

**CHINESE AND CHINESE-AMERICAN FAMILIES OF CHILDREN WITH DISABILITIES**

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*Cultural characteristics impact on parents' attitudes and perceptions toward children with disabilities. Therefore the unique family background could create a challenge for service providers. Professional who works with children with disabilities need information from families in order to provide effective intervention(Parette, Summer 2004).*

*The purpose of this paper is to review the perception and challenges Chinese-American families of children with disabilities encounter. Specific emphasis was placed on the influence of acculturation of Chinese-American and the intervention of professionals in educational decision making process.*

Cultural studies pertaining to young children with disabilities have emerged in the professional literature as a rather new field of study. A common theme of these studies has been the impact of ethnicity/culture on the families. Parette (1998) reported different perceptions with regard to children with disabilities between Asian American families to those of European American families. In light of demographical changes, it seems Parette (1998) and other similar reports need to be examined more carefully. Chinese-Americans have increased from 1.6 million in 1990 to 2.8 million in 2000, or up to 3.6 percent of the total U. S. population (U.S. Bureau of Census, 2002). However, studies of Chinese-American families of children with disability are still limited. These families are from many parts of the world with different levels of education, language abilities and attitudes toward children with disability. In order to better understand the issues of families of children with disabilities, it is important to focus on the following areas: United States laws related to disabilities, cultural impact on families, and the need for support and rehabilitation.

*Cultural Perspectives and Disabilities:*

Culture has a very strong impact upon people's understanding of disabilities and the usage of outside support. The term for disability in Chinese is *ts'anchang* or *ts'anfei* which means disabled, with obstacle or useless. A person with disability normally will be associated with helplessness or hopelessness. The birth of a child with physical or intellectual disability is perceived as evidence of a parent's bad karma from the past, or a curse from ancestors. Traditional Chinese mothers who gave birth to a child with disability have been reported to blame themselves for violating cultural taboo, for examples using sharp instruments, visiting cemetery, or eating the wrong kind of food (Ow, Tan, & Goh, 2004). Families often kept it a family secret as a way of coping with disabilities of their children. Therefore, they may have avoided seeking help outside the family. Similarly, Tsao (1999) stated that in the Chinese tradition a disability was believed to be a punishment for the disabled person's parental or past life sins.

According to Chan (1997) Asians tend to attribute the cause of a child's disability to supernatural influences or sins committed by the child's ancestors. Therefore, Asian parents with children of disabilities often experienced great shame and feelings of obligation toward the child (Chan, 1997; Sotnik, 1995). However, Chinn (1979) noted the parents were also the agent of change in educating their exceptional children. He further concluded parent participation can play an important role in designing educational programs for children with disabilities from culturally diverse backgrounds.

Holroyd (2003) studied Chinese cultures influence on parental care giving obligations toward children with disabilities in Hong Kong. She pointed out parents with children of disabilities in Hong Kong

sensed the child's disabilities become disruptions to natural order in family tradition especially with male children. Parents felt they could not give and receive the cultural expectation of moral debts and credits throughout family life. Thus, those parents experienced shame. This is understandable within a society where children's disability is attributed to something that the mother or her side of the family had done and she normally takes the blame for her child's disability. Holroyd (2003) further reported most mothers of children with disabilities assume the majority of caring duties for the child especially in the public settings. Some fathers denied or ignored the child with disability and frequently did not participate in caring for their disabled children.

#### *Special Education Law in the U. S.*

In discussing of individuals with disabilities, it is important to define what *disability* is within American educational as well as judicial system. American with Disability Act 1990 (ADA) and Individual with Disability Education Act (IDEA) are the two most important special education laws that impact services for individuals with disabilities. Within the ADA, disability is defined as *1. A physical or mental impairment that substantially limits one or more of the major life activities of such individual, 2. A record of such impairment, or, 3. Being regarded as having such impairment* (Hadadian & Duncan, 1994).

The definition of disability has been further categorized under Individual with Disability Education Act of 2004. Categories includes speech and language impairments, learning disabilities, emotional or behavioral disorders, mental retardation, physical or other health impaired, hearing impairment, visual impairment, autism spectrum disorders, and traumatic brain injury.

#### *Individual with Disabilities Education Improvement Act 2004*

The roots of this law can be traced back to 1975 when US Congress passed the IDEA law under the title of *The Education for All Handicapped Children Act*. This law is a program law which provides funds to states and local educational agencies. The main purpose of the IDEA is to insure that all children with disabilities age 3-21 (individual states provide early intervention services for birth to 3 under the part C of this Act) would receive a *free appropriate public education* (Weishaar, 2007).

IDEA 2004 is based on six major pillars. They are: zero reject/child find, nondiscriminatory evaluation, individual education plan, least restrictive environment, procedural due process, and parent participation.

##### *Zero Reject/Child Find*

Under this part of the law no child with disability could be excluded from free appropriate public education due to the nature or the degrees of their disabilities (Weishaar, 2007).

##### *Nondiscriminatory Evaluation*

All children need to be identified through a comprehensive evaluation which involves multiple measures and multiple settings. This assessment must be valid and reliable and needs to be administered by trained professionals (Boyle & Weishaar, 2001).

##### *Individual Education Plan (IEP) & Individual Family Service Plan (IFSP)*

All identified children within the age of 3-21 must have a written IEP (for children from birth to 3 they must have IFSP) outlining services to be provided. The IEP and IFSP are the road maps to what, where, how long, and how often the child receiving services. As the name indicates, these services are tailored to each individual child's needs.

##### *Least Restrictive Environment (LRE)*

The LRE provides a vehicle for children with disabilities to be included in academic and non academic activities to the maximum extent appropriate with typically developing peers. Separate schooling and removal of the children from the general education classes occurs if the nature and/or the severity of disabilities cannot be achieved with the use of supplementary aids.

##### *Due Process*

Under this law the parties have the right to due process. IDEA regulates two different types of conflict resolution: mediation and due process. If a conflict is not resolved through these steps, either party can appeal the decision to judicial court system. This is another safe guard to make sure that children with special needs have access to a free appropriate public education (Boyle & Weishaar, 2001).

##### *Parent Participation*

The rights of children with disabilities are also protected through different avenues that require parent participation. These avenues insure that a school district would not be able to make unilateral decisions about the identification, evaluation and placement of children with disabilities. Indeed, rights of parents are woven within the fabric of IDEA (Boyle & Weishaar, 2001).

#### *American with Disabilities Act of 1990*

The American with Disabilities Act (ADA) is perhaps the most significant piece of disability legislation since U.S. Congress passed the Education Act for All Handicap Children Act in 1975. The American with Disabilities Act was passed by U.S. Congress in 1990 in order to provide a comprehensive national mandate for eliminating discrimination against individuals with disabilities (Hadadian, Duncan, and Malone, 1994). The American with Disabilities Act has five major areas which provides opportunities and accommodations for individuals with disabilities. These areas includes: Title 1: Employment: public and private employers with more than 15 employees are prohibited from discriminating in hiring or promotion individuals with disabilities, Title 2: Public Services: under this part of the law, individuals with disabilities cannot be denied access to programs, services, or activities of any public entity; this title also includes public transportation, Title 3: Public Accommodations and Services Operated by Private Entities: this title requires accommodations for people with disabilities in all public places including restaurants, theaters, hotels, medical facilities, daycare centers, etc., Title 4: Telecommunications: telecommunications include all areas of communication including telephone companies, telecommunication relay services, not to discriminate against people with disabilities, particularly deaf and hard of hearing individuals, Title 5: Miscellaneous Provisions: in this section other areas have been addressed, including the relationship between ADA and other laws and regulations (Hadadian & Duncan-Malone, 1994).

#### *Intervention and Rehabilitation*

Within the context of these laws rehabilitation/intervention can be defined as a system established to assist the individual to achieve acceptable level of functioning and be able to take part in community activities regardless of the nature or the origin of disabilities (Richards, 1995; Gates, 2003).

However, the child rearing practices as well as perception of people with disabilities can impact the implementations as well as interpretations of intervention and rehabilitation. Chinese parents assume the responsibility of taking care of their disabled children. The rehabilitation programs are viewed as a last resort (Chan, Hedl, et al, 1988). Anderson's study (1986) concluded that different value and beliefs can lead to ineffective treatment and dissatisfaction for both the clients and the health care providers. One could argue that, within the cultural framework each country may adapt different philosophy as well as rehabilitation services. For example, in China acupuncture, massage, medication, physical therapy, special education, vocation training, and counseling are prevalent in treatments of disabilities. Alternative treatment has also been an important component of Chinese medicine and has been used as medicine for centuries (Cadwell, 1998).

In examining Chinese parents of children with disabilities Wong, Martinson, Lai, Chen, and He (2004) identified parental, informational, attitude towards the child, coping and support need as being important. However, a provision of correct concepts regarding the developmental disability was the most important for Chinese parents (Wong et. al., 2004). This issue becomes compounded by Chinese families who had only one child. Therefore, they lacked normal parenting experience and skills as well as parenting a child with developmental disability.

Ellahi and Hatfield (1992) reported that over a third of the Asian families received no support when they first discovered their child had a disability. Wong et. al (2004) further reported wide range of needs by Chinese parents of children with developmental disability. For example, in regard to *parental* they provided quotes such as *he always throws things into the street. or I hit her once she spills the medicine...She cries immediately. She behaves well in that immediate moment. However, she forgets everything in the next moment. Her misbehavior occurs within two hours. I don't know what to do. or He is incontinent. or I lack this kind of caring experience.* In regards to *informational* they provided quotes such as *I'd like to know whether all the children with mental retardation have epilepsy or not. or I don't know whether it is caused by heredity or not or I don't know whether cerebral palsy is the same as mental retardation or not or My main concern is to let the child receive treatment for recovery, others are not important.* In regards to *attitude towards the child* they provided quotes such as *I'm waiting for fortune, hoping that she can walk sometime in the future or I hope that she can totally recover or I'd prefer that he suffer from paraplegia and be wheelchair bound than to have mental retardation.*

In relation to perception of *coping* they provided quotes such as *I become more and more frightened or I seldom talk to other people...If people ask about his condition and the reason why he cannot walk, I will tell them that he has a calcium deficiency. I'm afraid of telling others that there was problem related to the brain or I don't tell others about my child. I'll be looked down on because of the child*

or *It is not a good thing to have a child like this...I am afraid of letting others know that I have such a child.*

As for support they reported statements such as *I'm hoping that we can be taught how to conduct physical and rehabilitation training so that we can carry it out at home upon her discharge or I wish to learn how to face the child, and how to teach her or In comparison with other children, his development is delayed. I'm very nervous. No one will tell me about how to rear a child with developmental disability.*

Parette (2004) reported similar responses among Chinese-American families and other Asian-American families. The participated parents indicated early intervention and other education programs to be important for their children to progress. In addition, even though most Chinese-American parents accepted their children with disabilities, they expressed difficulties in caring for them. They also had difficulties in managing their children's disturbing behavior. However, if we compare perceptions of Chinese-American with other families of children with disabilities we will see information about developmental disability and support for promoting their child development as the top priorities for both groups (Gowen, et al., 1993).

### **Discussion**

Across Chinese-American, Chinese, and other American families of children with developmental disabilities it seems parent needed to be equipped with parenting skills, information on developmental disabilities and system of support.

The limited literature in this area indicated the need for information and support as a major concern for most parents in both the east and the west. Understandably, parents need to have a thorough understanding of their child's condition before they can be actively involved and participate in rehabilitation programs. In addition, the developmental support group should be encouraged. It is found that most parents generally lack sharing of opportunities and lack of support from friends and even extended family members. Within support groups families have opportunities to discuss pertinent emotional issues, such as feelings of frustration and child rearing problems. It is also an effective forum for helping parents to develop realistic expectations for the child and engendering feelings of competence (Wong et. al, 2004). If parents concerns are carefully assessed and interpreted, professionals can make appropriate decisions in how to help each family based on their identified needs (Glascoe, 1997). Therefore, a child with a disability could also have positive influence on their entire family including family structure and functioning (Turnbull & Turnbull, 1990).

### **Recommendations**

The result from the literature review indicates similarities as well as differences among Chinese-American families of children with disabilities. Service providers need to become more knowledgeable about the degrees of acculturation experienced by Chinese-American families as well as acknowledgement of difference of cultural expectations. Parents' perception in regard to their children's disability/ interventions needs to become an important component of pre and in service teacher training programs. Further, school counselors need to be aware of Chinese American parents' cultural perceptions in order to communicate effectively with parents. Specific programs need to be tailored to meet the unique needs of Chinese-American families of children of disability.

In conclusion further research would bring more insight on the impacts of issues related to: a) understanding cultural background and its impact upon the families of children with disabilities, b) assessing effects of caring for children with disabilities, c) changing the families attitudes and the process of acculturation, d) providing informed professional support and services, and ultimately, e) educating the policy makers to become more cognizant of the special needs of Chinese-American families with children of special needs.

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