

RAISING CHILDREN WITH DISABILITIES IN CHINA: THE NEED FOR EARLY INTERVENTIONS

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In China, the national strategy for Early Childhood Care and Education (ECCE) is coherent with the national policy and the needs of children's families. This policy has raised the public awareness of the value of early childhood education (ECE). However, there is a gap in services for children with disabilities. Based on the available sources, children with disabilities are viewed mostly as a social issue rather than as a medical/ rehabilitative issue. As a result, children with disabilities may have not received the attention or resources, as have children in regular education programs. This paper addresses different issues related to children with disabilities in China. In particular the authors have made the attempt to highlight the importance and fluidity of brain development in early childhood years in the context of identification and intervention. Recommendations are made for national policies related to early identification and intervention for all young children. Such policies are of the utmost importance for China as a country with rapid economical growth as well as having a large number of newborn babies who may be at risk for developmental delays.

Introduction

Based on a report from Stratford and Ng (2000) in China, one child is born with a serious disability every 40 seconds. These researchers further reported that China could face with a monumental task in education and rehabilitation of more than 60 million persons with disabilities. Many of them are either completely illiterate or semi-illiterate.

According to the statistics of special education in China in 2007, 12,569 students with hearing impairment, visual impairment, and mental retardation were served in 13,594 classes in 1,605 schools for special education in 2007 (Ministry of Education of the People's Republic of China, 2007). At the primary school level, 190,324 students were reported to be included in general education classrooms (Ministry of Education of the People's Republic of China, 2003, in Ellsworth & Zhang, 2007). According to an UNESCO report, there are approximately 2.46 million children under the age of six who are considered to exhibit some type of disabilities in China (Corter, Janmohammed, Zhang & Bertrand, 2006) However, service for young children with special needs is a relatively recent phenomenon in the People's Republic of China (PRC). China, like many other countries, is confronted with the task of providing early intervention to this population. Available literatures indicate a number of issues, including: the shortage of appropriately trained professional, lack of sufficient numbers of early childhood special education programs, lack of sufficient funding for early childhood education, and inadequate support services for the parents and policies designating sufficient funds for early childhood services.

Giving birth to a child with disabilities in China can be overwhelming; raising a child with disabilities would be devastating. The traditional view of giving birth to children with disabilities is perceived as sins against their ancestors or curses from some gods. Many families are too ashamed to expose their child with special needs in public. It is almost like a *don't ask, don't answer* issue which has been in place for centuries. Parents with typically developing children may not realize how difficult it is to cope with the day-to-day challenges of raising children with disabilities. These parents with disabled children constantly are fighting for the rights of their children. At the mean time, they experienced stress and exhaustion due to the lack of social, political, and economical support from the public.

Herring (1996) has listed potential emotions that these parents may experience such as grief, guilt, fear, anxiety, resentment, denial and anger. Given the importance of the well being of the family unit, it is critical for the society to provide interventions to support these families during crucial years of child development. In China as well as many other countries disabilities are viewed as a social vs. medical issue (Jenks, 2005). Jenks (2005) further explained the difference between these two, is that the medical model of disability emphasizes changing the person to fit the environment; whereas the social model emphasizes changing the environment to fit the person (Quinn, 1998, in Jenks, 2005). Given this dichotomy, it seems the main difficulty for individuals with disabilities to fully participate in the society is due to the society itself, which has created such barriers.

Parents of children with disabilities in China normally are the only teachers of their children. These families face difficulties mainly due to social and cultural beliefs about disabilities. Researchers (Sloper & Turner, 1992) identified the service needs of parents of children with disabilities as discussing the child's progress regularly, having information regarding the child's condition, information on emergency service and classes to learn how to help their children. Hadadian and Merbler's study (1995) reported similar findings within a sample of American families. They reported families most needed resources such as reference library, parent training, consultation services and information regarding their child's disabilities.

Historical and Cultural Perspectives

The origin of special education in China can be traced back for more than two thousand years, while the Chinese noticed the existence of certain abnormalities and obvious disabilities in some individuals. Available ancient texts indicate advocating for treatment of people, including: disabilities with tolerance and provide care for those in need of support. Confucius' *The Book of Rites* indicated that *people should respect others' parents, and treat others' children like their own; all those who are bachelors, widows, orphans, single, handicapped and sick should be tended.* (Original sentence translated from the Book of Rites, Li, 2007). Influenced by Confucius' ideology of treating people with disabilities with love and respect, ancient Chinese were kind to people with disabilities compared to most part of the Western societies. However, people with disabilities occupied the lowest social status. Superstition and fatalism were common among Chinese. Some people believed that people with disabilities had magic powers that could predict the future or drive away evil spirits.

In the absence of systematic social and education programs, people with disabilities remained as a disadvantaged group for more than 2000 years in China until the late 19th century. Initial achievement of special education in China were introduced and funded by the U. S. and European missionaries in the late 19th century (Pang & Richey, 2005). Those missionaries introduced Western concepts of Braille and sign language to China and attracted social attention to the educational needs and humanitarian rights of children with disabilities (Piao, 1996). In early 20th century, the Chinese people also began to establish special schools for people with disabilities. In 1927, the Chinese government established Nanjiang Municipal School for the Blind and Deaf. By the end of 1948, only 42 special schools served more than 2,000 students who were visually and hearing impaired in China, and most of these schools were run by religious and charitable organizations. Education for individuals with mental retardation or other developmental disabilities were not existed. The development of special education in China can be divided into the following sequence:

Table 1
The Development of Special Education in China

Time Period	Focus
1874-1948	Influence from the West initiated special education
1949-1978	Private schools were transformed into state-run schools. Special education development was limited due to the political and economical difficulties.
1979 –the turn of 20 century	Special education remains a part of public education and is supported by government.
2001 - Present	Higher education institutions began to enroll students with disabilities. All 31 provinces in China had adopted local laws to implement the 1990, the Protection of Handicapped Person Law.

Disability, Child Development and Parent Involvement

In China, infancy is regarded as a unique period in development especially the first sixty days. In the infant's first year the emergence of smiling and walking are milestones in human growth (Trawick-Smith, 2010). Child development research has well documented that the rate of human learning and development is most rapid in the early childhood years. For example in the first year of life children gain control of their body and begin to walk (Berger, 2004). Socially, through interaction with their environment typical children are able to develop a secure bonding during the first year. The quality of this attachment relationship would ultimately provide the children with a social emotional foundation on how to relate to the world (Klaus & Kennel, 1982). The developmental growth happens mostly as a result of brain development. Based on the current research literature in the area of child development, we do know that human development interplay between nature and nurture. At birth, a baby's brain contains 100 billion neurons. The question that has been asked for decades is which one (gene vs. environment), plays a more critical role and does experience change the actual structure of the brain. Zero to Three a national organization in the USA has attempted to answer many of the questions related to these issues. According to Zero to Three (www.zerotothree.org), genes are responsible for the basic wiring of the brain, while experience is responsible for connecting and fine-tuning all the connection. So the answer to the question, is experience the architecture of the brain, is yes. Brain development is *activity dependent*. Every experience, whether seeing a rainbow for the first time, excites certain neural circuits. As neuroscientists say, *Cells that fire together, wire together*, those neurons that would get used will be eliminated through a process referred to as *pruning*. However in the absence of specific programs for (e.g. parent training for babies brain stimulation) early identification and intervention, brain development either be delayed or would never be reached its full potential.

The lengthy discussion of brain development and its impact on children's growth is beyond the focus of this paper, however through this brief discussion the authors wish to highlight the importance of the early intervention through brain stimulation for young children with special needs. This message needs to come to the forefront of public policy in China. Public awareness about the role of the parents in brain development in early infancy needs to be viewed as an urgent matter. Early interventions for children with disabilities are considered as an effective tool to support parents to teach and help their children. Stratford and Ng (2000) concluded that parents could be a powerful force for the development of services for their children with disabilities. Parents can actively provide children with the support that will foster children's ultimate development (McDevitt & Ormrod, 2004). Centuries ago John Locke (1664) emphasized the long-term impact of early experiences and the responsibilities parents bear for their children's character formation. Families are essentially the center for children to get support that they need to tackle life's many tasks and challenges (Gartbarino & Abramowitz, 1992). These available research findings suggest the family as the stable key factor in a child's life. Similarly, an organized and supportive family environment will facilitate and nurture children's growth. Helping parents to create environments that are developmentally appropriate for children, so each child's abilities and interests will be supported is critical (Bredenkamp & Copple, 1997).

Intervention programs that involve parents have been found to increase parents' sense of competence and confidence about their child's learning and development (Dunst, Hamby, Trivette, Raab, & Bruder, 2000) as well as providing support for reducing some of the stressors associated with having a child with disabilities. Parental involvement helps parents to transfer skills from school, home and community settings. All of this has been achieved due to parents' and advocacy groups' hard work. Lessons learned from different countries, including the United States, show that parental involvement through advocacy groups is the key to later child development and achievement. However without the government intervention very little can or will be done. Early identification and intervention through clear public policies may be the key to better services for children with disabilities and their families.

Early Childhood Special Education in China

China's early childhood education has been influenced by the educational philosophy imported from other countries including the early influences of the reform movement of 1898 and the missionary activities of foreign nations. Between 1874 and 1948, Christian missionaries funded schools in China, some of which taught religion and basic survival skills to students with hearing and visual impairments. Other charitable organizations also established schools for children with disabilities (Yang & Wang, 1994). Western early intervention research, experience, and successful programs such as Head Start in the U. S. have impacted the development of early intervention programs in China.

The Cultural Revolution in the 1960s caused schools to close their doors for nine years and early childhood education was also under serious attack. Until 1989, the Regulations for Kindergartens laid down that focused on child development, active learning and attention to individual differences. In addition, western missionaries created more opportunities for teacher training in the area of early childhood education.

The first regulations regarding preschool education were introduced in 1903 based on Japanese training institutions (Zhenghao, 1993). Following the 1911 revolution and after World War I the Chinese resisted Japanese influences in educational and cultural affairs and moved more toward American and European models of preschool education until the establishment of the People's Republic of China in 1949 (Zhenghao, 1993). However, from 1949 to 1978, due to the political and economic difficulties, Special Education in China did not receive much attention from the public nor the government (Ellsworth & Zhang, 2007).

The national strategy for Early Childhood Care and Education (ECCE) has brought many changes to services for young children including increased public awareness of the value of ECCE. Unfortunately the increase in public awareness did not extend to children with special needs. These Children did not receive the attention nor, resources to the same extent as children in regular education programs as reported in Corter, Janmohammed, Zhang, & Bertrand's report prepared for UNESCO (2006)). A survey conducted by China Youth Daily was published in 2007 (Li, 2007) which indicated that 86.3% of the total respondents (N=2,685) believed *A complete life must include children* while 78.5% (N=2,317) reported that they saw raising children as a burden. For the majority of Chinese, having children is perceived as the fulfillment of responsibility to their ancestors even though children also were perceived as burdens. Therefore, it is devastating to have a child with disabilities especially after the implementation of the one child policy.

According to Stratford and Ng's (2000) study in Guangzhou City in Guangdong, one of the richest and most industrialized provinces, the facilities for children with severe learning disabilities are extremely inadequate. They further explained in Guangzhou City around 4 % of the 212,000 people including the city's children, 80 percent were in need of rehabilitation; requiring special facilities, special equipment, or some other form of support. They perceived it as a growing problem for China.

The first author's recent personal conversation with eleven college graduates from Hebei, Sunsi, Sichuan, Gansu and Dalian in China (September 7-11, 2008) found that many children with disabilities did not receive attention or assistance from the government. According to their reports, parents of children with disabilities in China in those provinces or locations either abandoned their disabled children in the hope of having another normal baby; or kept their children at home and felt helpless and hopeless. This might explain why so many children with disabilities were adopted in orphanages in China. This issue is especially evident in the rural areas.

In regard to early intervention, China did not really implement any specific programs until the 1980s, when the Gesell Development Schedule and the Denver Development Screening test were translated and revised to identify at-risk infants and children. Since then, a great number of childcare centers and kindergartens across the country have begun offering intervention programs for children with disabilities. By 1991, more than 700 language-training centers had been established and about 10,000 children with hearing impairment have been trained (Mu, Yang, & Armfield, 1993). China has made great effort to build the public and political profile of ECCE and boost general levels of participation over the last two decades. Yingqi (2008) studied the funding of early childhood education and urged the government to allocate additional attention and financial support for children with special needs.

Early childhood special education has been making progress in Beijing, as reported in Ellsworth and Zhang's paper (2007). According to their report, one particular school in Beijing was established in 1987, which has 60 staff members who teach more than 200 children in 17 classrooms. The school provides professional development and resource centers and an intensive diagnostic and training center for three- and four-year-olds with autism, and special education classes for school-age students. At this center, parents are encouraged to accompany their children, and help with their children's evaluation and activities. This evaluation and training center appears to provide a prototype in early intervention model in China. In addition a child with disability could impact the entire nature of the family (Barr, 1996) and the family functions (Turnball & Turnball, 1997). Early identification and intervention for young children at risk for developmental disability and their families is a proactive approach to early

childhood education. Such programs have the potential to support many children with, or at risk, for developing disabilities to learn and grow (VanDerHeyden & Snyder, 2006).

Conclusions and Recommendations

China's rapid growth with economy has increases its competition to the developed countries. However, attention and policies to tend to early identification of children with special needs have not been a common practice in China. It is suggested by these researchers that policies be mandated to fund programs for screening of all the newborn in order to identify children who may be at risk for developmental delay. State sponsored programs, as such can assist and train parents and teachers in order to reduce the stress and create support for parents with children of disabilities. A government mandate for *child find* would be instrumental to locate children who are delayed or at risk for becoming delayed. For example in the United States, there is a federal mandate which requires all states to find and screen all children who may have special needs and provide early intervention from birth. Further parents of children with disabilities are full members of their child's educational team as mandated by the Individual with Disabilities Education Act (IDIEA 2004). Therefore understanding the concerns of parents can facilitate the provision of family focused intervention (Galascoe, 1999). Hayes (1997) claimed need-based investigations are of utmost importance in framing intervention and formulating policies. Accumulated (Bailey, 2001; Bailey, Hebbeler, Scarborough, Spiker & Mallik, 2004; Bailey & McWilliams, 1990; Blackman, 2002; Brazelton, & Greenspan, 2000; Bronson, 2000; Chen & McNamee, 2007) research has documented the impact of early intervention services for children with disabilities and their families. Consequently, China is at the new era in which a greater investment has been in special education (McLoughlin, Zhou & Clark, 2005). More sources were dedicated for education for people with disabilities especially in the western part of China (Ellsworth & Zhang, 2007).

In conclusion, it is important to acknowledge that over the last two decades, China has made great strides in establishing the public and political profile of ECCE. As a result, China has developed a countrywide ECCE policy that lays out progressive principles and complex management structures. The current ECCE policy reflects progressive, child-centered curriculum that recognizes the importance of evaluation (Corter, et. al, 2006).

However, concerns remains that many existing ECCE programs are not providing the supports necessary to ensure that all children with disabilities would benefit from ECCE programs. Given the population growth and the number of children born with disabilities in China and the impact of early intervention (brain development), it seems that there is an urgency to expand ECCE policies to include screening of all 20 million children who are between the ages of 0-3. Furthermore public awareness about the cost effective funding allocated for parent- infants stimulating programs needs to be echoed in every child related national policies.

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