

## **Perspectives of First Generation Asian American Parents towards Children with Disabilities and Their Educational Programs**

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The aim of this descriptive study was to examine the perspectives of first generation Asian American parents of children with disabilities regarding causes, meaning of disabilities, level of educational involvement and self-advocacy in their children's special education school programs. Using convenience sampling, 18 Asian American parents from the San Francisco Bay area participated in this study. The major findings in this study were interesting ones in that some were similar and others different from those previously reported in the past for Asian American families. First, the majority of the parents did not believe their past wrong doings caused their child's disability. Secondly, the majority of parents reported that they relied on the help and guidance of family members, friends, and family resource agencies over their religious or spiritual community. In addition, academic achievement was still held in high regard in their families and was the responsibility and obligation of the children with disabilities to achieve it and even pursue higher education degrees. Lastly, the levels of parent's involvement and self-advocacy were higher compared to previous studies. Implications for professionals working with Asian-American families and their children with disabilities are discussed.

According to the 2010 United States (U.S.) Census, Asian Americans were one of the fastest growing diverse group of individuals originating from China, Japan, Korea, the Philippines, Vietnam, Cambodia, Laos, and India. There has been a 43% increase from 2000 to 2010 with a total U.S. population now of 14.7 million people and 10 % are reported to have disabilities. Although from Asian descent each of these groups differs from one another in terms of language, religion and their unique cultural

customs and practices (Hayashino & Chopra, 2009), their acculturation stages differ as well due to different migration times, historical events, and discrimination (Ishii-Jordan & Petersen, 1994; Zhou & Xiong, 2005). Acculturation is defined as the cultural modification of an individual, group, or people by adapting to or borrowing traits from another culture (MerriamWebster, 2013). Through assimilation, the process in which one absorbs into the surrounding culture, Asian Amer-

ican families are able to decide which values and traditions they are willing to accept, modify, or forego. In short, research suggests that (a) these Asian American groups do assimilate overtime to the mainstream, but the outcomes are diverse; and that (b) the second generation (U.S.-born children of foreign-born parents) and third generation (U.S.-born children and parents) of individuals do evaluate themselves for the most part using the same standards as Americans (Zhou & Xiong, 2005). Although sociologists have examined this assimilation process in depth (Alba & Nee, 2003; Zhou & Xiong, 2005), there is still limited empirical data in the field of Special Education on how first generation Asian-Americans parents perceive their children with disabilities in the special education school system and what they find effective and meaningful for their family. To this end, professionals working in the field of Special Education need to be aware of both the cultural values and beliefs that Asian American families still maintain and those they have acculturated because these in combination influence their decision-making process, level of involvement in the school program, and overall perceptions of the special educational school system (Lee & Nihira, 1997; Lieber, Chin, Nihira, & Mink, 2001). Some background literature on the topics of Asian-Americans in relation to their children with disabilities is first presented.

### **Cultural Influence and Disabilities**

Causes of disabilities may be influenced by the cultural beliefs and values within a family's particular Asian culture. Huer, Saenz, and Doan (2001) reported in their study that the rate of incidence of Asian American children with disabilities was historically underreported due to religious beliefs, fear, shame, lack of understanding, and social stigma. In comparison to the European American

scientific view of disabilities, Asian American families may believe that children are born with disabilities due to bad spirits and karma (Chan, 1986; Chan & Lee, 2004; Fadiman, 1997; Rodriguez, 1995; Yalung, 1992). Past actions from a previous life may also affect the future of an individual as well. For example, in areas of China, disability is seen as a punishment for the sins of the individual or the individual's parents (Groce & Zola, 1993; Liu, 2005). Ryan and Smith (1989), in a study of Chinese American parents, found that although most parents agreed with the diagnosis from their doctors, they attributed causes to supernatural influences and immoral deeds, and even viewed their children's disability as a temporary problem.

Cho (2009) reported that causes of disabilities may be due to spiritual reasons as well. The physical location of an individual's home in relation to ancestral spirits is an important influence, as feng-shui, the belief system in which important structures and dwellings had to be placed in specific areas in order to create an auspicious environment, were taken into serious consideration. Some parents may believe that their child's disability is not medically related and therefore, seek out alternative treatments rather than educational ones (Ishii-Jordan & Petersen, 1994). For example, Vietnamese medical traditions are more accessible and less expensive than Western medicine (Holleman, 1991), resulting in the help-seeking choices of Vietnamese parents of children with disabilities to choose more traditional medical aid (Sue & Sue, 1999). Sage and Jegathessen (2010) found that one Vietnamese mother attributed the cause of their son's autism to "pay for the debt of her ancestors" (p. 203) and that her "terrified childhood during the Vietnam War had connections to her child having autism" (p.203). Moreover, Sonnander and

Claesson's study (1997) reported that some Vietnamese American parents avoided taking their children with disabilities out in public for shame of embarrassment and rejection, and that they often times refused services for their child with disabilities as well. For Asian American parents of children with disabilities, the aforementioned cultural factors may hinder parental involvement in their child's educational program (Cho, 2009; Harry, 1992; Harry, Kalyanpur, & Day, 1999), and may affect how parents interact and collaborate with the special education team members (Cho, 2009).

### **Parent Involvement and Self-Advocacy**

The Individuals with Disability Education Improvement Act (IDEIA, 2004) mandates parent involvement in the decision making process for their children's special education programs. Studies found that the level of parent involvement in their children's education programs varied according to the family's ethnic background (Hill et al., 2004; Hill & Taylor, 2004; Jeynes, 2003), and self-advocacy was challenging when navigating through the maze of the special education system (Rubin, Chung, & Huang, 1998).

Furthermore, the American educational system is built on values such as individualism, choice, and equality for children with disabilities as shown by the Individualized Education Plans (IEPs) and laws to protect both families and children with disabilities (Harry, 1992; Kalyanpur & Harry, 1999). However, these values embedded within the education system may not align with the values and high educational expectations of Asian American parents (Ali, Fazil, Bywaters, Wallace, & Singh, 2001; Harry, 1992; Lynch & Hanson, 2004). There have been some studies on the self-advocacy of Asian-American families and research has shown that they were less assertive compared to their non-Asian

American families (Bornstein et al., 1998; Cho, 2009; Klassen, 2004). This could be due, in part, because individuals in Asian cultures value the idea of harmony and discourage individualism (Faye, 1997; Toupin, 1980). In Park and Turnbull's (2001) study on Korean American parents of children with disabilities, they found that these parents rarely asked questions of the professionals working with their children, as a sign of respect for authority. If a parent were to disagree or question a person in public that would cause a *loss of face* to the other party, which is highly discouraged in Asian culture as it breaks the degree of connectedness. This *loss of face* belief is not a practice typically observed in European American cultures (Markus & Kitayama, 1991; Sage & Jegatheesan, 2010; Triandis, 1995). On a similar note, Lian (1996) also found that Asian American parents may refuse services through governmental agencies, including courts or the judicial system, to fight for the educational rights of their children with disabilities due to their belief of *loss of face* with the teachers and professionals they highly revere. Lau et al. (2004) compared Asian American parents with European American parents and their children with disabilities and found that when Asian American parents were confronted with their children's behavioral issues many chose to deal with these issues within the family structure and only sought assistance from outside agencies as a last resort. They were also less likely to use special education related services as a result of their traditional values (Chan, 1976; Won, Krajicek, & Lee, 2004).

A recent review of literature by Cho (2009) found that Asian American parents of children with disabilities were (a) more involved in home-based than school-based programs, (b) had high expectations and aspirations for their children, (c) expected their children to graduate from college, and

(d) provided their children with the opportunity and means to pursue higher education. An in-depth study conducted by Huang et al. (2004) found that there were positive relations between Asian American parents' self-advocacy skills and the level of social support they received. Huang et al. also found that the longer Asian American families lived in the United States, the higher their level of advocacy skills, and that self-advocacy was not based solely on a families' level of acculturation. Other factors emerged as important in promoting more self-advocacy such as (a) communicating children's needs, (b) being knowledgeable about the disability, (c) willingness to defend their legal rights, (d) expressing issues in public forums, and (e) learning assertiveness skills.

### **Research Question or Purpose of the Study**

For the most part, the literature suggests that special education teams still use more Western communication styles and methods when working with Asian American families than culturally diverse ones and do not fully recognize Asian cultural beliefs and values in the team decision-making process. Moreover, past studies report that the causes of disabilities in children are attributed to different beliefs in the Asian culture and that this can lead parents to raise and view their children with disabilities differently from Euro-Americans. Consequently, this may also affect the way the Asian American families view, understand, and use the special education services available to them and their children with disabilities. In addition, past empirical data indicates that many families from Asian cultures are still not as involved as they would prefer to be with their children's educational programs, and are not as competent in their self-advocacy skills. Even though there have been several major studies on Asian American parents of children with

disabilities, there is still a lack of information in the areas of acculturation, disability types, types of services that these children receive, and parental advocacy styles. We were particularly interested in examining first generation families from Chinese and Vietnamese cultures who had lived in the United States more than ten years and had children with disabilities. We wanted to find out what perspectives do first generation Asian American parents have on their children with disabilities and what level of involvement they had in their child's special education programs.

### **Method**

#### **Participants**

The criteria to participate in this study was twofold: a participant had to be a first generation parent of a child with a disability (born outside of the United States) and have lived in the United States 10 years or longer. A convenience sample of 18 Asian American parents of children with disabilities with a mean age of 44 years and age range from 40 to 58 years participated in this research study. The participants included 16 Chinese American parents (89%), two Vietnamese American parents (11%), seven males (39%), and 11 females (61%). In general, this group of participants were highly educated as follows: (a) 11 (61%) had graduate degrees, (b) three (17%) had bachelor degrees, (c) one (6%) had some college, (d) two (12%) had high school diplomas (e) one (6%) participant had less than a high school diploma. All 18 participants were born outside of the United States and the average length of residence in the United States was 22 years with a range of 10 to 39 years.

#### **Measure**

A survey of 38 questions in English was developed with 12 demographic and 26 Likert scale questions (see attached survey). To ensure the content validity, survey

questions were based on past literature from 1976 to 2011 regarding Asian Americans' involvement and attitudes towards education, disabilities, and support systems. Pilot testing of the survey was conducted with one parent that met the requirements of the study, and this individual was not included in the study. Based on the input of the parent, the first author made formatting changes to the survey by changing the order of the questions and numbering them. Parents were required to be able to read and write in English, unless they had a translator present to aide them in completing the survey.

### Data Collection Procedures

The data collection was the sole responsibility of the first author and was collected at two non-profit family resource agencies, Parents Helping Parents (PHP) and Friends of Children with Special Needs (FCSN). The investigator attended a parent group meeting at PHP, where nine Vietnamese parents of children with disabilities were provided information and resources in Vietnamese. The investigator also attended a FCSN parent support group meeting for 28 Asian American parents of children and adults with special needs. The first author distributed surveys, consent forms and cover letters to the parents who were interested in participating in the study and met the criteria.

## Results

### Data analysis

Descriptive statistics (i.e., percentage scores) were used to analyze agreement using a 5 point Likert scale. The scores were collapsed from the Likert rating scale anchors and reported as one percentage score for *strongly agree* (5 rating) and *agree* (4 rating), one percentage score for *strongly disagree* (2 rating) and *disagree* (1 rating), and one percentage score for the rating of three which indicated *neither agree nor*

*disagree*. The percentage scores are reported as one of the three categories: (a) *agree*, (b) *disagree*, and (c) *neither agree nor disagree (or neutral)*. It should be noted that not every participant responded to every question, which would account for some not totaling 100%.

### Education and Parental Involvement

Overwhelmingly, 94% of the parents (n=17) *agreed* that it was important to provide their children opportunities and means to pursue higher education with only 6% of the parents (n=1) *disagreeing*. In terms of academic achievement, 67% of the parents (n=12) had high regard for education, 28% of them (n=5) did not report academic achievement as a priority and 6% of the parents (n=1) were neutral on this topic. Another finding indicated that 94% of the parents (n=17) *agreed* that children with disabilities should have access to regular education, where only 6% (n=1) *disagreed*.

In terms of self-advocacy, 94% of the parents (n=17) found it is disrespectful to ask questions about their child's education or to *disagree* with his or her teacher as well. However, the majority of the parents, 89% (n=16), *agreed* that it was not the sole responsibility of the teacher to make decisions about their child's special education program, 6% (n=1) reported that it was and 6% (n=1) reported *neither agreed nor disagreed*. Regarding educational concerns, 72% of the parents (n=13) reported that it was acceptable for a family to report educational concerns to the teacher or special education team, while 22% of the parents (n=4) indicated that they did not need to report these concerns to their child's teacher or school program and one parent did not respond.

In terms of communication with the school teacher, 61% of the parents (n=11) reported that it was important to communicate on a weekly basis with their child's teacher, 22% (n=4) indicated *neither agreed*

*or disagreed*, 12% (n=2) reported it was not necessary to communicate weekly and one did not respond. In addition, 44% of parents (n=8) reported that they participated in their child's school program more than one hour a week, 33% (n=6) did not participate at all, and 21% (n=4) indicated neutral. At home, 61% of the parents (n=11) indicated that they worked daily with their child on school work; however, 22% of the parents (n=4) *neither agreed or disagreed*, and 16% (n=3) indicated that they did not.

### **Cultural Beliefs and Values**

When the parents were asked about whether they had a good balance between their Asian and American traditions and values, 78% of the parents (n=14) *agreed* to having a good balance, while 17% (n=3) responded *neither agreed or disagreed*, and 6% (n=1) said they did not have a good balance. Forty-four percent of the parents (n=8) reported that their Asian traditions and cultural values were more important than their American ones, 39% (n=7) *neither agreed or disagreed* and 17% (n=3) *disagreed*. Participants were also asked whether their parenting styles were similar to their own parent's styles, and 44% of the parents (n=8) reported their styles differed, 35% (n=6) *neither agreed nor disagreed*, 18% (n=3) reported similar styles and one parent did not respond.

In times of receiving emotional support (i.e., guidance) from their religious or spiritual community, 56% of the parents (n=10) did not, 33% (n=6) did, and 12% (n=2) *neither agreed nor disagreed*. Parents were also asked if they turned to friends, family members or agencies for guidance and a large majority or 94% of them (n=15), indicated that they did seek help and support from family, friends and community agency personnel while 6% (n=1) of them did not and two parents did not respond. Specifically in terms of child care, the majority of the families (72%; n=13) received more than

five hours of help per week from family members and friends.

Whether or not these participants made their family decisions based on their religious and cultural beliefs, 33% (n=6) *agreed* to this statement; 39% (n=7) *neither agreed or disagreed*; and 28% (n=5) said they did not base their decisions on their religion and cultural beliefs. When asked specifically if they made their decisions about their child's special education program based on their own life experiences, 59% of the parents (n=10) *agreed*, 24% *neither agreed or disagreed* and 18% (n=3) *disagreed*.

### **Causes of Disabilities**

Participants were asked whether they believed that parents of children with disabilities must have done something wrong in their past to have a child with a disability. Eighty-nine percent of the parents (n = 16) *disagreed* with the statement and did not believe their past wrong doings caused them to have a child with a disability. However, one parent (6%) did believe so and one parent (6%) indicated *neither agreed nor disagreed*. Of the 18 parents, 56% of them (n=10) did not believe their child's disability was due to bad luck, while 17% of the parents (n = 3) did and 28% (n=5) indicated *neither agreed nor disagreed*. It made sense then that 61% of the parents (n=11) *agreed* that a child's disability may be due to psychological or psychiatric issues and could be treated with appropriate interventions; however, 22% of the parents (n=4) *disagreed*, and 17 % (n=3) indicated they *neither agreed nor disagreed*. More than half of the parents (56%; n=10), indicated that they *agreed* with the idea that individuals with disabilities are valued and seen as capable of contributing to their family and their cultural society; however, 33% of the parents (n=6) *disagreed* and 11% (n=2) indicated *neither agreed nor disagreed*.

## Discussion

There were four major findings in this study. First, an overwhelming majority of this first generation group of Asian parents had a high regard for education including institutes of higher education (IHEs). They reported that it was important to provide their children with disabilities as many opportunities as possible to be successful in their K-12 school programs and for them to pursue higher education. Similar to past literature (Park & Turnbull, 2001), the majority of Asian American parents did report it was disrespectful to ask their children's teachers questions about the educational program or to even disagree with them. However, in contrast to former empirical research, one finding in this study indicated that the large majority of parents did not seek the help and guidance from their religious or spiritual community, but rather from friends and family. Moreover, the majority of parents did not attribute their children's disabilities to their past wrong doings or any other traditional beliefs. Lastly, this group of participants had higher levels of involvement in both schools and homes, and communicated more regularly with teachers than reported in past literature.

## Education

Academic achievement was ranked very high in this group of Asian parents, which is reflective of their traditional value of high educational expectations. That is, an overwhelming majority of the parents indicated that it was important to provide their children with disabilities (a) all the educational support and resources they needed and to pursue higher education; and (b) to receive all their special education services in the general education classroom. It seems that this group of Asian American parents still expect their children to fulfill this traditional cultural responsibility and family obligation of obtaining a high quality

education regardless of their level of severity.

## Parental Involvement and Self Advocacy

For the most part, past literature indicated that Asian American parents of children with disabilities were less assertive in self-advocating for their children with disabilities in the public school programs (Faye, 1997; Huang et al., 2004; Lian, 1996; Park & Turnbull, 2001; Toupin, 1980). Again in contrast, the Asian American parents reported that it was not the sole responsibility of the teacher or special education team to make all the decisions about their child's educational program. That is, more than half of the parents reported that it was important to meet with their child's teacher on a weekly basis and become a partner of the team. This first generation group of parents wanted to be regularly involved in their child's education and did demonstrate a stronger sense of self advocacy than reported in the past.

Huer et al. (2001) reported that Asian American children with disabilities have been historically underreported due to cultural beliefs. However, the majority of participants in this study indicated quite the opposite, and that it was unacceptable to not report their children's educational concerns to the teachers. According to Park and Turnbull's (2001) study of Asian American parents of children with disabilities, their sample of parents rarely asked questions of the professionals working with their children, as a sign of respect for their authority. Similarly, the findings in this study indicated that almost all of the parents maintained this traditional value and reported it was disrespectful to disagree with or to question their children's teachers as well. Specifically, if a parent were to disagree or question a person of authoritative status that would cause a *loss of face* to the other party and this is highly discouraged in cultures that practice Confucianism.

### Causes

There has been documentation that the causes of disabilities for Asian American families were influenced by their traditional beliefs and values of the Asian culture (Chan, 1986; Fadiman, 1997; Groce & Zola, 1993; Rodriguez, 1995; Ryan & Smith, 1989; Yalung 1992). In contrast, the majority of the parents in this study did not believe that their children's disabilities were due to past wrong doings, but three of them did believe it was due to bad luck. Interestingly, Ishii-Jordan and Petersen (1994) found that Asian American parents who were more acculturated may understand that their child's disabilities could be due to psychological or psychiatric issues and could be treated with appropriate interventions. Again over half of the parents in this study confirmed this more western belief and practice, and very few still attributed the cause of their child's disability to the traditional belief of bad luck.

Religion and spirituality play a significant role in the lives of Asian American culture. Hayashino and Chopra (2009) reported that when Asian American families were in need of guidance and support to help cope with the stressors of having a child with a disability, these families tended to seek advice from their religious or spiritual leaders. In contrast, findings from this study revealed that the majority of the parents did not seek advice from religious leaders or their religious community, but instead sought out help from friends, family, and individuals from family resource agencies. This may suggest that the families in this study still value the traditional sense of community; however, they seek advice from others and not from their religious leaders.

### Conclusions

It appears from the results of this study that many years of assimilation may have influenced the majority of these Asian parent perceptions as some findings are different from those reported in previous literature. For this group of Asian parents, they still embraced some of their traditional Asian values and beliefs such as (a) high regard for teachers and *loss* of face, (b) high educational expectations, and (c) a sense of community. In terms of more western and modern values and beliefs, this group of parents did report (a) more self-advocacy and involvement in their children's special education program, (b) no religious or past spiritual causes for their child's disability only bad luck, and (c) more support from their friends, family and community than religious or spiritual leaders.

### Implications for Practice and Research

There are some implications for professionals and special education team members to consider and perhaps implement into their practice when working with Asian families and their children with disabilities. First, it appears that these families for the most part are not attributing the cause of their child's disability to traditional beliefs and may be more accepting of more modern reasons such as medical or psychological ones. Therefore, when first sharing the diagnosis of the child's disability with families, special education professionals should be prepared to provide any and all verbal and written information about the cause and the characteristics of the disability with the families in their preferred language. Moreover, it appears that Asian families still seek the traditional sense of community but are more open to advice and support from community agencies. It would be beneficial if special education team members provided families with information about all the local community family resources particularly agencies whose membership has similar

cultural backgrounds. Teachers could actually be involved in helping families make this connection to agencies by making appointments for them, etc. Teachers also need to consider the fact that most Asian families want to be more involved in the educational programs of their children either in school or at home than they might expect; therefore they should solicit each family's preference and plan together a meaningful way to ensure this happens.

Special education team members need to be culturally responsive to the fact that most Asian families have very high educational expectations even for their children with disabilities, and they should not confuse a family's effort to achieve this expectation as them just being difficult. Instead, they should be very prepared to provide all appropriate programs and resources available to the child and family according to the Individual with Disabilities Education Improvement Act (2004). In line with this, professionals need to understand that some Asian families might not express their true opinions about the team's recommendations at the public and more formal Individual Educational Plan meetings due to their traditional Confucius belief of *loss of face*. Therefore, when professionals are aware of the traditional cultural beliefs of families, they may need to consider having more sensitive conversations or informal opportunities prior to the formal group meetings where families can truly advocate for themselves and their children regarding their priorities, needs and concerns. Ultimately, this may ensure that IEP goals are not only reflective of the team's recommendations but also of the families input.

In terms of future research, it would be interesting to examine the perspectives of a more recent first generation of Asian American parents who have lived in the United States for fewer years to see if the

results vary with this more modern and technically advanced generation. That is, what traditional Asian values and beliefs would they still uphold and which American ones would they embrace compared to Asian parents of children with disabilities in former studies?

### Limitations

Several limitations may have influenced the outcomes of this study. First, this was a small convenience sample, and therefore generalization to a larger population is limited. Another limitation was that the survey was in only in English even though the parents reported they were literate in English. That is, a few of the parents noted after they completed the survey that they had to leave out several questions because they did not understand them, and it would have been helpful if the survey was translated in their native language. Future descriptive studies should include a more thorough piloting of the survey or written measure when the survey is done in the native language of the participants.

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