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A Comparison Study of the Needs of Parents with Mentally Retarded Children in China and in United States

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A COMPARISON STUDY OF THE NEEDS OF PARENTS WITH MENTALLY RETARDED CHILDREN IN CHINA AND IN UNITED STATES

A Thesis
Presented to the
Department of Special Education
and Communication Disorders
and the
Faculty of the Graduate College
University of Nebraska

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts: Mental Retardation
University of Nebraska at Omaha

by
Keli Mu
July 1993

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THESIS ACCEPTANCE

Acceptance for the faculty of the Graduate College, University of Nebraska, in partial fulfillment of the requirements for the degree Master of Arts: Mental Retardation, University of Nebraska at Omaha.

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ABSTRACT

The purpose of this study was to investigate the needs of parents of mentally retarded children in both China and America and to determine whether a significant difference exists between the needs of the two groups. It was hoped that the study would also help American readers understand more about the needs of Chinese parents.

Participants in this study were 72 parents of mentally retarded children. They were composed of 45 Chinese parents from six provinces across China and 28 American parents from Nebraska. The parents responded to a questionnaire on which they rated their needs in the areas of parent training, understanding the cause of the disability, medical care, respite care, collaboration with teachers, understanding by the community, financial assistance, and information. They indicated their highest hope for the future of their child in a separate question. They also ranked their need priorities in an open ended question.

Chinese parents responded to a questionnaire written in Chinese and the American parents responded to a nearly identical questionnaire written in English. The questionnaire was developed by the author with the help of University of Nebraska at Omaha students and professors, Nebraska parents, and Chinese special education leaders.

The central question addressed was, "How would the rating of needs by a sample of Chinese parents compare to the rating of needs by a sample of American parents on the topics of parent training, financial assistance,understanding by the community, respite care, understanding the cause of the disability, medical care, collaboration with teachers, and information?"

Results of the study indicated that there was a significant (.05 level) difference in the need for parent training, understanding the cause, medical care, respite care, and collaboration with teachers. There was no significant (.05 level) difference in the need for understanding by the community, and financial assistance.

Limitations of the study were discussed. Suggestions were made for further study that included expansion of the study to wider populations of parents after improving the instrument with the help of information gained from parent responses to the open ended questions. Concluding comments included the observation that some of the differences found may have been due to a lack of availability of service in China and a high degree of need for Chinese parents.

THE COMPARISON STUDY OF THE NEEDS OF PARENTS WITH MENTALLY RETARDED CHILDREN IN CHINA AND IN UNITED STATES

CHAPTER I

Introduction

Parents of disabled children have been involved in the education of their children since earlier 1970s. The passage of PL 94-142, PL 99-457, and PL 101-476, Individuals with Disabilities Education Act (IDEA), brought about new participation options for parents' involvement. The advantages of parent participation were well documented by research and practice. In order to involve parents in their children's education, it was necessary to assess the special needs of raising their children. In the United States, a number of studies concentrated on this area (Bailey & Simeonsson, 1988; Turnbull & Turnbull, 1986; Helm, J. 1988; Meyers & Marcenko, 1989; and Shea & Bauer, 1991). In China, however, special education was a extremely new area. Its history had been little more than one century (Rong, 1984; Piao, et al. 1990). The history of education for mentally retarded persons was even shorter, starting in 1979 (Rong, 1984; Piao, et al. 1991). The assessments of parents' needs in the field were very scarce in China. This study was to investigate the needs of parents of the mentally retarded in both China and America and to determine if a significant difference exists between the two cultures.

Statement of the Problem

Much research has been done on the needs of parents who have children with disabilities. The birth of a child with disabilities has brought about severe stress for the parents. Parents of the children with disabilities show urgent needs in the areas of information, training, services, collaboration, financial, and social support (Darling, 1979; Bailey & Simeonsson, 1986; Turnbull & Turnbull, 1986; Charleston, 1987; Dangel, et al, 1988; Taylor, D. 1988; and Shea & Bauer, 1991). In China, there are few studies focused on this area. The differences in Chinese and American culture, economy, and education suggest a possible difference in parents' needs in the two cultures. This comparison study is to investigate whether a difference exists in needs of Chinese and American parents of children with mental retardation. It is also hoped that this study will shed some light in the field of parents' needs in China, therefore the problems examined in the study include:

1. The rank order of needs of a sample of parents with mentally retarded children in China.
2. The rank order of needs of a sample of parents with mentally retarded children in America.

3. The determination of a possible differences in the needs of Chinese and American parents in respect to information, training, services, collaboration, medical treatment, financial assistance, and social support.

Procedural Limitations

Conducting a comparative study between two continents and two very diverse cultures presented some challenges. Some of most important limitations were:

1. Communication. While the postal service was relatively efficient in both countries, a response from a Chinese colleague often took more than two months. International postage for a Chinese correspondent was extremely expensive.

2. Duplicating services. Making copies of the questionnaire was very expensive and quite inconvenient, in some cases, for Chinese correspondents.

3. Parent access. Although twenty six Chinese colleagues received a copy of the questionnaire, only six actually had direct access to parents of retarded students. The author intended to provide the questionnaire for information purposes to the remaining twenty colleagues.

Definition of Terms

Mental retardation. The definition offered by the American Association of Mental Retardation (AAMR) was used. The AAMR definition stated that, "Mental retardation refers to significantly subaverage general intellectual functioning, associated with impairments in adaptive behavior and manifested during the developmental period" (Grossman, 1983, p. 1). Programs in China also refer to the AAMR definition as the guide for identifying persons with mental retardation.

Parents of the mentally retarded. In this study, parents of the mentally retarded refers to those parents whose children are labeled as mentally retarded and who go to education programs for the mentally retarded. In China, parents of the mentally retarded were selected from special primary schools for students with mental retardation. In the United States of America, the majority of the parents surveyed were selected by the Greater Omaha Association for the Retarded Citizens (GOARC).

America. In this study, America, USA, and the United States are used interchangeably. The reference is to residents and laws specific to United States.

Research Questions

The specific questions in this study were:

1. How would a sample of Chinese parents of mentally retarded children rate their needs for parent training, financial assistance,understanding by the community, respite care, understanding the cause of the disability, medical care, collaboration with teachers, and information?

2. How would a sample of American parents of mentally retarded children rate their needs for parent training, financial assistance, understanding by the community, respite care, understanding the cause of the disability, medical care, collaboration with teachers, and information?

3. How would the rating of needs by a sample of Chinese parents of mentally retarded children compare to the rating of needs by a sample of American parents of mentally retarded children?

Hypotheses

1. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for parent training.

2. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for financial assistance.

3. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for understanding by the community.

4. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for respite care.

5. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for understanding the cause of the disability.

6. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for medical care.

7. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for collaboration with teachers.

Summary

This study was to investigate the needs of a sample of parents of students with mental retardation in both China and America and to determine if differences between the two cultures did exist.

CHAPTER II

Literature Review

Considering that this was a study to compare the needs of Chinese and American parents of mentally retarded children, the following literature review is composed of two parts: Chinese issues and American issues. The Chinese part includes information on Chinese parents with children in special education in China. The American part is on meeting parents' needs in regard to information, training, services, financial assistance, collaboration, and social support.

CHINESE ISSUES

Historical background of Chinese family life

People's Republic of China is a huge country with 9,600,000 square kilometers, located in southeast Asia. The population in China was 1,100,000,000 in 1987 (Li. Z. et al. 1988). China has a long history, which has been called by Chinese a "5000-year history." In its culture, China was highly affected by three types of philosophy, the Confucianism, Buddhism, and Taoists. Among them, Confucianism is the dominant philosophy. It has highly influenced all the aspects of Chinese society. When talking about Chinese culture, people usually call it Confucianism Culture. In family values, Confucianism maintains that "the more descendants, the more fortune" (Chinese proverb), which means the more descendants in the families, the more happiness the family will have. If one family has many children and grandchildren, it will be considered as a prosperous family. Therefore in old time China, even during the 1930s-40s, three or more generations living in one family was very common as well as praised by other people. On the other hand, if one family had no later generations, others would ridicule them, implying that their ancestors had done some immoral thing, and the Heaven was punishing them by the way of having no descendants in their family. The family itself would feel ashamed, too. Confucianism also indicated that there were several ways of showing no filial obedience. The worst offense was to have no descendants. The Confucianism's philosophy on family values has a historical origin. China is an agricultural country. In ancient times, people worked on the farm for themselves. More descendants meant more laborers in the family in the future. During the ancient times, the life span was short. More children created more opportunity for survival of the family and that is why people expected more children and grandchildren in their families. At present, changes of economy and the society in China have resulted in the changes of the values of Chinese people have placed on the family. However the Confucianism's philosophy still impacts on the people's concern for the family, especially for the 80% families in China who reside in rural areas.

In order to solve the population problem in China in the early 1980s, the Chinese government mandated the one child policy. At the beginning, realization of this policy was confronted with much difficulty because of the Chinese tradition. Today, however, more and more people are aware of the importance of birth control and are willing to accept the one-child policy. The Chinese government has emphasized the flexibility of the implementation of the one-child policy. In rural or minority areas, people are allowed to have more than one child. In many areas, the Chinese government has recognized the problem of the parents if their first child was disabled and has permitted that family to have another child.

Expectations of parents for their children

The expectations that parents have for their children can be summarized as a Chinese idiom: "Expect their son to become a dragon and expect their daughter to become a phoenix" (Chinese proverb). In China, the dragon is the symbol of the king and the phoenix is the symbol of the queen. When a person becomes the king of the country, he will wear the dragon-robe which is decorated by dragon-pictures and sit down in the first chair of the nation. Similarly, when a woman becomes a queen, she will wear the phoenix-skirt, which is decorated by phoenix-pictures. To expect their son to become a dragon does not really mean that he is expected to become a king, however, parents do expect their child to become an outstanding person. In ancient times, parents expected their child to win the imperial examination and became an important official. This would allow their child to come to back his hometown in treasure cloth and to bring reputation to their parents and grandparents. It is called "come back hometown with treasure" and "bring reputation to their family" (Chinese proverb). In China today, although we can not say "back hometown with treasure," it still brings a high reputation to the whole family if their child becomes an outstanding person. Moreover many parents believe that children are the extension of themselves. They keep their own hopes for their children and expect their children to do what they wish to do and to achieve what they wish to achieve. Every parent expects his/her child to be healthy, active, smart, and good looking. They begin to dream of their child's future and happiness even when the mother is just first pregnant. The birth of a healthy infant brings great happiness to the family. Parents are proud of having a son or a daughter; grandparents are very happy with having a grandchild; and relatives and friends will visit and congratulate the parents upon the birth of a new life. Many families will hold a grand party or formal dinner to celebrate the important event in the family. Also the family begins to take the responsibility of raising its child. As the child grows up, parents devote different levels of energy, time and money to their children and show different methods of treating their children. Based on the prior study and experiences of working with parents, the author noted that the treatment of parents for their child can be divided into four categories.

1. Overprotection. Such parents overprotect their child. They meet their child's every requirement no matter whether it is wrong or right. As the economy improved in China, many parents became capable of providing their child's requirements regarding money, food, clothes, and toys, etc. Such parents hold that their child is the bright pearl in their palm, and it is reasonable to meet all of the child's requirements, and people ridicule such treatment as "They (such parents) are afraid the child will fall and break if they put the child on the hand, and they are afraid the child will melt if they put the child in the mouth." Sometimes when the parents reject the child's unreasonable requirements or correct the child's inappropriate behavior, grandparents will come over and protect their treasured grandchild. Similarly, in other families, when grandparents try to appropriately treat their grandchild, the child's parents will shield their child. Without question, such overprotection and inconsistency

is not beneficial for their child's psychological and physical development. Some children growing up in such families dare to insult their parents, teachers and friends, and do what they want to regardless of others. It is very difficult for such children to get along with others. Some of them even commit crimes.

2. Abandonment. The common characteristic of such parents is that they do not pay much attention to their children. Three groups of parents are included in this category. One group of parents is involved in their own achievement. They know how to raise children and have the capability to educate their children well. However, the love of their work motivates them to spend almost all their energy and time on it. Although they are willing to take the responsibility of taking care of their children, they do not have the time to spend on such a concern. Most of parents in this group are usually well educated, similar with the white collar class. The second group of parents comes from the blue collar class. Such parents are willing to educate their children, and they also have time to spend on raising a child. However, they do not have the knowledge and skills to do so. After work, such parents usually play cards, take part in a party, or watch TV or movies during their spare time. They seldom ask their children about their school, education and progress, and ignore their children's growth. The third group of parents is involved in their own business and do not spend proper

time on their children. Since China implemented the open policy in earlier 1980s, free market economy has become an important status in the national economy system. Many people opened their own businesses, such as grocery stores, clothing markets, bicycle workshops, hotels and even factories and hospitals. Many of them spend all their time in their businesses and do not place proper attention on their children. Some of them maintain that the important thing is to make money. It does not matter whether their children are able to obtain appropriate education or not. Some parents even ask their children to drop out of school in order to help them in their businesses. Such parents emphasize the substantial aspect of life, and they are willing to meet all their children's requirements no matter how expensive they are. However, they do not concern themselves in their children's intellectual development.

3. Domination. Parents in this category believe that children should always respect their parents. Children should obey adults' orders or requirements regardless whether they are wrong or right. Such parents do not care about their children's concerns, interests and appropriate requirements. Parents are the "kings" in such families. No matter what they say or do is always right and the child must follow.

4. Democratic. Parents in this category can raise their children appropriately. They do not hold the philosophy that children must respect their parents, and

the younger should always respect the older. Whether they accept or reject the requirements and opinions depends on whether they are appropriate or not. They have both the knowledge and skills in regard to raising children. They are not overprotective and do not abandon their children. They seriously care about their children's concerns and accept their reasonable opinions. In such families, nobody is always right. Parents are not only parents but are friends of their children.

Parents of disabled children

As discussed before, parents always dream of having a healthy, active, smart, and good-looking child. It is not difficult to image the disaster that the birth of a child with disability brings to the parents. The reactions of parents to the advent of a child with disability in China is similar to that documented in the American literature (Wu, W., 1984; Wu, Q.,1984; Zeng, 1984; Chou,et al., 1990; Friedrich, & Friedrich, 1981; Gallagher, et al., 1983; Ross, 1985; Yura, 1987; Wilgosh, 1990). Parents usually experience a variety of stages of emotions; such as suspicion, doubt, depression, anger, shame, guilt, or self-blame.

The first reaction of parents to the disabled child is rejection. They refuse to admit something is wrong with their child even though doctors and others tell them that again and again. If the child has problems, they believe: "It is not possible at all!" and believe "The doctors made a mistake; He/She is not my child; He/She must be somebody else's child" (Wu, W. 1984; Wu, Q. 1984; Zhou,1991). They keep hoping that the diagnosis was a terrible mistake and hope that someday the doctor will tell them nothing was wrong with their child. Meanwhile parents also keep seeing doctors to prove the diagnosis is wrong regardless of the money, time, and energy spent. Many parents of mentally retarded children could not understand the diagnosis, and they believe mental retardation is a kind of disease. Therefore, they keep visiting medical doctors and hope to find some medicine that is able to cure their children. Quite a number of parents, especially those living in rural or remote areas, search for help from the supernatural being and Buddha. Such continuing search disturbs the normal daily life of families with disabled children. Many charlatans take advantage of such urgent need of parents with disabled children. When the parents finally learn that the condition is not reversible, and that their search for the cure is ineffective, parents suddenly lose their self-esteem. They feel totally exhausted, upset, depressed, and are in despair. Such feelings further develop into resentment and anger. The parents might make statements asking, "Why such a terrible event occurred to us," or state that, "It is not fair because we have always been nice in our lifetime," and the "Heaven is unfair or it should not happen in our family" (Chou, et al, 1990; Wu, Q.,1984). Such questions are a common feeling in the families of the disabled at this stage.

When parents finally learn that the disability of their children is a fact they have to face, parents enter the adaptive stage. At this stage, parents calm down and adapt to the irreversible fact. Feelings experienced by parents at this stage include shame, guilt, and self-blame. Having the disabled children often makes parents feel ashamed. These parents keep thinking that it must be their ancestors who have done an immoral thing, and the supernatural being punished them by giving them such a child. Some of them may believe it is their fault that they have a disabled child. All these parents are ashamed of talking about their children with others, and of showing their children in the community.

Parents' attitude toward a child with a disability

Many studies have examined the attitudes of parents toward their disabled children (Wu, C., 1984; Chou, 1990; and Zeng, 1984). Wu (1984) divided parent attitudes into six groups on which the following was based:

1. The refusal to accept the status of their children. Parents do not admit the disabled condition of their child. They attribute their child's disability to other reasons; such as, the child does not study

hard, the child is too young to know how to study, or their intelligence has not developed. Some of parents may argue and prove how helpful their children are at home.

2. The blaming of God and men for status of their children. Such parents attributed the faults to the God or somebody else. They believe that their life arranged by the supernatural being is not well. It is their child who makes parents feel ashamed when meeting other people. Such parents keep negative attitudes about their children and they do not like to pay much attention to their children.

3. The blaming of themselves for their children's status. The parents in this group are the opposite of those in the second group. The attitudes of these parents to their child are overprotective.

4. Concealment of their children to avoid family scandal. These parents believe that having such children is shameful for their families. They are afraid it will affect their reputation and social status, therefore some parents lock their children at home and do not allow them to go outside.

5. Ignorance. Parents in this group include three subgroups: (a) parents who are disabled themselves; (b) parents in vocations that are not socially acceptable; and (c) parents of low social status. The common characteristic of these parents is that they are unwilling to care or they do not have the capability to

care about their children.

6. Positive and collaborative with their children's teachers. These parents can treat their children appropriately. They can cooperate with teachers or other professionals. They are willing to provide help for professionals to meet their child's special needs.

Chou (1990) studied the parents of mentally retarded children and found that three unappreciated attitudes existed among these parents: rejection, discrimination and confinement. All these attitudes will negatively influence the intellectual development of the children. In the discussion of education for parents and relatives of the mentally retarded, Zeng (1984) wrote that the common attitudes among them were:

1. Inferiority complex. Parents feel self-abased. They avoid talking about their children with other parents of the regular children.

2. Contradiction. Parents show negative attitudes toward their children, and even expect them to die earlier. On the other hand, such parents are not able to avoid their responsibility of taking care of their children.

3. Depression. Parents lose confidence in their disabled child.

4. Guilt. Parents maintain a feeling of guilt.

5. Sacrifice. The mentally retarded child becomes the focus of the family and the parents. Parents devote themselves to their children regardless of time, energy,

money, even their job, or their school.

6. Escape. The common phenomenon of such parents is that they put their children in the institutions and are unwilling to visit them.

7. Inappropriate expectation. Such parents keep inappropriate expectations for their children. For example, one parent mentioned that his or her hope for the child is that she or he can complete high school.

Parents' attitudes toward special education

The history of special education in China has just lasted a short period (Rong, 1984; Li, et al., 1988; Piao, 1991). Its history and development will be discussed in detail in the part of special education in China. In China today, the services of special education are restricted to the hearing impaired, visually impaired, mentally retarded and physically disabled. The education for the visually impaired and the hearing impaired children has been more than one century, since the first school for blind and for deaf was founded more than one hundred years ago (Piao, Y., et al. 1991). The education of the blind and deaf children is easily and appropriately accepted in the society. Most of the parents are willing to provide education for their blind or deaf children. Based on the past working experiences, financial concern impedes the education for the blind children in rural or remote areas. Because people live far apart in these areas, the children usually live at the school. At present, China has not completely provided compulsory education for the disabled children. Thus, such living expenses are a hard burden for many parents in the rural areas. Moreover, some of these parents maintain that their disabled child is not able to make a great achievement in the society of the future, and they are very satisfied if their child can help them in do farm work. Therefore it does not make a big difference whether their disabled child receives proper education or not.

The attitudes of parents of the mentally retarded toward education of their children are quite complicated. They are related to several factors; such as occupations of parents, economic status of the family, severity of the level of the disabled, and educational level of the parents (Chou, 1990; Wu, 1992). The level of severity of the disabled children is highly related to the attitudes of parents to their children's education.

Parents of mildly mentally retarded children are unwilling to send their children to special schools or classes. They feel ashamed if their child is in the "retarded" school. Also, they care that enrollment in such a school will bring a bad reputation for their child in the future. Such a reputation may highly impact upon their child's friendships, job finding, and marriage. So parents prefer to enroll their child in a regular school rather than in a special program, even though their children may not obtain an appropriate education or training. Such parents are satisfied that their child is able to graduate from elementary or junior high regardless the education their child receives.

Parents of moderately or severely mentally retarded children are willing to enroll their child in special schools. In present China, however, there are only a few institutions which provide education and services for the moderately or severely mentally retarded, and such institutions are centrally located in the cities. Most of the moderately or severely mentally retarded children across the country are taken care by their grandparents or other family members. For those families not living with the children's grandparents, the children's care has become an extreme burden. Such a problem has a considerable negative impact on the family's whole life. Thus, relieving the families' hardship, parents send their children with disabilities to special schools for their education and care (Zhou, 1991; Guan, 1991).

Special Education in China

Brief history of special education in China

Concern for persons with disabilities and their families can be dated back to ancient times in China. About two thousand years ago, it was proposed in the

Liyuen section of the famous Confucian classic, Liji, that a society should support all widowers, widows, orphans, elders living alone, and persons with disabilities. (Li, et al. 1988; Piao, 1990). This interpretation of Confucian philosophy reflects a concern for how such persons should be included in an enlightened, successful culture.

Another example of concern for including the less able in the total fabric of an ideal society was expressed in 1859 by Hong Renxuan, one of the leaders of the Taiping Heavenly Kingdom. He wrote that schools should be established for the blind, deaf, mute, and crippled. The Taiping Heavenly Kingdom was a revolutionary organization of farmers who hoped to create a new country in China that would reflect the needs and aspirations of ordinary persons. China at that time had been greatly weakened by the Opium War and other invasive activities by foreign interests. The history of special education, as a modern concept, began not long after that (Piao, 1990; Rong, 1984) when missionaries came to establish schools for students who were blind or deaf.

In 1874, the first school for the blind in China was founded in Beijing by a British minister, Moon William. In 1887, the first school for the deaf was established in Dengzhou (now called Penglai), Shandong Province, by an American couple, Mr. and Mrs. Mills (Piao, 1990; Rong, 1984). The founding of these two schools is considered to be the first milestone of special education development in China. A number of private schools for deaf and blind subsequently was established. By 1949, there were 42 schools for the blind, deaf, and nonverbal. The total number of students enrolled in these schools was more than 2,000 (Li, et al., 1988; Rong, 1984). The People's Republic of China was founded in 1949. Soon after, the government took over all the private and missionary special schools. Special education gradually gained more attention from the government. A variety of measures, such as setting education goals, modifying education content, and reforming teaching materials and methods were taken to improve the quality of special education. National policy and administrative committees were established to enhance and guide the development of special education. Special education expanded and was included in the national education system. By the end of 1965, there were 266 schools for blind and deaf. The number of enrolled students reached 22,850, which was 10 times greater than that in 1949 (Li, et al., 1988; Piao, 1991).

During the period of 1966 -1976, all education in China suffered from the "Cultural Revolution." By comparison, special education may have suffered less. Government sources reported cases of soldiers helping in the schools and dramatic miracles brought about through the use of folk medicine. Reports of such activities were intended to demonstrate a high level of humanistic activity by ordinary citizens. The size of the schools remained about the same as or lower than that of 1965. By the end of 1975, the number of special schools was 246 and a total of 26,782 students were enrolled (Rong, 1984).

The development of modern special education in China started in 1978. In 1978, China's government implemented the "Reform and Open" policy. China, after a long period of restriction, began to open its doors to the world. Special education gained more recognition. Shortly before 1980, special schools in large population areas began to report that they were working with children who were mentally retarded. In 1979, an experimental class for mentally retarded students was started in a Shanghai School for Deaf (Yin, 1989). The founding of this class, another milestone in the history of special education in China, signaled a departure from special education only for deaf and blind students. Teachers from many parts of China were sent to observe the classes for mentally retarded in Shanghai.

Beijing Normal University and other universities expanded teacher education programs to reflect the new demands. Reports from other parts of the world about special education were being read. Foreign visitors were asking to establish special education exchange programs. Since 1978, numerous steps have been undertaken to facilitate the development of special education (Chen, 1990). Establishing a national law on special education, allocating special funds, and emphasizing administrative work at all levels of government illustrated the new emphasis.

Special education legislation

Legislation on special education has been an important measure for forcing the widespread development of special education. On December 4, 1982, Article 45 of the Constitution of the People's Republic of China was adopted. It stated that state and society should provide support for students who are blind, deaf, nonverbal, and other handicapped citizens with their labor, life, and education (Li, et al. 1988; Piao, 1991). Article 9, Law of The People's Republic of China on Compulsory Education, passed on April 12, 1986, said that local government at all levels should establish schools with special classes for students who are blind, deaf, and mentally retarded (Li, et al., 1988; Piao, 1991). This was the first time in the developing history of China that special education was included in requirements for compulsory education. The purpose of this inclusion in the process was to protect the rights of the disabled persons to receive education from the agencies that delivered compulsory education system services. Private philanthropic groups and welfare enterprises continued to provide support for certain special education programs, but the government became the major provider following the 1986 law. Such progress also eliminated the inappropriate opinion that it made no difference whether or not special education was provided on a local basis.

On December 28, 1990, the Law of the People's Republic of China on the Protection of Handicapped Persons was passed. It was praised as another milestone in the modern history of special education development in China. The Law of the People's Republic of China on the Protection of Handicapped Persons declared that disabled persons had equal rights with other citizens in politics, economy, culture, society, and family. Citizen rights and personal dignity of disabled persons were protected by the national law. Government sponsored education at all levels was admonished to take leadership in the integration of special education for the disabled persons into the national education system. The legislation on special education reflected a determination on the part of the government to insure further and greater development of special education.

Services for the handicapped

There were 51,640,000 handicapped persons (including visually impaired, hearing impaired, mentally retarded, physically disabled, mentally ill, and multiply handicapped) in China, according to the National Sample Survey for the Handicapped in 1987 (Li, et al, 1988). Among them, the number of disabled children between the ages of 0-14 was 8,170,000, including:5,390,000 mentally handicapped, 1,160,000 hearing-speech handicapped, 1,810,000 visually impaired, 620,000 physically disabled, 140,000 mentally ill, and 860,000 multiply handicapped. In comparison with the needs of disabled children, services for these children were very poor in modern China.

The services for disabled children include:

1. Services for prevention and early intervention of disabled children

The importance of prevention and early intervention has been getting more and more attention. However, prior to the early 1980s, little or nothing had been done in this area. When a child was born with defects, the parents were responsible for obtaining help for the child. With the development of special education, The Ministry of Health, The China Disabled Persons Federation, The Child Development Center of China and other organizations have emphasized the work of the disabled (UNICEF, 1989). The Child Development Center of China (CDCC) initiated a national project to set up the first national network to monitor and to study the birth defects. Nearly 1000 hospitals across the country participated in this project. The CDCC maintained that such project not only "provides a better appreciation of birth defects and associated disabilities but also provides information to develop services for the child who is disabled at birth" (UNICEF, 1989, p.154).

Child-care centers and kindergartens in some urban areas have begun to offer intervention programs for the disabled infants. Unfortunately in rural areas, such services are still in short number.

2. Services of rehabilitation

The Ministry of Civil Affairs of China (MCA) is mostly concerned with the rehabilitation of the handicapped. In 1985, MCA reported that there were only 60 institutions in urban areas and 700 welfare institutions that offered special programs for 11,000 disabled children. In 1988, the number of social welfare institutions which provided care and rehabilitation to the disabled children reached 860. Also, a number of community day-care centers were established in urban areas to care for 20,000 disabled children. Fifty rehabilitation centers were found in urban areas to provide comprehensive programs for children with different disabilities. MCA reported in 1988 that there were 75 hearing and speech training centers offering programs for 20,000 hearing-impaired children, which was under 20 percent (20%) of the estimated population of hearing impaired children below the age of 14 years. Proper attention has also been placed on the rehabilitation of the physically handicapped (UNICEF, 1989). There is still a shortage of services of rehabilitation in most rural areas.

3. Educational placement for disabled

The State Education Commission is mainly responsible for the education of the disabled in China. Educational placement for the disabled before 1980 had mainly been restricted in special schools. In present China, the educational services for the disabled have been broadened into many types, including residential, self-contained classes in special schools, self-contained classes in regular schools, and enrollment in regular classes (mainstream).

The numbers of special schools and special classes for the handicapped had increased dramatically by 1990. The total number of special schools was 746, including 25 schools for blind, 50 schools for blind-deaf, 480 schools for deaf, and 191 schools for mentally retarded students. The number of special classes was 1053. More than 70,000 students were enrolled in special schools or special education classes (Piao, 1990; Zhao, 1991).

Influenced by the international trend and based on practical need, some Chinese schools began mainstreaming experiments around 1986. The experiments included integration of visually impaired, hearing impaired, and mentally retarded students. A national project on mainstreaming was initiated by the Department of Special Education in the State Education Commission and the Division of Special Education in the Central China Educational Institute. Over 12 provinces participated in this huge project. As positive experiences were reported, "mainstreaming" for learners with disabilities spread throughout the country.

Collaboration between parents and school

More attention is being placed on parental involvement in China. Educational practice and research has indicated the significance of collaboration between parents and school (Chou, 1990 and Zheng, 1992). A variety of special schools in China has taken measures to initiate or strengthen such work. For example, some schools have formed parent committees to enhance collaboration between school and parents (Zheng, 1992). At present, such collaboration in China is realized by such methods listed below:

1. Parent committee. Selected parents (about three members) are organized into a parent committee for a grade or a school. The main responsibility of the committee is to participate in school-work planning with the school, providing information from the school to the parents and parents' comments and suggestions to the school.

2. Parent school. Many special schools open training programs to the parents of the school for disabled children. Parents attend the parent-school at night or weekends to learn information and training skills. Information and comments from parents is also exchanged with teachers through such programs.

3. Parents visiting school and teachers visiting parents. Through two-way visiting, information, comments, and suggestion are exchanged.

4. Schoolbag letter. Information about the child in

school and at home is exchanged through letters carried in the student's school bag every day. Comments are communicated to each other this way.

5. Information exchange. Newsletters, journals, and monographs are written and delivered to the parents by the school. This provides parents with information about specific disabilities, experiences of treating children, events happening in school, and requirements from the school.

AMERICAN ISSUES

Information Needs

Information is one important aspect of parents' needs with disabled children. Professionals have well documented its significance in addressing the parents' needs of disabled children (Cooke and Lawton, 1984; Bailey & Simeonsson, 1988; Bailey, et al. 1986; Turnbull & Turnbull, 1986; Shea and Bauer, 1991). Compared to the parents of nonhandicapped children, parents of disabled children have more concern resulting from their children's special condition. Shea and Bauer (1991) indicated that parents with handicapped children may be interested in such following topics:

1. Laws, rules, and guidelines regarding the education of preschoolers and other students with disabilities
2. Health and medical care and insurance

3. Estate planning
4. Tax information for persons with disabilities or persons with dependents who are disabled
5. Community resources--that is, available resources and how to locate and use them. (p.194)

Legislation on special education and the rights of parents and their children is one of the important concerns for parents of disabled children. Although the passage of PL 94-142 (now IDEA) mandated that parents of disabled children had the responsibility to be involved in their children's educational programs, not all parents were very clear about their legal responsibilities and rights in educating their children.

Lowry (1983) studied the inner-city and the low-income black family with disabled children. Thirty-eight percent of parents responded in the negative concerning their children's legal rights and PL 94-142 (now IDEA). In the survey conducted by Boone and Smith (1981) in rural Arkansas, results indicated that parents knew little of their role in PL 94-142 (now IDEA). The 11-item survey focused on whether parents knew of any law concerning their children's or their own rights in their children's education. A majority of parents responded "no." For example, ninety two percent (92%) of parents answered "no" to both questions: (a) do you know of any law that says more than one test must be used to evaluate a child for special education and (b) do you know of any law that protects handicapped students from testing and evaluation that is racially or culturally discriminatory? According to the results, the researchers concluded that the information parents received was not only inadequate but not understandable (Boone & Smith, 1981).

In a study involving parents of seriously emotionally disturbed, learning disabled, mentally retarded, and multiply handicapped students, results showed that twenty percent of the parents were not provided with information on the Individualized Education Program. A majority of those parents reported a lack of knowledge about PL 94-142 (now IDEA) (Barton, et al. 1984).

Parents of handicapped children also need information concerning their children's special condition. Parents who learn of their children's disabilities will need information about the handicapped and about services are available for their children (Bailey & Simeonsson, 1988; Iowa State Department of Public Instruction, et al. 1988). Berg (1983) surveyed 40 parents of mildly retarded high school students, 108 community service agencies, and 21 directors of guidance and special education in Iowa. A majority of parents (78%) responded that they valued the information concerning counseling, education, financial assistance, legal aid, recreation and vocational training. The order of information that parents ranked according to the importance was counseling, education, legal aid, financial assistance, and recreation. Simenson and

Simenson (1981) also found that parents wanted specific types of information regarding their children's handicapped conditions. Cirillo and Sorrentino (1986) examined the effects of onset of a handicap on family subsystems: extended family, the couple, and the sibling, and indicated the high priority need of information about the child. In the 3 year-period · project conducted by Cone (1982), parents were surveyed in seven areas of parent/family involvement needs. About 94% parents expressed that they wished to get more information regarding the handicapping conditions. This was one of the three greatest concerns rated by the parents among the seven areas.

In the investigation of parents with disabled infants, Bailey and Simeonsson (1988) surveyed 34 two parent families, and asked mothers and fathers to rate individually the importance of their needs. Fifty three percent of mothers and forty seven percent of fathers said they definitely needed help on the item, "I need more information that my child's condition or disability, "Fifty six percent (56%) of mothers and 59% of fathers said they definitely needed help on the item, "I need more information about the service that my child might receive in the future;" and "I need more information about how children grow and develop."

Parents of handicapped children also emphasize the information providing services for their children. In a project conducted by Iowa State Department of Public

Instruction, the returned 229 surveys showed that a significant percentage of parents failed when they tried to access services for their children. When asked the most serious problems they faced in trying to get services for their child and family, 23.5% of the parents addressed the lack of information about services. In their large study, O'Connell and others (1989) interviewed a statewide, representative sample of 536 parents and caregivers of infants and toddlers with developmental disabilities and asked them to identify the kind of information they wanted. Fifty percent of parents responded that they needed information on available services, and ranked it as the most needed information. Holland and Hattersley (1980) also found that all the parents in the parent support group of their study wanted to have more information about services available to the handicapped and their families.

Other studies suggested that parents of disabled children not only need information concerning their children's special condition, but also information regarding normal child development (Gibson & Young-Brockopp, 1982; Bailey & Simeonsson, 1988; Turnbull & Turnbull, 1986; Cone, J., 1982). LaMonda (1982) pointed out that parents should know the information regarding child development in order to meet their child's psychological needs. Parents need to know information on their children's developmental age, personality type, and the basics of developmental psychology. In the research of the educational needs of parents of handicapped students by Bush and Simon (1988), the data suggested that the parents' greatest needs were common information about how to work with all children, rather than information about school-services for disabled children.

Also, information on financial aid is needed by the parents of handicapped children. Jarzab (1987) examined the awareness of Supplemental Security Income of parents of the disabled. Although there are funds available for the eligible children with disabilities, ninety-six percent of parents in the study were unaware of available Supplemental Security Income funds for their children.

Training needs

Training parents with handicapped children is not new in special education. The need for parent training has been well documented in literature (Altman & Mira, 1983; Heifetz, 1975; Shearer & Shearer, 1977; Turner & Macy, 1980; Bailey & Simeonsson, 1986; Turnbull & Turnbull, 1986). Several reasons contribute to the importance of parent training. First, parents are the earliest teachers of their children. Parent involvement can help children maintain and generalize what they learn in schools. Another reason is the continuity that parents provide in their children's whole life (Altman & Mira, 1983). In their early study, Johnson and Katz (1973) pointed out that, "The advantage of parents as change agents is that they constitute a cheap, continuous treatment resource which is able to augment existing therapeutic manpower capabilities and work conveniently within the home" (p.181). O'Dell (1974) also suggested that parents have a significant impact in formative pre-school years and remain in the best position to prevent future problems of their children. Moreover, parents are available to solve the problems resulting from the shortage of professionals. From these considerations, it is not a surprise that the extension of the Education for the Handicapped Act (PL 94-142, now IDEA) affirmed the rights of parents to receive training and charged the schools to fulfill it. According to Turnbull and Turnbull (1986), three relevant legal requirements were included in this legalization:

> 1. inclusion of parent training in the definition of related services.
> 2. inclusion of parents as one of the groups to receive in service training through the mandatory Comprehensive System for Personnel Development.
> 3. preparation of surrogate parents to represent the child in educational decision making.
>
> (p. 278)

During the 1960s and 1970s, the parent training programs concentrated on the area of behavior management skills. Williams (1959) conducted the pioneer work in this area. In his study, a mother successfully eliminated her child's bedtime tantrums by contingent ignoring. Since then, research in parent training proliferated (O'Dell, 1974). Over the past two decades, research has shown the success of parent training in modifying their children's behavior (Holland & Hattersley, 1980). These children included children with autistic problems (Wetzel, Baker, Roney, & Martin, 1966; Moore & Bailey, 1973; Moroz, 1989), emotionally disturbed/behaviorally disordered (Goodman, 1975; Rinn, Vernon & Wise, 1975), and mentally retarded (Arnold, Sturgis, & Forehand, 1977; Rose, 1974; Tavormina, 1974). Behaviors to be changed included a decrease in tantrums, self-destructive behaviors, excessive crying, verbal aggression and thumb sucking, and an increase of self-help skills, communication skills, playing with other children, and social approach responses (Rose, 1974; Arnold, Sturgis, & Forehand, 1977).

Filler and Kaiser's study (1981) examined the effects of instructing mothers how to teach their severely handicapped infants three tasks. Results indicated that mothers learned quickly. Once they implemented what they had learned, infants performed the desired tasks easily. Gelfand and Hartmann (1968) reviewed the literature on the behavior therapy and found that teaching parents to modify their children's behavior proved not only more effective than laboratory or clinical treatment with a therapist, but also a preventive measure for problem behavior in the future. Other similar studies also found that parents are effective agents in changing their children's behavior (Johnson & Katz, 1973; O'Dell, 1974; Reisinger, Ora, & Fragia, 1976).

Parents also need training in teaching skills and strategies in order to work with their children. Dangel and others (1988) conducted a survey in spring of 1988 to examine the educational needs of parents of handicapped children. More than 3000 parent needs surveys were distributed to a sample of parents of handicapped students. The 990 returned surveys suggested that the first three most frequent needs of parents are: motivating children, having children take responsibility, and developing learning activities to support social work. This indicated that parents wanted to learn teaching strategies to work with their children. Charleston (1987) investigated the barriers of providing free appropriate public education for handicapped children in West Virginia. Six out of eight regions indicated that parents were not adequately trained to participate meaningfully in the education process. Polirstok, Rovet, and Brian (1984) concluded that, "Parents lack skills and coping behaviors necessary for dealing effectively with their handicapped children" (p.22). Mcloughlin, Kershman and Metick (1984) also pointed that parents of disabled children needed both information and skills to perform certain services for their children. Havertape (1982) discussed the specific concerns and skills that parents need in meeting the psychological needs of their handicapped children, such as; use of simplified language in giving directions and in conversation, reduction of instructions to one or two demands, providing structure to all activities, and organizing activities and insisting on stepwise solutions in problem solving.

In the Bailey and Simeonsson study (1986), sixty five percent (65%) of mothers and fifty six percent (56%) of fathers showed they definitely needed more information about how to teach their child, and forty one percent (41%) mothers and twenty seven (27%) fathers answered they definitely need more information about how to handle their child's behavior (Bailey & Simeonsson, 1986). In an observational study of an IEP conference, Goldstein, Strickland, Turnbull, and Curry (1980) found that parents wanted to know how to help their children develop skills, but none of them received definitive answers from professionals. Other studies indicated that parents also need future plan training (Turnbull, et al. 1984; Turnbull & Turnbull, 1986; Bailey & Simeonsson, 1988). Several studies examined the effectiveness of parent training programs, and recommended various remedies for improvement. In their large review study, Helm and Kozloff (1986) believed that quite a few parent training programs just "teach parents a limited number of skills for changing selected behaviors" but fail "to equally teach the parents to recognize and productively alter those perceptions, coping strategies, and interaction patterns in the family" (p.3). They also suggested that parent training programs usually focus the attention of family on the child rather than the family system. In the studies examining teaching specific techniques alone versus teaching specific techniques plus general principles, researchers found the effectiveness of the addition of general principles is usually better than specific techniques alone. Parents in the plus principle training program were more satisfied with the training and rewarded their children more often. Moreover, they maintain the ability of generalizing their methods and techniques (McMahon, Forehand, and Griest, 1981).

Financial needs

The birth of handicapped infants will create financial problems for the families. This hardship not only comes from the increase of the family's consumptive demands but also from the decrease of family's productive capacity (Turnbull, et al. 1984). Unlike their normal peers, handicapped children have additional demands for their daily living skills, such as therapies, special equipment, and medical treatments. Such special requirements bring more bills to the families. Parents might be faced with greater needs for medical insurance, medical equipment, medication, may miss more work, or even a van for transportation (Brower & Wright, 1986).

A group of studies has examined the financial problem that families with handicapped children faced (McAndrew, 1976; O'Connell, et al. 1989; Brotherson, 1985; Dangel, Bush, and Simon, 1988). When one father of a physically disabled child was asked to indicate the most stressful factor in planning his child's future, the father answered: "Finding finances. I do not know where the money comes from" (Brotherson, 1985). O'Connell, and others (1989) interviewed the parents from 536 families with handicapped children, and found that over 1/4 of the families reported spending $ 1000 to $ 5000 annually for their children's special needs. Fifty-two percent of parents reported their children used special equipment and supplies. Forty-six percent of these parents reported paying for the equipment themselves. Obviously, for some families with handicapped children, special equipment and home adjustment is costly. Based on their interview with families of handicapped children, Brower and Wright (1986) concluded:

> Most of the families of disabled children are faced with some added financial burdens. Families of disabled children are affected by insurance -- obtaining it, keeping it. What it will cover is a constant consideration which even influences whether or not a family can move or change jobs. The probability is that if a child is identified as

> having a disability, the family will probably have some sort of medical expense. This may be medication for the child with a learning disability or adaptive equipment for the child with physical disabilities, or psychotherapy and medications for a behavioral impaired child. (p.10)

In Dangel, Bush, and Simon's study (1988), thirty three percent of parents reported needing for planning their children's financial future. In the investigation of both barriers and facilitators of parental involvement in the inner city, low income Black families, Lowry (1983) maintained that lack of money is the most important factor relating to low-income families because everything else becomes secondary.

The work of Bailey and Simeonsson (1988) found that twenty one percent of mothers and twenty one percent of fathers of handicapped infants definitely needed more help in paying for therapy, day care, or other services. Eighteen percent of mothers and eighteen percent of fathers need more help in paying for babysitting or respite care. In the report by Iowa State Department of Public Instruction and others (1988), researchers examined the causes of failure of parents in searching for services for their exceptional children. More than seventeen percent of parents reported a problem with the cost of services. Therefore, professionals recommend that more money is needed in order to deliver adequate services for handicapped children. In the same study, a large number of respondents needed more financial support. Jarzab (1987) also wrote that special care is the common need for some families with disabled children in both home and schools; moreover, such costs often remain the same or increase through the whole life of the handicapped.

Medical treatment is another need that costs money. Frequently, medical problems of the disabled children require extra spending in some families (Darling 1979; Gallagher & Gallagher, 1985). Bardellini and others (1982) described the financial aid for the students of disabilities. In their study, they pointed out that disabled students faced more expenses than nondisabled students, including:

> ... special equipment related to the disability and its maintenance; expenses of services for readers, interpreters, note takers, or personal attendant care; transportation necessary to pursue an academic program; medical expenses relating directly to the individual's disability that are not covered by insurance. (p. 2)

Several studies examined the financial support for the families of the handicapped. The survey by Agosta and Bradley (1985) found that 49 states provide some kind of support services for the families of developmentally disabled children. Among them, 33 states administer supportive service programs, 9 states provide cash assistance without supportive services, and

7 states administer a combination of these two services. Berg (1983) surveyed 108 community service agencies. Among the 94 community service agencies that responded, only 2 agencies (8%) reported financial assistance for mildly mentally retarded persons.

Zimmerman (1984) examined the impact of a subsidy program on the families with severe mentally impaired persons. One hundred and eighty seven families were involved in the program. By a retrospective telephone survey with thirty seven families, Zimmerman further indicated that a subsidy program was instrumental in assisting families with a child who has a severe handicap. A subsidy program is especially beneficial for families of lower income. Since many families with handicapped children are poor, subsidy programs should be widely extended. In the similar study by Meyers and Marcenko (1989), researchers examined the impact of the subsidy program (families involved in the subsidy program received $225 dollars monthly for caring for their severely mentally impaired children) on maternal stress, life satisfaction, and plans for out-of-home placement of the child. Results indicated that after one year of implementation, a significant change was found in areas of financial stress, such as additional income needed to cover expenses or inability to save much money because of the expense of child care or that need to borrow money to help pay for their child care.

Financial hardship of families with handicapped children is a universal phenomenon. Van Walleghem (1988) described the financial assistance for the mentally retarded persons in Belgium. According to Walleghem, three types of allowances are paid for the mentally handicapped person (or his/her parents) by the Department of Social Service: (a) The family allowances: The supplementary family allowances paid to the parents of mentally handicapped children each month, (b) The income-substituting allowance: This is paid to persons who are not able (or not totally able) to earn their own living because of their handicap, (c) The integration allowances: This is paid to handicapped persons who experience problems in their self-care and social integration.

Service needs

Parents of disabled children need a variety of services for their children, such as medical care, consultation, day care, and respite care service etc. Such parents' needs have been well documented in the literature (Bailey & Simeonsson, 1988; Ayer, 1984; MacEachron, Pensky, & Hawes, 1986). In Bailey and Simeonsson's study, a majority of parents (40% of mothers and 27% fathers) reported they definitely need help in locating baby-sitters or respite care providers and twenty seven percent of mothers and twenty seven percent of fathers definitely needed help in locating a day care center or preschool. Parents in this study also reported that they needed help in locating a dentist, locating a doctor, and in getting appropriate care for their children (Bailey & Simeonsson, 1988). In the study by Whitehead, Deiner, and Toccafondi (1990), researchers surveyed families' needs by using the Survey of Family Needs. A majority of parents reported needing help in finding baby-sitter (78%) and future services for their children.

Physicians play an important role in the services of the disabled children. In the summary of a national conference on the participation of physicians in the implementation of Part H of P. L. 99-457, Fullagar and others (1991) found that the participants recommended that primary care physicians participate actively in the location of, assessment of at risk infants and in the development and management of Individual Family Service Plans (IFSP). McDavis, Nutter, and Lovett (1982) surveyed 30 handicapped students and 30 parents of disabled students to investigated their counseling needs. In responding to the question of "When you found out your child had an impairment or disability and that you may need specific care and services, who was most helpful in providing assistance to you?" The majority of parents reported the physician as most helpful. Ripley and Suzanne (1990) emphasized the importance of parents with disabled children of choosing a physician for their children. They stated that the function of a primary care physicians is to treat the whole child.

They should be concerned with the child's health and development and be able to refer families to specialists and clinics. They should be responsible for obtaining developmental and psychological evaluations and for interpreting results of these tests.

Counseling is also a significant need for the families with disabled children. Lombana (1980) investigated the in-service training needs of school counselors in Florida. When responding to the question of what percent of their work time was spent with programs for handicapped students, thirty-six (36%) percent of the respondents reported they spend about 10% of their work time with special education programs, Twenty-three percent (26%) of respondents spend 11% to 25% of their work time with these programs. In the same study mentioned earlier by McDavis, Nutter, and Lovett (1982), researchers examined the counseling needs of handicapped students and their parents. The results showed that disabled students and their parents appreciate counselors' help by:

> .. providing accurate information about areas such as careers and community resources, by listening to their concerns and problems with empathy, by being available to meet and talk with them individually or in groups, and by helping them to make important decisions. (p. 236)

Slide (1988) studied the counseling needs of siblings of disabled children and found that the siblings of disabled children need open and honest communication about the disability of a sibling. Also, the siblings of disabled children would like more discussion of family problems caused by the disability.

A number of studies have focused on the parents' needs for respite care (Upshur, 1982; Blacher & Prado, 1986; Deiner & Whitehead, 1988; Moore & others, 1982; Neef & others, 1986). Respite care is the providing of temporary relief from caregiving responsibilities to families of developmentally disabled (Upshur, 1982; Blacher & Prado, 1986; Salisbury, 1986). Cohen and Warren (1985) also define respite care as "the temporary care of a disabled individual for the purpose of providing relief to the primary caregiver." (p.26) Besides providing relief to the family with disabled children, respite care also assists to improve family function, such as reducing levels of stress experienced by family members, influencing parents to develop more positive attitudes toward their children, and helping the family to become more socially active (Salisbury, 1987). Upshur (1982) surveyed 42 respite care agencies and 339 families to examine program models and family needs. Results showed that the mentally retarded were the most clients served in the respite care (88%), and the epileptic and the autistic was the least served (20%). Need for relief time, recreation or vacation, medical emergencies, and personal needs were reported as the reasons for respite care. When asked what problems families encountered in obtaining day, evening, or overnight respite care, respondents reported not knowing where to find help to obtain the service at all (30.7%), feeling reluctant to leave the client with a stranger (28.3%), not having enough time to make arrangements (21.8%), and meeting costly care expenses (19.5%). Other studies showed that availability, cost, service accessibility, and competence of the service provider were the major concerns of parents with disabled children in obtaining respite care services (Cohen, 1982; Upshur, 1982; and Salisbury & Griggs, 1983). Neef and others (1986) examined the effectiveness of respite care provider training programs. Results suggested that self-instruction methods were more effective in teaching respite care skills when it was combined with remedial training.

Collaboration needs

A great deal of attention has been focused on the collaboration between parents and professionals. The passages of Public Law 94-142, PL 99-457 and PL 101-476 have mandated the involvement of parents and the collaboration of parents and professionals. PL 94-142 (now IDEA) brought about new relationship between parents and schools. It maintained that parents should be involved in individual education programs, decision making, and program evaluation (Wolf, 1982). PL 99-457 viewed the family from the system perspective, mandating that the family involvement be based on a written Individualized Family Service Plan (IFSP). PL 101-476 integrated various services for the disabled children and their families and recognized the rights of the parents to influence their child's program.

Research has well documented the benefits of the collaboration of parents and professionals. Parents, as the children's first teachers, can provide information on children's development, personalities, current problems, home activities, and home environment. Such information helps teachers understand the children more insightfully and more completely, making the school more effective (Croft ,1979; Shea & Bauer 1991). Parental involvement in the school programs can yield more knowledgeable child advocates, and increase the number of people available to foster the child's development. The additional available people will increase the time that the children devote to learning and individualized instruction (Lillie 1976; Shea & Bauer 1991).

Professionals indicated that involving parents in the early intervention will increase the likelihood of generalizing intervention targets across different setting and people, making the intervention more effective (Filler 1983). Training parents as an effective interventionists will result in reducing the cost of delivering services (Shearer & Shearer 1976). Thus, many early intervention programs have used it as an acceptable duration strategy to train parents as interventionists (Carney 1983; Gray & Wandersman 1980; Bruder & Bricker 1985). In the study of the influence of family life aspects on children's school achievements, Clark (1983) found that parent involvement in their children's formal education can improve the students' achievements. This impact is most effective when parent involvement is comprehensive, long lasting, and well-designed. Peterson's study also suggested that parent involvement lead to the improvement of students' achievements. In a review of 49 studies of effects of parent involvement on child academic achievement and the performance, Henderson (1987) concluded that the benefits of parent involvement include: higher grades and test scores of students, longer term academic achievements, more positive attitudes and behaviors, more successful programs, and more effective schools. In the case study of inner-city children, the researchers indicated that information about children must be obtained from their families, and not by just questioning the child. To understand the children, the appropriate way is through understanding the families. Taylor (1988) maintains that when teachers work with the children, it is important and essential to know the family. Based on the observations of the children in the classroom, teachers can only make tentative interpretations.

Although collaboration between parents and professionals provides numerous benefits for the children, parents as well as professionals, there are still a number of barriers standing in the way of the collaboration. Gibson and Young-Brockopp (1982) studied the perceived versus the expressed needs of parents of handicapped children. In their research, sixty-one parents of handicapped children and fifty-one professionals were asked to fill out the parental needs questionnaires, which were composed of 20 items focusing on parent's feelings of having a child with disabilities. Results found that the professionals perceptions of feelings of parents with handicapped children were not accurate. The overall responses were significantly different between parents and professionals. According to the results, the authors indicated that when they worked with parents of children with disabilities, professionals often maintained false assumptions about parents' concerns. Professionals may often imagine the parents needs and feelings rather than assessing their actual needs. Such inappropriate behavior could obviously reduce the professionals' ability to intervene. On the other hand, when parents feel they are misunderstood they are less able to build a trusting relationship with the professionals. Darling (1979) studied the interaction between professionals and parents by interviewing parents and pediatricians. He found that pediatricians are not willing to work with parents of children with disabilities and usually place the parents on the role of victim-blame, trying to avoid the interaction with them as much as possible. A majority of parents accepted the advice of professionals during the initial period that followed the birth of the child. However, soon after that, most of them quickly became "disenchanted" with professional's suggestions. The Gallaghers (1985, 1972), as the parents of handicapped children, described their own experiences of intervention with professionals. A common feeling is that parents are automatically stripped of any knowledge or expertise and they are only listener and acceptor rather than partner or cooperators. Victim-blame is another common feeling among parents. This feeling, the Gallaghers believe, obstructs the relationship between parents and professionals and probably creates other unfavorable results as well. In fact, most parents experienced mistreatment when they interacted with professionals such as medical educational, social and psychological specialists (Darling, 1979).

A discrepancy also exists between parents and professionals in other aspects. Rose (1974) pointed out that concerns of parents may differ from those of professionals on values, objectives and priorities, temporal orientation, and competition. If parents and professionals are to work together effectively, those areas need to be cleanly recognized and openly discussed.

A number of studies have examined the priority differences of parents and professionals. In the research by Gadman, Goldsmith and Bashim (1984), parents and clinicians were asked to rate the importance of seven areas including normal functioning, mobility, communication, mood/behavior, independence in self-care, cognition, and family-child interaction, after receiving the descriptions of the functional abilities and limitations of certain children. Results indicated that professionals were different from parents in the ratings of mobility and mood/behavior. While clinicians rated mood/behavior as most important, parents rated mobility as most important. Blackard and Barsh (1982) compared the responses of parents and professionals on the perceptions of the handicapped child's impact on the family in examining the extent professions are able to accurately predict parents' responses to the questionnaire. Researchers found that overall, professionals were more likely to predict a more negative impact on the family than parents did. They overestimated the extent to which parents reported restriction of home activity because of handicapped children and rejection by the community and lack of support. On the other hand, they underestimated the parents' ability of using appropriate teaching methods and behavior management techniques.

A number of studies examined the parents' participation in the IEP conferences and investigated the cooperation between parents and professionals (Salett & Henderson, 1980; Goldstein, Strickland, Turnbull, & Curry, 1980; McKinney & Hocutt, 1982; Gilliam & Coleman, 1981; Lynch & Stein, 1982). In an early study, Goldstein and others (1980) observed 14 IEP conferences and learned that none of the 14 observed conferences was attended by both of the parents of the students. Parents were the primary recipients of the statements made in the conferences (63% of statements), and resource teachers were the dominant speakers who talked most at 11 out of 14 conferences. Results also found that the IEP had been written primarily by the resource teachers prior to the conferences. In the survey of 2,500 parents in 46 states, Salett and Henderson (1980) found that fifty-two percent (52%) of the parents reported that IEP's had been completed prior to the conferences and forty-five percent (45%) of the parents indicated that annual goals were not appropriate to meet the child's needs. McKinney and Hocutt (1982) interviewed 32 parents to examine their involvement and implementation in their child's IEP. Results indicated that forty three (43%) of parents reported that they did not participate completely in the IEP development. In a large study, Lynch and Stein (1982) surveyed 400 parents by using a 64-item questionnaire and found that seventy-one percent of parents reported participation in IEP development. Among them, only about fourteen percent (14.6 %) of parents reported they had expressed opinions and gave suggestions, and only six percent (6.3 %) of parents reported they understood everything involved.

In reviewing the research on parent participation in IEP conferences, Turnbull and Turnbull (1986) concluded that: "On the whole, parents can be characterized as passive participants in IEP conferences." In the analysis of barriers to parent participation, research showed there were differences identified by parents and by teachers (Turnbull & Turnbull, 1986; Lynch & Stein, 1982; U. S. Department of Education, 1984). Turnbull and Turnbull summarized that parents identified barriers as feelings of inferiority, communication problems, logistical problems, lack of understanding of the school system, and uncertainty about their children's disabilities and the ways they can help; while teachers identified barriers as parents' lack of time, energy, and understanding, parent apathy, and the devaluation of parent input by the school personnel (Turnbull & Turnbull, 1986).

Social support

The birth of disabled infants brings additional burdens and unique problems to the families, and such problems have been well documented in the literature (Wilton, Renaut, 1986; Friedrich & Friedrich, 1981; Roos, 1985; Marcus, 1987; Yura, 1987; Turnbull & Turnbull, 1986; Wilgosh, 1990). Many studies have examined the stress on the family resulting from the presence of the disabled children (Price-Bonham and Addison, 1978; Wilton & Renaut, 1986; Friedrich and

Friedrich, 1981; Dyson & Fewell 1989; Gath,1977; Featherstone,1980).

Wilton and Renaut compared the stress level of 42 mothers with preschool children who were intellectually handicapped (moderately and severely retarded) and 42 mothers of nonhandicapped preschool children. Results showed that mothers of intellectually handicapped children scored significantly higher stress levels than mothers of nonhandicapped children on 13 out of 15 subscales in Questionnaire on Resources and Stress.

Dyson and Fewell (1989) investigated the stress and adaptation of parents with disabled children and nonhandicapped children. Fifteen families with disabled children were compared to 15 families with nonhandicapped children. The results suggested a significant difference between the two groups. Parents of preschool-aged handicapped children exhibited a high level of stress. Friedrich and Friedrich (1981) compared parents of 34 handicapped children with parents of 34 nonhandicapped children on a variety of psychosocial assets. Results showed a significant difference, indicating that parents of handicapped children experience more stress and less marital satisfaction, psychological well being, social support, and religiosity. Also, Friedrich and Friedrich believed that parents of infants and preschool children experienced more stress in comparison with parents whose children's mean age is 9 years old in the study.

Many studies focused on the marital conflict caused by the presence of the handicapped children (Price-Bonham & Addison, 1980; Gath, 1977; Friedrich & Friedrich, 1981). In their literature review, Price-Bonham and Addison (1980) found increased divorce and suicide rate among parents with handicapped children. Gath's study (1977) showed that a higher rate of marital breakdown was found for parents with infants with Down's syndrome. Bristol (1987) examined the adaptation of mothers of children with autism or communication disorders to their handicapped children. The findings strongly supported the hypothesis that healthy family adaptation would be positively predicted by greater family cohesion, greater adequacy of informal and formal support regarding the handicapped child, and more adequate coping patterns. The results also showed that mothers who had more adequate support from spouses, immediate and extended family, and other parents, reported happier marriages, and were rated by interviewers as having better family adaptation.

Psychological adaptation is another problem that families with handicapped children face. Several studies have focused on the reactions of parents to the birth of the handicapped children (Gallagher, Beckman, & Cross, 1983; Featherstone, 1980; Yura, 1987; Roos, 1985; Wilgosh, 1990; Lynch, 1981; Simons, 1985). Roos (1985) described the major psychological stress that most parents of handicapped children experienced, as loss of self-esteem, shame, ambivalence, self-sacrifice, and defensiveness. Other problems found in the families of handicapped children are fatigue (Marcus, 1987; Featherstone, 1980), child abuse (Gath, 1972; Gaines, Sandground, Green, & Power, 1978), lower-self-esteem (Cummings, 1976; Yura, 1987), and financial difficulty (Richards and McIntosh, 1973; Turnbull & Turnbull, 1986). Lynch (1981) described the problems that parents of handicapped children suffered as child care problems, lack of time, and communication problems. Therefore, in comparison with the parents of normal children, parents of handicapped children experience more stress and less psychological well-being, which indicate the significant importance of social support to the families with handicapped children.

Social support can be defined from a number of different perspectives. Sarason, I., Levine, Basham, and Sarason, B. (1983) define social support as the "existence or availability of people on whom we can rely, people who let us know that they care about, value, and love us" (p. 127). Cohen and Wills (1985) and others described it as having a number of dimensions, such as information provision, instrumental assistance, understanding and emotional empathy (Cohen & Wills 1985; Thoits, 1986; Dunst, Trivette, & Cross, 1986). Turnbull & Turnbull (1986) considered social support as the "assistance one can get from extended families, friends, co-workers and others in the community" (p.315).

Bronfenbrener (1979) considered social support on a variety of ecological levels, such as; support from spouses, friends, relatives, professionals, and parents of other handicapped children (Gallagher, et al. 1983; Segal, 1985). The following literature review uses such ecological perspectives:

1. Support from spouses

A number of studies have investigated the importance of satisfactory marital relationships in the families with handicapped children (Friedrich, Wilturner, & Cohen 1985; German & Maisto, 1982; Brower & Wright, 1986). In the classic study, Holroyd (1974) compared the stress experienced by mothers and fathers of handicapped children by using a 285-item questionnaire. The sample consisted of mothers of mentally retarded children, mothers of emotionally disturbed children, mothers living with husbands, and mothers living alone. According to the results, Holroyd concluded that mothers who do not have a husband sharing in child care see themselves as having too many demands on their time resulting stifled personal development. German and Maisto (1982) examined the relationship of a perceived family support system to the institutional placement of mentally retarded children. One hundred and twelve families were randomly selected and interviewed. The studies found that the presence of both parents in the home is an important reason to allow the family to maintain the mentally retarded child in the home. In this study, over one-half of the residential children came from single parent families. Brower and Wright (1986) interviewed eight families with handicapped children. These families varied in their socio-economic, educational, professional, and religious backgrounds. When they were asked what they felt their husband or wife had done to offer support, many of the parents answered that their spouses always provided emotional support or had been a quiet support, and was always positive and wanted to know what could be done to help. However, the study also found that there was an urgent need to increase communication or more effective communication for the couples of the handicapped children (Brower & Wright, 1986).

The parents maintained that a satisfactory marital relationship was crucial to the adaptation to their disabled children. However, several studies have shown that mothers of handicapped children bore the main burden in the families (Wilson, 1982; Cooke & Lawton, 1984; Darling, 1979; Holroyd, 1974). In the early study, Darling (1979) suggested that mothers tend to spend more time with their children. In a large follow up study, Cooke and Lawton (1984) analyzed the fathers' participation in child care and house work. Based on the results, the researchers maintained that mothers of handicapped children shoulder the major burden in the family and there is no evidence to suggest that large numbers of fathers were participants in domestic life. Holroyd's study also found that mothers of handicapped children experienced more time demands and less opportunity for personal freedom than their husbands (Holroyd, 1974). Thus, Wilson (1982) suggested that caution should be taken when considering the assumptions about the extent to which care is shared within families and about the contribution of support from the community. In practice, she maintained that for "community" we should read "family" and for "family" read "mothers."

2. Support from relatives, friends and neighbors

Many studies have shown that support from relatives, friends, and neighbors is important for the families with handicapped children (German & Maisto, 1982; Schell, 1981; Cooke & Lawton, 1984; Carey, 1982). German and Maisto's study (1982) showed a significant difference among three groups of mentally retarded children (such as mentally retarded children living at home versus mentally retarded children living with respite care versus mentally retarded children living in residential) in respect to support from grandparents. The results indicated that support from relatives to the maintenance of the disabled children at home was important. However, other studies have shown that support from these sources was infrequent and negligible (Carey, 1982; Cooke & Lawton, 1984). In Cooke & Lawton's study, the results indicated that only a minority of the severely disabled children groups received help from relatives, friends, or neighbors, although some evidence suggested that the parents of more severely handicapped children received support from these sources more frequently. In the study of families with mentally retarded children, Wilkin (1979) found families with handicapped children do not generally receive support from relatives, friends and neighbors in their day to day life. Relatives, friends and neighbors only contributed to the families at the times of crisis.

3. Support from professionals

Support from professionals refers to formal support. Professionals are one of the important sources of support for parents of handicapped children and meet their special needs, particularly at the initial time of diagnosis. Parents need emotional support from professionals to help them deal well with personal and family stresses (Wilgosh, 1990).

Several studies have emphasized the role of physicians or other medical persons in providing support for the families with handicapped children (Wilgosh, 1990; Lynch & Staloch, 1988; Iowa State Department of Public Instruction and others, 1988). The recognition of the child's disability resulted in parents seeking help from medical personnel, physical therapists, occupational therapists, audiologists or others (Iowa State Department of Public Instruction and others, 1988). During such searching periods, physicians were usually the first persons that many of parents contacted, according to Wilgosh (1990). In the study by Iowa State Department of Public Instruction and others (1988), when parents were asked how they got information about their children's disabilities or services available for their children, more than sixty percent of parents responded that they received information from physicians, nurses, or other medical personnel. Similarly, O'Connell and others (1989) found that parents reported the medical doctor as the major sources of their children's needs. Darling (1979) also emphasize the importance of physicians and pediatricians during this period.

McDavis, Nutter, and Lovett (1982) investigated the counseling needs of handicapped students and their parents. Thirty students and thirty parents of handicapped students responded to the surveys. Results of this study showed that physicians, relatives, and spouses were the most helpful sources in providing assistance to the parents of handicapped students during their initial adjustment period. However, all of the parents in this study reported that it was difficult for them to find assistance from any sources when they were first informed of their children's disabilities. They also highlighted the importance of receiving care and support from any person. Despite the significance of support from professionals, several studies indicate that the relationship of parents and professionals was not overwhelmingly positive. In a large study, Baxer

(1987) interviewed 131 mothers and fathers of intellectually disabled children or adults to determine the function of social support of professional services. The results showed that most of the interviewees had received no help from the professional services, although a majority of parents (at least 90%) indicated such help was very important. Based on his study, Wilgosh (1990) also wrote that parents needed help from qualified professionals, and such professionals should maintain sensitivity and knowledge of parents and their children's needs.

Other studies also found that parents have often been blamed and criticized by professionals for certain reasons (Gallagher & Gallagher, 1985; Marcus, 1977; Darling, 1979; Turnbull & Turnbull, 1985). Such findings indicate that the interaction between parents and professionals needs to be improved.

4. Support from other parents of disabled children

Another significant resource providing assistance to parents of handicapped children is other parents of disabled children. A number of studies have emphasized the importance of this kind of support (Skillings & Pheeny, 1984; Holland & Hattersley, 1980; Gage & Wishon 1988; Segal 1985; Polirstok & Hurwitz, 1984; Naseef 1989). As Skillings (1984) stated : "The strongest support by far comes from people like ourselves - other parents of handicapped children. 'They have know-how, experience, and serve as role models.' We look to them for knowledge of community resources, coping skills, and the understanding which seems to come only from "those who have been there.'" Segal (1985) interviewed twenty parents of children with handicap in a parent-support group and investigated their sources of support. Other mothers of handicapped children were described as one source of support by all the parents in the study, while grandparents and spouses were seldom mentioned. In Naseef's case study (1989), parents of seven functional families also found that other parents of handicapped children were significantly helpful to them. One father stated that:

> For most people who have not gone through this, the situations are too horrible to talk about. They think about their own children and how horrible it would be to for them ... The only people you can really talk to about this are people who have been through this. (p. 10)

Since the early 1980s, the development of family support programs has become a major movement (Gage & Wishon, 1988). In their study, Gage and Wishon described the major areas of assistance of most parent-support groups.

The areas included:

1. providing emotional and psychological support
2. offering opportunities for families to socialize
3. providing information about community resources, educational opportunities, legal rights, etc.

4. serving as activists and advocates on behalf of special needs children
5. improving community attitudes toward children with handicaps
6. supporting research about various handicapping conditions. (p. 51)

In their study, Holland and Hattersley (1980) maintained that the group provided regular contact between parents and professionals. In Segal's study mentioned earlier, thirteen out of twenty parents in the study described the parent support group as their most important resources (Segal, 1985).

SUMMARY

Chinese literature

The culture of China has attached great importance to how a child's success or failure reflects upon the parents and the rest of the family. Parents have responded to this pressure by overprotecting their children, abandoning the parental role to others, dominating their children, or by establishing a democratic family style. Chinese parents of disabled children have been faced with the prospects of being considered a failure and of trying to explain the disability to themselves and others.

Several reported patterns of parental attitude toward their children with disabilities appeared to exist:

refusal to accept the disability, blaming others, concealment, uncertainty and ignorance, feelings of guilt, depression, shame, self sacrifice, and positive collaboration with professionals. Descriptions of the attitudes of parents with mentally retarded children toward special education were complicated. They were related to several factors; such as occupations of parents, economic status of the family, severity of the level of the disabled, and educational level of the parents.

The history of special education in China has been short. Schools for deaf and blind have existed for more than a century. Programs for mentally retarded, as recognized by the international community, have existed for only about a dozen years. Recent Chinese legislation has closely paralleled American legislation. Judicial, financial, and personnel training support has lagged far behind legislation. This review found a wide variety of educational, rehabilitative, vocational, and community programs developing at a dramatic pace in urban China. The customary close connection between family and school in China seemed to apply to active collaboration between parents and school programs for special education.

American literature

American families expressed many needs for information, ranging from legal rights to estate planning. Parents reported a lack of information special education laws, available services and how the disability would affect their child. Active participation in educational planning was reported to be low.

Programs to train parents to assist in educational intervention was reported to be very desirable for all concerned. However, studies found many parents wishing for such training.

Financial hardship was reported as a need for the following: equipment, respite care, medical treatment, therapy, and other supportive services. In addition, the availability of services were a concern.

Parents of disabled children reported an usually high need for the support of spouses, relatives, friends, and neighbors, professionals, and other parents of disabled children.

Questions

The review suggested certain questions:

1. How would Chinese parents rate their needs for parent training, financial assistance, understanding by the community, respite care, understanding the cause of the disability, medical care, collaboration with teachers, and information?

2. How would American parents rate their needs for parent training, financial assistance,understanding by the community, respite care, understanding the cause of the disability, medical care, collaboration with

teachers, and information?

3. How would the rating of needs by Chinese parents compare to the rating of needs by American parents?

CHAPTER III

Methodology

Sample

The sample in this study includes seventy two parents with mentally retarded children. The 72 parents were composed of 45 Chinese parents and 28 American parents. The parents were sought using the procedures listed below.

Procedure

1. Chinese parents

Twenty six questionnaires were mailed to twenty six colleagues of the author. Each colleague and the author had attended a personnel training program at Beijing Normal University in 1988. The twenty six colleagues were located in twenty three provinces in China.

An attached invitation letter was distributed to each colleague. In the letter, the author asked each colleague if she/he had access to parents of mentally retarded children and, if so, to randomly select up to twelve of the parents of mentally retarded children and ask them to participate in the survey. If a parent wished to participate, the colleague was asked to make a copy of the questionnaire for the parent's response.

Six colleagues had direct contact with parents of mentally retarded students and were able to accept the invitation. A maximum of seventy two questionnaires was distributed to the parents of the mentally retarded students in China. The six correspondents did not report that any of the selected parents failed to return the questionnaire so it's likely that less than sixty questionnaires were actually distributed.

Forty six questionnaires were returned. One of the responses was eliminated because of incomplete answers. The 45 returned parental need questionnaires came from six cities around China, which is shown in Table I.

Table I

City Distribution of Returned Questionnaires in China

Name of City	Number of Return	Number Used
Beijing	9	9
Zhenzhou	6	6
Yingkou	3	3
Changchun	10	10
Guizhou	6	5
Xian	12	12
Total	46	45

2. American parents

Three ways were used to distribute questionnaires in English:

1. Fifty copies of The Parent Survey were directly mailed to parents of the mentally retarded children by the Greater Omaha Association for the Retarded Citizens (GOARC). GOARC randomly selected those parents from the GOARC mailing list. A cover letter was attached by the executive director of GOARC, which invited parents to fill in the survey questionnaire and to mail it back to the author directly. Nineteen questionnaires were returned.

2. In one of the parent training workshops held by the Nebraska Parents Information and Training Center, the trainer distributed six copies of the questionnaires to six parents with mentally retarded children. Six responses were returned.

3. In one special education class at University of Nebraska at Omaha, the instructor announced that a graduate student needed help to finish his thesis, which concerned needs of parents of disabled children and that parents of mentally retarded children were eligible to answer the survey. Three students in the class requested a copy of the questionnaire because they knew parents who would like to participate. Three parents of mentally retarded children responded with completed questionnaires.

Instrument development

A Parent Need Survey in Chinese (Appendix A) and a Parent Need Survey in English (Appendix B) were used in this study. The Parent Need Survey in Chinese was used with parents with mentally retarded children in China, and the Parent Need Survey in English was used with American parents with mentally retarded children.

1. Development of the Parent Need Survey in Chinese

The development of the Chinese parents' need survey followed five steps.

Step 1. Based on the experiences of working with parents of the disabled children in China and a review of literature on parents' needs, the author listed basic concerns of parents with disabled children.

Step 2. In one special education class at the University of Nebraska at Omaha, thirty students who were working with parents with disabled children were asked to list the needs being expressed by the parents. The list was coalesced into thirteen categories which corresponded to the needs identified in the literature. The categories included academic improvement, vocational training, financial help, social skill development, parent's group support, physical or occupation therapy, service need, communication skill, family counseling, collaboration between parents and school, legal assistance, independent living, and equipment needs.

Step 3. An initial questionnaire was developed which included the topics from a Chinese perspective.

Step 4. The initial questionnaire was sent for review to three very prominent Chinese professionals in special education: Long Qing Zu, Director, Special Education Division, State Education Commission of China, Beijing; Tang Sheng Qing, Director of Special Education, East China Normal University, Shanhai; and Chen Yung Ying, Director, Special Education Division, Central Education and Research Institute of China, Beijing.

Step 5. Responding to comments and suggestions of the selected prominent Chinese professionals in special education, a final version was constructed. The questionnaire consisted of three sections: nine close ended questions, one open ended question, and comments. Before filling out the survey, parents were asked to supply background information about themselves and their children to include: the child's age, sex, and school and the parents' age, vocation, and education level.

The close ended question section in the survey was composed of nine items. In the first eight, parents were asked to rank, on a five point scale from extreme to none, needs in the areas of information, training, services, medical treatment, support, financial assistance, collaboration, and information about the cause of the disability. Item nine listed four statements expressing parents' highest hope for their children and the parents were asked to choose one.

The open ended question asked parents to list the five most important needs of their families. The instructions suggested that the most important needs of the family could be different from those listed in the close ended question section. At the very end of survey, parents were asked to freely express any comments and/or suggestions.

3. Development of the Parent Need Survey in English

The development of American parents' need survey followed two steps.

Step 1. The Chinese questionnaire was translated to English with only minor adaptations to fit American expressions.

Step 2. Using the first revised questionnaire, the author sought feedback from two professors in the Department of Special Education and Communication Disorders, University of Nebraska at Omaha. Both professors made comments and suggestions on the questionnaire. In light of the suggestions, the questionnaire was revised a second time. Also during the revision, the author interviewed three parents with disabled children at the Nebraska Parents Information and Training Center. Using their suggestions, the survey was revised a third time and finally developed into The Parent Need Survey (Appendix B). The final survey consists of closed-ended questions and open-ended questions.

The eighth question was significantly modified. In the Chinese version, question eight related to needing specific help, such as hearing aids, obtaining child care services, and more time for the parents to themselves. Question eight in the American version referred to general information about the disability. Question eight was not included in the comparative analysis between Chinese parents and American parents.

Question nine was also modified. In the Chinese survey, it provided four options for the parents to choose, They were: a. graduating from school, b. being able to find a job in the future, c. independent living: getting married, living independent by themselves without care from family members, and d. gaining acceptance by the community. In the American survey, this item was composed of five choices in order to meet American culture. Choice d., "gaining acceptance by the community" was divided into two parts: (d) being accepted in the community while living at home with the family and (e) living outside our home with support from the community. The American choice "e." was very much the same as the Chinese choice "d."

To adapt to American culture, the questions concerning information about parents and their children were adjusted appropriately. Information requested included the child's age, sex, type of classroom, and grade in school; whether the questionnaire was answered by the father or the mother of the child; and the highest grade completed by the father or mother. Questions about parental age and occupation were not included in the American version.

Description of the sample

1. Parents with mentally retarded children in China

The forty five sets of parents were from six different provinces in China. Information was supplied about both mother and father without designation of which person actually completed the questionnaire. The mothers' average age was 39.80 years and the age range was 31-53. The father's average age was 41.6 and the age range was 33-55. Among the 45 mentally retarded students, twenty seven were boys and eighteen were girls. Their average age was 10.13 years old and age range was 8-17.

Among 45 fathers and 45 mothers, five mothers (11.1%) and four fathers (8.89%) graduated from primary school. Thirty three mothers (73.3%) and thirty one fathers (68.9%) finished middle school. Four mothers (8.89%) and eight fathers (17.8%) received higher education. Three mothers (6.67%) and two fathers (4.44%) did not receive any education. The average grade completed by the mothers was 9.76 and the fathers' average grade completed was 10.51. The average educational level of forty five parents was 10.13 grade.

2. Parents with mentally retarded children in America

In the returned twenty eight surveys, twenty seven were answered by mothers and one was answered by the father. The average educational level of the parents was 13.77 grade and the standard deviation of the educational level was 1.80. Among twenty eight mentally retarded children, eighteen were males and ten were females. Their average age was 10.15 years old and the age range was 14.50. Six of them (22%) were placed in a resource room; nine (32%) were placed in self-contained classrooms; and thirteen students (46%) received education in regular classrooms. Seventeen of the children (60%) were in primary school; ten (36%) were in intermediate and one (4%) was in junior high.

CHAPTER

Results

Results from the questionnaires returned by Chinese and American parents were tabulated and analyzed. This chapter displays and discusses the results in responses from 45 Chinese and 28 Americans. In each of the seven compared closed questions, the percentages of responses in each category of described need, the mean averages, and the ranking of the mean averages were inspected for the Chinese parents and the American parents. The responses and rankings of the Chinese parents were compared with the responses and rankings of the American parents with combined data tables and a test for significant differences of means.

Chinese and American parent ranking of future hopes for their children were tabulated. The ranking by Chinese and American parents were displayed together.

Responses to the open ended request for parents to identify the five highest priorities of need were tabulated, categorized, displayed and compared to the rank order of mean averages by Chinese parents, by American parents, and between Chinese and American parents. Chinese parents responded with 203 priorities that were categorized into 14 topics. American parents responded with 112 priorities that were categorized into 14 topics. Results were displayed in the following tables:

1. Table II

A majority (64.4%) of Chinese parents indicated an extreme need for parent training. Nearly nine percent (8.9%) indicated an above average need, 26.7% indicated average need, and not one Chinese parent indicated below average or no need for parent training (See Table II).

No strong feelings appeared among Chinese parents in the area of financial need. Indicated was: 15.6% extreme need, 11.1% above average need, 26.7% average need, 15.6, below average, and 31.1% no need. That was nearly one third indicating no need contrasted with only 15.6% feeling an extreme need. Average need for community understanding was indicated by 42.2% of Chinese parents. Indicated was only: 22.2% extreme need, 13.3%, above average need, and 8.9% below average need. Thirteen percent (13.3%) suggested they had no need for understanding by the community.

A full sixty percent (60.0%) of Chinese parents saw no need for respite care. The remaining percentages were: 20.0% had extreme need, 8.9% had above average need, and 8.9% had below average need.

More than half (51.1%) of the Chinese parents felt an extreme need to know about the cause of the mental retardation. Another 37.8% felt only average need and 6.7% felt above average need. Only 2.2% of the Chinese parents felt no need to know about the cause of the mental retardation.

Medical care was labeled an extreme need by 64.4% of the Chinese parents. The remaining percentages were: 0.0% had above average need; 28.9% had average need; 0.0% had below average need; and 6.7% had no need for medical services.

Table II

Percentages of Indicated Need[*]

by Chinese Parents

N = 45

Question	5	4	3	2	1
Parent Training	64.4	8.9	26.7	0.0	0.0
Financial Assistance	15.6	11.1	26.7	15.6	31.1
Understanding by Community	22.2	13.3	42.2	8.9	13.3
Respite Care	20.0	2.2	8.9	8.9	60.0
Understanding Cause	51.1	6.7	37.8	2.2	2.2
Medical Care	64.4	0.0	28.9	0.0	6.7
Collaboration with Teachers	60.0	4.4	35.6	0.0	0.0

[*] Extreme Need = 5, Above Average Need = 4, Average Need = 3, Below Average Need = 2, and No Need = 1

An extreme need for collaboration with teachers was indicated by sixty (60.0%) of Chinese parents. More than on third (35.6%) felt average need and 4.4% felt above average need. No Chinese parent marked below average need or no need for collaboration with teachers.

Table III

Percentages of Indicated Need*

by American Parents

N = 28

QUESTION	5	4	3	2	1
Parent Training	14.3	28.6	39.2	3.6	14.3
Financial Assistance	3.6	17.9	32.1	17.9	28.6
Understanding by Community	25.0	39.3	21.4	3.6	10.7
Respite Care	25.0	7.1	28.6	7.14	32.1
Understanding Cause	14.3	10.7	32.1	21.4	21.4
Medical Care	17.9	14.3	28.6	7.10	25.0
Collaboration with Teachers	14.3	25.0	32.1	10.7	17.9

* Extreme Need = 5, Above Average Need = 4, Average Need = 3, Below Average Need = 2, and No Need = 1

2. Table III

In the area of parent training, more than one third of American parents (39.2%) indicated average need. Nearly twenty eight percent of American parents reported above average need. An equal percentage of parents (14.3%) indicated extreme need and no need. Only about three percent of American parents (3.6%) showed below average need (See Table III).

More than one fourth (28.6%) of American parents expressed no need for financial assistance. Over one third of the respondents (32.1%) reported average need. The remaining indicated: 3.6 % extreme need, 17.9 % above average need, and 17.9 % below average need.

American parents showed relatively high concern in the area of understanding by the community. Twenty five percent (25.0%) of American parents indicated extreme need, over thirty nine percent (39.3%) of parents saw above average need, and twenty one percent (21.4%) of them indicated average need. Only three percent (3.6%) and ten percent (10.7%) of American parents expressed below average need and ten percent (10.7%) of American parents expressed no need for understanding by the community.

Although twenty five percent (25.0%) of American parents showed extreme need in the area of respite care, nearly one third (32.1%) indicated no need. Other levels indicated by American parents were: 7.1% of above average, 28.6% average, and 7.14% below average need for respite care.

The three highest percentages indicated by American parents in the need for understanding the cause ot mental retardation were: 32.% extreme need, 21.4% below average, and 21.4% no need. The remaining percentages were: 14.3% extreme need, and 10.7% above average.

No strong need appeared in the area of medical care. Nearly one third of American parents (28.6%) felt average need and twenty five percent (25%) of American parents indicated no need. The remaining need levels were: 17.9% extreme need, 14.3% above average, and 7.1% below average need.

The responses in the area of collaboration with teachers were somewhat even. Indicated was: 14.3% extreme need, 25.0% above average need, 32.1% average need, 10.7% below average need, and 17.9% no need.

3. Table IV

Highlights of the comparison between the response of Chinese parent sample and the American sample indicated certain differences. An overall inspection of the results suggested a concentrated response by Chinese parents in some cases as contrasted with a more even distribution across choices by American parents.

Table IV

Comparison of Chinese and American (USA) Percentages of Indicated Need[*]

QUESTION Chinese Responses N = 45 American Responses N = 28	5	4	3	2	1
Parent Training - China	64.4	8.9	26.7	0.0	0.0
Parent Training - USA	14.3	28.6	39.2	3.6	14.3
Financial Assistance - China	15.6	11.1	26.7	15.6	31.1
Financial Assistance - USA	3.6	17.9	32.1	17.9	28.6
Understanding by Community - China	22.2	13.3	42.2	8.9	13.3
Understanding by Community - USA	25.0	39.3	21.4	3.6	10.7
Respite Care - China	20.0	2.2	8.9	8.9	60.0
Respite Care - USA	25.0	7.1	28.6	7.14	32.1
Understanding Cause - China	51.1	6.7	37.8	2.2	2.2
Understanding Cause - USA	14.3	10.7	32.1	21.4	21.4
Medical Care - China	64.4	0.0	28.9	0.0	6.7
Medical Care - USA	17.9	14.3	28.6	7.10	25.0
Collaboration with Teachers - China	60.0	4.4	35.6	0.0	0.0
Collaboration with Teachers - USA	14.3	25.0	32.1	10.7	17.9

[*] Extreme Need = 5, Above Average Need = 4, Average Need = 3, Below Average Need = 2, and No Need = 1

Although a majority (64.4%) of Chinese parents showed an extreme need in the area of parent training, only fourteen percent (14.3%) of American parents felt an extreme need. No Chinese parents indicated below average or no need, while over three percent (3.6%) and fourteen percent (14%) of American parents reported in the two levels.

More than fifteen percent of Chinese parents (15.6%) indicated extreme need for financial assistance, contrasted with only three percent (3.6%) of American parents who felt extreme need. It appeared that Chinese parents showed more concern in the area of financial assistance than American parents (See Table IV). American parents expressed more strong feeling for understanding by the community than Chinese parents. Although almost the same percent of Chinese parents (22.2%) and American parents (25.0%) indicated extreme need in this area, nearly forty percent (39.3%) of American parents showed above average need, contrasted with thirteen percent of Chinese parents.

A majority of Chinese parents (60.0%) indicated no need for respite care, while thirty two percent (32%) of American parents expressed such feeling. This finding suggested that American parents had more concern in the area of respite care.

In the area of understanding the cause of mental retardation, over half of Chinese parents (51.1%) indicated extreme need, contrasted with fourteen percent (14.3) of American parents. A very few Chinese parents did not feel high concern in this area (2.2% below average, 2.2% no need), while more than twenty percent of American parents indicated below average or no need (21.4% below average and 21.4% no need).

In comparison with American parents, Chinese parents reported higher concern for medical care. More than sixty percent (64.4%) of Chinese parents indicated extreme need in this area while only about eighteen percent (17.9%) of American parents showed the same level need. On the other hand, a little over six percent (6.7%) of Chinese parents felt no need for medical care, contrasted with one fourth (25.0%) of American parents.

Collaboration with teachers is another high concern for Chinese parents. A full sixty percent (60.0%) of Chinese parents felt extreme need for collaboration, while only fourteen percent (14.3%) of American parents expressed the same feeling.

Table V

Chinese Mean Averages of Indicated Need*

N = 45

Question	$\overline{x}$	SD
Parent Training	4.38	0.88
Collaboration with Teachers	4.29	0.93
Medical Care	4.16	1.23
Understanding Cause	4.02	1.09
Understanding by Community	3.22	1.26
Financial Assistance	2.64	1.42
Respite Care	2.04	1.55

* Extreme Need = 5, Above Average Need = 4, Average Need = 3, Below Average Need = 2, and No Need = 1

4. Table V

The mean response value by Chinese parents to each compared question was arranged from the highest to the lowest. The range was from a high of 4.38 to a low of 2.04. The order from the highest to lowest was: parent training, collaboration with teachers, medical care, understanding cause, understanding by community, financial assistance, and respite care.

Table VI

<u>Mean Averages of Indicated Need</u>[*]

<u>by American Parents</u>

N = 28

QUESTION	$\overline{x}$	SD
Understanding by Community	3.64	1.20
Collaboration with Teachers	3.07	1.28
Parent Training	3.05	1.18
Respite Care	2.89	1.52
Medical Care	2.79	1.47
Financial Assistance	2.50	1.18
Understanding Cause	2.05	1.30

[*] Extreme Need = 5, Above Average Need = 4, Average Need = 3, Below Average Need = 2, and No Need = 1

5. Table VI

The mean average and rank order by American parents to each question was illustrated in the Table VI. The mean average from the highest to lowest were 3.64 to 2.05. The order arrangement for highest to lowest were: understanding by community, collaboration with teachers, parent training, respite care, financial assistance, and understanding the cause of mental retardation.

Table VII

Highest Priority of Need Indicated by Chinese Parents

Compared to Rank Order Mean** in Closed Questions

Response	Total Raw Score*	Raw Rank	Mean Rank**
Medical Care**	69	1	3
Good Educational Program	67	2	-
Parent Training**	66	3	1
Collaboration with Teachers**	57	4	2
Finding a job	54	5	-
Hope for Future	47	6	-
Understanding by Community**	41	7	5
Graduation from School	31	8	-
Understanding Cause**	28	9	4
More Community Services	26	10	-
Social Support	24	11	-
Financial Assistance**	17	12	6
More Time for Self	12	13	-
Transportation	5	14	-

* Raw Score = 5 points for each highest ranking, 4 points for each next highest ranking, 3 points for each middle ranking, 2 points for each next to lowest ranking, and 1 point for each lowest ranking.

** From Table V

6. Table VII

As shown in the Table VII, Chinese parents reported concerns in the open ended question that were not included in the closed questions. Besides the seven areas in the closed questions, Chinese parents expressed an additional eight areas of concerns. They were: good educational programs for their children, their children finding a job, hopeful expectations for their children in the future, their children graduating from school, more community service for their children, more time for themselves, and transportation for their children.

Moreover, some of the additional concerns were rated very high by Chinese parents. Good educational programs for their children, their children finding a job, and expectations for their child's future were rated in the top six highest concerns by Chinese parents.

Chinese parents also expressed certain concerns in both closed questions and the open ended question. Overlapping topics of similar concern in both the closed question and open ended sections were: medical care (first in open ended and third in closed), parent training (third in open ended and first in closed), collaboration with teachers (fourth in open ended and second in closed), understanding by the community (seventh in open ended and fifth in closed), understanding the cause of mental retardation (ninth in open ended and fourth in closed), and financial assistance (sixth in open ended and twelfth in closed).

While similarity appeared in the rank order of the concerns on medical care, parent training, collaboration, community understanding, and the cause; large differences appeared between the areas of understanding the cause of mental retardation and of financial assistance. In the closed question section, understanding the cause of mental retardation was rated fourth, while it was rated number ninth in the open ended question. Financial assistance was marked sixth among the closed questions, contrasted with twelfth in the open ended question. Respite Care was not included by Chinese parents as a concern in the open ended question.

7. Table VIII

As with Chinese parents, American parents expressed more concerns in the open ended question. They provided eight additional parental concerns besides the areas listed in the close end question. These eight concerns were: social support, information about mental retardation, more community services, employment for their children, good education program, transportation, more time for themselves, and friendship for their children. Social support and information about mental retardation were rated very high concern by American parents. Social support was ranked first, and information was ranked third in the open ended question.

Table VIII
Highest Priority of Need Indicated by American Parents
Compared to Rank Order Mean** in Closed Questions

Response	Total Raw Score*	Raw Rank	Mean Rank**
Social Support	97	1	-
Parent Training**	44	2	3
Information	42	3	-
Respite Care**	38	4	4
Financial Assistance**	26	5	6
Understanding by Community**	25	6	1
More Community Services	20	7	-
Medical Care**	16	8	5
Collaboration with Teachers**	14	9	2
Employment for Child	13	10	-
Good Educational Program	10	11	-
Transportation	8	12	-
More Time for Self	6	13	-
Friendship for Child	5	14	-

* Raw Score = 5 points for each highest ranking, 4 points for each next highest ranking, 3 points for each middle ranking, 2 points for each next to lowest ranking, and 1 point for each lowest ranking.

** From Table VI

American parents also reported some similar concerns in both closed and the open ended question. These concerns were parent training, respite care, financial assistance, understanding by community, medical care, and collaboration with teachers. Parent training was ranked second in the open ended question and third in closed questions. Respite care was ranked fourth in the open ended question and fourth, also, in the closed questions. Financial assistance was ranked fifth in the open ended question and sixth in closed questions. Financial assistance was ranked fifth in the open ended question and sixth in the closed questions. Such findings suggested that there were certain consistencies in the rank order between closed and open ended questions in the top nine categories on the open ended question (See Table VII).

There were certain differences in rank order of the two areas: understanding by community and collaboration with teachers. Understanding by community was rated sixth in the open ended question and first in the closed questions. Collaboration with teachers was ranked ninth in the open ended question and second in the closed questions. Understanding cause was not included.

Table IX

Parental Hope for the Future

Chinese Parents Hope for the Future of Their Child

N = 45

Choices	No.	%	Rank
a. Graduation from School	15	18%	3
b. Finding a Job	32	39%	1
c. Married, Living Independently	26	32%	2
d. Acceptance by Community	9	11%	4
Total Responses	82		

American Parents Hope for the Future of Their Child

N = 28

Choices	No.	%	Rank
a. Graduation from School	4	12%	4
b. Finding a Job	7	27%	2
c. Married and Raising Family	4	12%	4
d. Community Acceptance, Living at Home	6	18%	3
e. Community Acceptance, Ind. Living	12	36%	1
Total Responses	33		

8. Table IX

The ninth question in the questionnaire addressed the parent's greatest hope for their children's future. The percentages of responses and rank order by Chinese parents and American parents were shown in Table IX.

For Chinese parents, their highest expectation for their children future was finding a job. Nearly forty percent of Chinese parents (39%) selected this choice. This was followed by married and living independently choice (32%). The combination of the two top choices was 71%, leaving only 18% for graduation and 11% for community acceptance.

For American parents, their number one hope (36%) for their children was to be accepted by the community and living independently and their third choice was to be accepted by the community while living at home (18%) for a total of 54% of the parents showing concern for the independence of their child. Finding a job followed with 27% and graduation from school with 12%.

9. Table X

A comparison of the rank order based on the mean averages of indicated need by Chinese and American parents was made to display similarities and differences of expressed mean average need on Table X. The highest average mean for Chinese parents was for parent training. Parent training was third highest for American parents. Collaboration was second for both Chinese parents and American parents.

Table X

Comparison of Chinese and American Rank Order Based on Mean Averages of Indicated Need*

QUESTION Chinese Responses N = 45 American Responses N = 28	x	Rank Order
Parent Training - China	4.38	1
Parent Training - USA	3.05	3
Collaboration with Teachers - China	4.29	2
Collaboration with Teachers - USA	3.07	2
Medical Care - China	4.16	3
Medical Care - USA	2.79	5
Understanding Cause - China	4.02	4
Understanding Cause - USA	2.05	7
Understanding by Community - China	3.22	5
Understanding by Community - USA	3.64	1
Financial Assistance - China	2.64	6
Financial Assistance - USA	2.50	6
Respite Care - China	2.04	7
Respite Care - USA	2.89	4

* Extreme Need = 5, Above Average Need = 4, Average Need = 3, Below Average Need = 2, and No Need = 1

Medical care was ranked third in mean average by Chinese parents and fifth by American parents (See Table X).

The mean average differences were greater for the need for understanding the cause (fourth by Chinese and seventh by Americans) and the need for understanding by the community (fifth for Chinese and first for Americans). Both Chinese and Americans ranked the need for financial assistance at sixth. A disparity between mean averages appeared again on the need for respite care (seventh by Chinese and fourth by Americans).

10. Table XI

The mean average differences of need indicated by Chinese parents were compared to those of American parents by submitting the differences to a "t" test. They were arranged in Table X from the highest to the lowest result. They were: collaboration with teachers (4.62), parent training (4.59), understanding cause (4.45), medical care (4.23), respite care (-2.26), understanding by the community (-1.39), and financial assistance (0.44).

At .05 level of significance, results indicated that there was a significant difference between Chinese parents and American parents in the areas of parent training, understanding cause, medical care, collaboration with teachers, and respite care. There were no significant difference between Chinese parents and American parents in terms of financial assistance, understanding by the community.

Table XI

Comparison of Chinese and American Mean Averages of Indicated Need*

QUESTION

Chinese Responses N = 45

American Responses N = 28	$\bar{x}$	SD	Df	t
Collaboration with Teachers - China	4.29	0.93	71	4.62**
Collaboration with Teachers - USA	3.07	1.28		
Parent Training - China	4.38	0.88	71	4.59**
Parent Training - USA	3.05	1.18		
Understanding Cause - China	4.02	1.09	71	4.45**
Understanding Cause - USA	2.05	1.30		
Medical Care - China	4.16	1.23	71	4.23**
Medical Care- USA	2.79	1.47		
Respite Care - China	2.04	1.55	71	-2.26**
Respite Care- USA	2.89	1.52		
Understanding by Community - China	3.22	1.26	71	-1.39
Understanding by Community - USA	3.64	1.20		
Financial Assistance - China	2.64	1.42	71	0.44
Financial Assistance - USA	2.50	1.18		

* Extreme Need = 5, Above Average Need = 4, Average Need = 3, Below Average Need = 2, and No Need = 1

** Significant at the .05 level.

CHAPTER V

Summary

Questions

The specific research questions in this study were:

1. How would a sample of Chinese parents of mentally retarded children rate their needs for parent training, financial assistance, understanding by the community, respite care, understanding the cause of the disability, medical care, collaboration with teachers, and information?

2. How would a sample of American parents of mentally retarded children rate their needs for parent training, financial assistance, understanding by the community, respite care, understanding the cause of the disability, medical care, collaboration with teachers, and information?

3. How would the rating of needs by a sample of Chinese parents of mentally retarded children compare to the rating of needs by a sample of American parents of mentally retarded children?

To address the questions, seven statements of null hypotheses were made. Table XI in Chapter IV specifically tests each hypothesis and Table X provides additional insight for considering the hypotheses. Each hypothesis is repeated, results of statistical comparisons and inspected comparisons are described, and each hypothesis is rejected or accepted according to the results.

Hypotheses

1. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for parent training.

The results of the t-test comparison, as displayed in Table XI, showed a significant difference (4.59) at the .05 level of significance. The hypothesis was rejected. There was a significant difference. To further support the hypothesis rejection, results in Table X showed that the the highest average mean for Chinese parents was for parent training. Parent training was third highest for American parents.

2. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for financial assistance.

At the .05 level of significance, according to the results in Table XI ($t = 0.44$), the hypothesis was not rejected. This suggested that there was no significant difference in rating their needs for financial assistance between Chinese parents and American parents. This finding was supported by the results illustrated in

Table X, which showed that both Chinese and American parents rated the need for financial assistance as sixth.

3. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for understanding by the community.

According to the results shown in Table XI (t = 1.39), the hypothesis was not rejected at 0.05 level of significance. There was no significant difference between the two sample of parents.

4. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for respite care.

Based on the results of the t-test comparison, as showed in Table XI (t = 2.26), the hypothesis was rejected. There was a significant difference at .05 level of significance. This finding was also supported by the rank order rated by Chinese parents and American parents displayed in Table X. Chinese parents ranked the need in this area as the seventh highest while American parents rated it as the fourth.

5. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for understanding the cause of the disability.

At .05 level of significance, the results of the comparison study (t = 4.45, Table XI) suggested there was a significant difference in rating the needs for understanding the cause of the disability. The hypothesis was rejected (t=4.45, Table XI). To further support this finding, Table X showed that the mean average (4.02) of indicated need by Chinese parents in this area was much higher than the mean average (2.05) rated by American parents.

6. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for medical care.

The results of this study indicated that there was a significant difference in this area. The hypothesis was rejected at .05 level of significance (t = 4.23, Table XI). This results was supported by the mean average rated by Chinese parents and American parents. The finding in Table X showed that the mean average marked by Chinese parents was much higher than that by American parents (4.16 v. 2.79).

7. There is no significant difference in how a sample of Chinese parents and a sample of American parents of mentally retarded children would rate their needs for collaboration with teachers.

According to the results, at .05 level of significance, the hypothesis was rejected (t = 4.62). There was a significant difference in rating needs for collaboration with teachers between Chinese parents and American parents. The rejection of the hypothesis was not supported by the results displayed in Table X. The reason may be due to the concentration of Chinese parents' responses.

A comparison of the rank order based on the mean averages of indicated need by Chinese and American parents was made to display similarities and differences of expressed mean average need on Table X. Collaboration was second for both Chinese parents and American parents. Medical care was ranked third in mean average by Chinese parents and fifth by American parents.

The mean average differences were greater for the need for understanding the cause (fourth by Chinese and seventh by Americans) and the need for understanding by the community (fifth for Chinese and first for Americans). Both Chinese and Americans ranked the need for financial assistance at sixth. A disparity between mean averages appeared again on the need for respite care (seventh by Chinese and fourth by Americans).

Implications of results

Chinese parents of mentally retarded children reported a higher level of need than did American parents in the majority of the areas represented on the closed questions. This was particularly true in the areas of parent training and collaboration with teachers. Yet both groups put the areas at or near the top in the open response question. Inspection of the patterns of response showed that the percentage of Chinese parents who marked "extreme need" was much higher than the percentage of American parents. The responses of Chinese parents were more concentrated at extreme, average, and no need while the responses of American parents were more evenly divided across the five levels.

There may have been several reasons for the difference between Chinese and American response patterns. One significant reason could have been the difference in the status of special education between the two countries. Special education in China has existed for a shorter period of time. Most Chinese parents with disabled children knew little about disabilities. Under such conditions, many parents were frustrated and faced a major challenge for an appropriate education for their children. Another significant reason could have been that the availability of services for disabled children was quite poor in China at the time of the survey. Therefore, Chinese parents indicated a higher intensity of parental needs concerning their children's education and life.

Special education in America has a comparatively long history and advanced experiences had been accumulated, although new challenges had continued to emerge. An awareness of special education in the whole society was greater. Many American parents had common information and skills for dealing with their disabled children and were able to handle general problems relating to disability. Service systems were also advanced in America. The availability of service was higher. Thus, American parents indicated lower needs than their Chinese counterparts.

There was also a difference between the groups in the rank ordering of needs. Chinese parents indicated more concern about parent training, collaboration of parents with school, medical treatment for their children, and knowledge of the cause of the disability. American parents emphasized the need for support from society, parent training, collaboration with school, and obtaining services for their children.

A major discrepancy emerged in the area of medical treatment. Chinese parents rated medical treatment as the third highest need while American parents ranked it as the sixth highest need. Such a difference was probably because many Chinese parents of mentally retarded children believed that mental retardation was a special kind of disease. They believe medicine or surgery will cure their children. Thus, Chinese parents rated it as very high parental concern. Again, this concern was probably due to the shorter history of special education in China.

The open ended question was an important part of the survey. It allowed parents to have an opportunity to express their own concerns and problems. Both Chinese parents and American parents reported a variety of needs for their children. Responses to the question provided additional information to us regarding parents' concerns and needs that could help in the modification of the questionnaire. An important finding in the responses to the open question was in the areas of parental need for social support, good education programs, and respite care.

The author did not include social support in the closed questions, yet, in the open ended question, American parents rated social support as the greatest need. Chinese parents expressed the same concern and rated social support as eleventh, in contrast with first by American parents. American parents ranked respite care as the fourth highest need while Chinese parents reported no need for respite care. The differences between the two groups may have come from the difference between the two countries in their family structure and parents' attitudes toward their disabled children. In China, many children are cared for by their grandparents or other family members, especially in rural areas. Therefore, it is easier for Chinese parents to get assistance in the care of their disabled child than it is for American parents. This probably reduces the parental need for social support. In addition, many parents of disabled children in China feel shame or guilt. They believe that having a disabled children is their fault. Such feelings result in self-blame and self sacrifice rather than a search for outside help.

Both Chinese and American parents expressed a need for improving the educational programs for their children, especially the Chinese parents. Chinese parents rated this as the second highest need in the open ended question. The open ended responses suggested that Chinese parents were less satisfied with the school programs available than were the American parents. Some of the service areas that Chinese parents hoped would improve were school lunch care, vocational training, and transportation.

Responses to open ended questions did reveal a tendency for Chinese and American parents to place certain needs in a similar priority ranking. Three need areas appeared to cluster: parent training, teacher collaboration, and financial need. This may have meant that, in some ways, the needs of Chinese parents was more like the needs of American parents than they were different.

Limitations

Several limitations should be taken into account when considering the results of this study.

1. The instrument was brief. Each topic area was covered by only one question in the closed question of the instrument. This did not provide a basis for testing item reliability.

2. Level of severity of the mental retardation was not directly addressed, although the sample selection

process would have tended to include only persons who involved in some service program.

3. Although Chinese professionals used the American Association on Mental Retardation definition, the concept of mental retardation was probably considered somewhat differently by Chinese parents.

4. Accurate interpretation was a concern. Culture differences made it difficult to present and report the same concept for each country.

5. Nebraska was the only state represented in America, whereas six provinces were represented in China.

6. Chinese families tended to include a wider constellation of members than American families so that concerns about child care and responsibility could have been different.

7. Special education was still an extremely new field in China at the time of the study. Chinese parents may not have been aware of possible choices.

8. The literature review did not provide a direct comparison between China and America. The section on American issues paralleled the instrument and was the basis for the topics in the instrument, while the Chinese issues section provided a basis for understanding the issues facing Chinese parents.

Indications for further research

1. American studies have explored the differences

between the perception by professionals of parental needs and the perception by parents of parental needs, such studies may be helpful in China to help understand the implications of the needs reported by Chinese parents.

2. A study which sought to describe how Americans strive to meet the high priority needs described in China may help Chinese parents and educators create educational and related support systems.

3. A study which sought to describe the financial and personnel impact of meeting high priority parent needs would help support administrative plans for special education in China.

4. A feasibility study which sought to describe the transfer of low cost special education practices to China may help Chinese educators meet the high priority needs.

5. A study which includes parents of persons with other disabilities and a questionnaire that has possibly been improved by: using responses to the open ended question as a guide to expand the closed questions, and adding a Not Applicable section to the available choices.

Conclusions

There appeared to be a difference between the needs of Chinese parents and American parents of mentally retarded students in the areas of parent training, understanding the cause, medical care, respite care, and collaboration with teachers, but not in the areas of understanding by the community and financial assistance as demonstrated in closed questions. However, responses to open ended questions revealed a tendency for Chinese and American parents to place certain needs in a similar priority ranking. Three need areas appeared to cluster: parent training, teacher collaboration, and financial need. This may have suggested a question, "Does a Parent Culture transcend a Chinese Culture and an American Culture?" If so, some of the differences found may have been due to a lack of availability of service and a high degree of need for Chinese parents.

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APPENDIX A

学生年龄 ____ 性别 ____ 学校 ____________

父亲年龄 ____ 职业 ________ 教育程度 ____________
母亲年龄 ____ 职业 ________ 教育程度 ____________

亲爱的家长：为了提高特殊教育质量，我们进行了这项调查。请您根据您的实际情况回答每一个问题。您不必署您的姓名。感谢您的大力协助！

一 从下列所列的父母需要中，选择一项最符合您的实际情况的答案。

(一)懂得如何教育自己的孩子
十分需要 较需要 需要 较不需要 不需要
(二)获得社会上的经济资助
十分需要 较需要 需要 较不需要 不需要
(三))获得他人的同情和帮助
十分需要 较需要 需要 较不需要 不需要
(四)找到福利机构抚养孩子
十分需要 较需要 需要 较不需要 不需要
(五)想知道造成孩子特殊的原因
十分需要 较需要 需要 较不需要 不需要
(六)对孩子进行治疗
十分需要 较需要 需要 较不需要 不需要
(七)希望家长和学校间进行更多的合作
十分需要 较需要 需要 较不需要 不需要
(八)具体的帮助：例如：助听器，放大镜，他人照看自己的孩子，希望自己有更多时间照顾孩子等。
十分需要 较需要 需要 较不需要 不需要
(九)您对孩子最大的希望是：
从学校毕业
将来能找到工作
能独立生活：结婚成家，不用父母和兄弟姐妹的抚养
获得他人的同情和帮助

二 请列出您的五项最大需要(可以是上述所列的，也可以不是)

第一

第二

第三

第四

第五

三 如果您还有其他问题需要帮助或其他的建议和想法，请写在下面。

TRANSLATION OF CHINESE PARENT NEED SURVEY

Students' Age _____ Sex_____ School_________________________

Father's Age _____ Profession_____________________ Educational Level___________

Mother's Age _____ Profession_____________________ Educational Level___________

Dear Parents: In order to improve the quality of education, we undertake this survey. Please answer every question according to your situation. You need not sign your name. Thank you very much for your collaboration!

1. Please choose the response that is most fitted to your family's needs for each statement below.

(1) Knowing how to educate my child
  a. extreme need b. above average need c. average need d. below average need e. no need

(2) Needing financial help from society
  a. extreme need b. above average need c.average need d.below average need e. no need

(3) Getting sympathy and help from others
  a. extreme need b. above average need c. average need d. below average need e. no need

(4) Finding welfare service which can take care for my child
  a. extreme need b. above average need c. average need d. below average need e. no need

(5) Understanding the cause of my child's disability.
  a. extreme need b. above average need c.average need d.below average need e. no need

(6) Obtaining adequate medical treatment for my child.
  a. extreme need b. above average need c.average need d. below average need e. no need

(7) Hoping more collaborative between parents and school
  a. extreme need b. above average need c. average need d. below average need e. no need

(8) Specific help, such as: hearing aid, magnifying glass, babysitter, hoping more time to take care of my child
  a. extreme need b. above average need c. average need d. below average need e. no need

(9) My highest hope for my child is:
  a. graduating from school
  b. getting a job in the future
  c. living independent: getting married, not taken care of by parents or siblings
  d. getting sympathy and help from others

2. Please list the 5 most important needs of your family (they may or may not be same needs listed above).

The first ____

The second____

The third____

The fourth____

The fifth____

3. If you have other comments or suggestions, please write down below.

APPENDIX B

PARENT NEED SURVEY

Thank you for helping us learn about your concerns as a parent. Before you begin answering questions, would you please tell us a little about your child and yourself?

YOUR CHILD'S: age_______ sex_____.

IDENTIFY the type of YOUR CHILD'S classroom: resource room____or self contained classroom____or regular classroom____ .

YOUR CHILD'S grade in school: primary ______intermediate_______ junior high_______ high school___________.

CHECK ONE: The answers are given by mother _______ The highest grade that you have completed is________________.

The answers are given by father _______ The highest grade that you have completed is ________________.

Introduction and Instruction: The purpose of this survey is to determine your needs as parents of a child in special education. Please answer every question according to your situation. Circle the response that is most fitted to your family's needs for each statement below.

(1) Training on ways to support my child's education at home or in the community.

a. extreme need b. above average need c. average need d. below average need e. no need

(2) Needing financial help for equipment or aids other than what is provided in school.

a. extreme need b. above average need c.average need d.below average need e. no need

(3) Understanding by the community of the problems I have as a parent of a child with disabilities.

a. extreme need b. above average need c. average need d. below average need e. no need

(4) Respite care for my child with disabilities.

a. extreme need b. above average need c. average need d. below average need e. no need

(5) Understanding the cause of my child's disability.

a. extreme need b. above average need c.average need d.below average need e. no need

(6) Obtaining adequate medical treatment for my child.

a. extreme need b. above average need c.average need d. below average need e. no need

(7) Working in a more collaborative way with my child's teachers.

a. extreme need b. above average need c. average need d. below average need e. no need

(8) Information about my child's disability.
a. extreme need b. above average need c. average need d. below average need e. no need

(9) My highest hope for my child is:
a. graduating from school b. getting a job in the future
c. getting married and raising a family
d. being accepted in the community while living at home with the family
e. Living outside our home with support from the community

Please list the 5 most important needs of your family (they may not be according to the needs listed above).

The first (greatest need)____

The second____

The third____

The fourth____

The fifth____

Please write any comments below or on the back. Thank you very much for taking time to complete this survey!