously in studies on the problems associated with siblings of persons with IDDs and social relations.

Second, the notion that each sibling of persons with IDDs has a social function, which is to increase the good and decrease the bad by internalizing cultural models, may itself be cultural. This idea may be grounded in the different ideological bases of those siblings who have lived with persons with IDDs from infancy. Diverse as they might be at first glance, different ideological bases are all rooted in a holistic conception of the universe and a world where everything is interconnected. It is these interdependencies that determine what has happened, what does happen, and what will happen.

Finally, the literature on siblings of persons with IDDs has so far been based on traditional viewpoints. Although useful in mapping generalizations, this methodology has inherent limitations. The cultural perspective presented here suggests that future research should focus on the fact that cultural meaning is often tacit.

Notes

1 Intellectual and developmental disabilities hereafter abbreviated to IDDs.

2 Self-schemata are 'cognitive generalizations about the self, derived from past experience, that organize and guide the processing of self-related information contained in the individual's social experiences' (Markus 1977, 64).

3 Masten, Best & Germezy (1990) defines 'resilience refers to the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances (426)'. The concept of resilience is important in understanding the wide range of human psychological adaptive processes. However, where to place the emphasis is unclear. Depending on the researcher, focus could be placed on adaptive processes, capacity, or outcome. There is no unified interpretation.

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