Parents as Teachers of Children with Autism in the Peoples’ Republic of China

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Abstract

In the People’s Republic of China, many children with autism are excluded from government supported schools and parents are expected to deliver educational services. Parent training centers offer short term solutions by providing information regarding autism and instructional methods to parents of children with autism. In order to further refine teaching services, one training center encouraged parents to indicate which topics in a curriculum were important to them. Participants were 55 parents of children with autism ages 3–8, who completed a questionnaire in which they identified referral services received, needs and concerns for further training, and attitudes towards collaboration. Results indicated that parents’ most important needs were centered on developing their children’s communication skills and a desire to collaborate with teachers, and that they received very few initial referral services. Findings are discussed in the context of human and social capital for parents of children with autism in the People’s Republic of China.

Key Words: Autism, Parent Training, Human Capital, Social Capital
collaborators with teachers, therapists, and other support services (National Research Council, 2001). Parental involvement offers opportunity for communication and for sharing educational practices between the home and school.

In China, parental involvement in the education of children with autism is much more extensive in service delivery than in western countries. Most parents enter into the surprising new world of their child with little awareness and no preparation. They eventually discover that very little assistance is available, and that they themselves will need to become advocates and teachers of their children.

Given the extensive needs of many children with ASC, dedicated families must put aside personal needs to teach their children. Parent involvement often means one parent or family member must become a full time caregiver and teacher, thus limiting their opportunities for social interaction and employment. Alternately, private schools for children with autism, when they are available, have tuition rates exceeding most annual salaries, putting tremendous pressure on most family resources. The financial drain and limited availability of educational resources impacts the development of talents associated with individuals with ASC, limiting the development of economic, human and social capital of the nation.

THE ROLE OF PRIVATELY SPONSORED PARENT CENTERS

Privately sponsored parent centers have recently arisen in China to provide educational training for parents of children with ASC. These centers do not provide direct service to the children; instead they provide information to parents about autism and train them in techniques for teaching their own children (McCabe, 2007). These centers perform a valuable service for those families fortunate enough to enroll in their programs by teaching them evidence based practices and advocacy skills. Although these centers provide a valuable service to parents, they do not have sufficient resources to provide services for all parents of children with ASC. Too few of them exist given the large numbers of children with ASC and the geographic vastness of China. In addition, the centers only provide short term programs, for example eleven weeks or less, and typically do not have monitoring or follow up services once the parents return to their home.

This paper highlights the training needs of parents who were attending one such center. The purpose of this investigation was to assist the parent center with the identification of instructional topics which could result in developing a curriculum aligned with parent perceptions of their needs. Through an informal questionnaire, parents indicated their needs in several areas: referral services, their training needs, and their views about collaboration with other professionals. The information solicited from the parents was targeted for possible incorporation and development of instructional offerings by the center. In addition, these findings add to the literature base on the status of services for children with autism in China.

Given this context, we begin with a brief introduction to educational policies and services for children with autism and other disabilities in China as well as descriptions of private centers that provide instruction for parents. Because educational policy contributes to the economic development of a nation, the contributions that these parent centers make towards advancing human and social capital are examined. Methods, results, and a discussion of findings regarding needs of parents of children with autism follow. Recommendations for policies and practice conclude the article.

GENERAL AND SPECIAL EDUCATION SERVICES IN CHINA

Official policy in China guarantees nine years of compulsory education for all children in primary and junior secondary government sponsored schools (Kritzer, 2011). After the ninth year, students with a minimum eligibility score on an entrance examination may be admitted to senior secondary education (high school). Throughout each level, class sizes are usually large, ranging from 40 to 70 students per teacher. Schools are structured around a whole class teaching model with a prescribed curriculum for each level. Children are expected to pay attention and to memorize much of the content. Achievement scores, as compared to other nations, indicate that for many students, especially those who are able to conform, this system works quite well (Bhattacharjee, 2004).

Recognition of Disability Categories

Although some students with disabilities are officially included in the guarantee of a compulsory education, in reality they are often excluded from schooling (Kritzer, 2011). China publicly recognizes visual impairment, hearing impairment, intellectual disability, physical disability, emotional disability, and multiple disabilities as categories of special needs, but the government takes responsibility only for the education of children in three of these categories: intellectual disabilities, visual impairments, and hearing impairments. Children categorized with one of these three disabilities are typically served in special government sponsored schools. Studies of enrollment figures for these schools offer a mixed view of actual attendance (Ding, Yang, Xio, & Van Dyke, 2008). In 1987, the first year for which nationwide statistics were available, 45% of all children with disabilities received no schooling, that is, were not enrolled in any school, general or special. These enrollment statistics are gradually improving. As of 2008, school attendance rates for children with these three disabilities are listed as being over 80% (Ding, Yang, Xio, & Van Dyke, 2008). Many students with other disabilities...
Learning in Regular Classrooms (LRC)

Acknowledging that limited facilities, shortages in personnel, lack of funding, and a vast geographical service area make reliance on special schools alone impractical, the Ministry of Education of the People’s Republic of China (1994) promoted a “Learning in the Regular Classroom” (LRC) program as an attempt to integrate students with disabilities into regular school classrooms (Wang, Zan, Liu, Liu, & Sharma, 2012). The LRC Program can be defined as government-supported arrangements for children with disabilities. This relatively new and developing model for providing special education services is loosely based on the Western concept of mainstreaming, only without provisions for support services like speech or occupational therapy (Stratford & Ng, 2000).

Not all children with intellectual disabilities, visual impairments, and hearing impairments qualify for services in an LRC (Kritzer, 2011). Government sponsored schools are not required to enroll children with special needs who cannot help themselves in school or classroom environments, or who cannot “adapt” to the curriculum (Kritzer, 2011; Wilde, 2001). Many children with autism and other disabilities are not able to meet the criteria for school attendance; most lack the ability to adapt themselves to a regular public school curriculum, texts, instructional formats, and prescribed curricular timeframe (McCoy, 2011).

Need for Appropriate Educational Services

Chinese researchers have acknowledged that although students with disabilities may be physically present in a classroom, they are not offered an appropriate education and are seldom able to benefit from the instruction (Ding et al., 2010; Yu, Su, & Lui, 2001). Classroom teachers receive almost no support for children with special needs, and given the typically large class sizes in China, students with disabilities rarely receive specialized instruction that would promote successful inclusion. No special alternative settings, resource rooms or special education classrooms are provided in general public schools. Support services such as physical or occupational therapy are rarely offered. The lack of policy support from the government and shortages of resources to implement the LRC program are cited as major barriers to the success of this program (Wang, Zan, Liu, Liu, & Sharma, 2012). Despite these difficulties, the LRC model is emerging as the symbol of inclusive education in China.

The Regulations on the Education of Persons with Disabilities (State Council of the People’s Republic of China, 2008) requires a national standard of special/inclusive education as well as a national system for teacher certification in special/inclusive education. These standards and systems have yet to be established. Furthermore, no centralized authority exists to mandate adhering to any of the compulsory schooling regulations. Because public schools are not required to enroll students who cannot be successful independent learners, most general schools do not encourage or accept children with disabilities; these children receive no services (Wilde, 2001). Children with disabilities who do not qualify for either general school attendance or special education school attendance are not acknowledged in the educational system. If these children are to receive an education, they do so without governmental support (McCabe, 2008).

GOVERNMENT PRACTICES ASSOCIATED WITH CHILDREN WITH AUTISM

China does not provide state services for the estimated 1.95 million individuals at various functioning levels of ASC (Huang & Wheeler, 2007). The ministry of education acknowledges that no government sponsored education programs specifically designed for children with autism have been established (Clark & Zheng, 2005). Chinese children with mild or high functioning autism usually do not fit into either the general school or the special school system. If they attend public special schools, they are often grouped with children with intellectual disabilities, even though the condition is officially classified as a mental disorder (Sun et al., 2013).

Loneliness Disease

The term autism, as translated into Chinese, means loneliness disease (Tao, 1987). This unfortunate interpretation is the basis of much misunderstanding and discrimination. Most children with autism have communication and language difficulties which create great difficulty in relating to others and for others to relate to them (McCoy, 2011). Because of their behavioral and special learning needs, many children with autism are not able to meet the criteria for school attendance. Children with comorbid conditions of autism and severe mental disabilities are typically institutionalized, whereas individuals with a diagnosis of mild cognitive impairment or high functioning autism are usually not eligible for the LRC programs (Gray, 1998; Huang & Wheeler, 2007).

However, some children with milder forms of ASC are able to meet attendance criteria, at least for a few years. Often, a parent will attend school with the child as a condition of enrollment. Children with ASC and normal intelligence can stay in public schools as long as their examination scores do not influence the mean performance of the class. Once their atypical behavior or academic performance is recognized by the teachers and the other
children as detrimental to the class standing, they will most likely be asked to leave (Sun et al., 2013).

**Referral Systems**

Adding to the difficulty of providing educational services to children with ASC is the lack of comprehensive referral systems to give parents direction on where they might access appropriate assistance. Since China has no public schools specifically for children with autism, government officials recommend that parents seek educational services in private schools (Clark & Zheng, 2005). These schools are few in number and not always located close to home communities; many families change their work and living arrangements in order to access these services. Furthermore, few assurances regarding program quality are available. In addition, no regulations are in place to mandate appropriate training, and many private schools employ teachers without sufficient experience or knowledge in the area of autism (Yu et al., 2001).

**PRIVATE PARENT CENTERS**

Because factors such as limited access to the public education system, high cost of private schools, and lack of referral systems, many parents are unable to obtain educational services for their children. Private parent centers, non-governmental organizations (NGO’s), are among the few choices for assistance. Parents learn of these training centers through informal means, often by word of mouth or on internet sites (McCabe 2008).

The first parent center for autism opened in the early 1990’s (McCabe & Tian, 2001). Approximately 250 such centers currently collaborate through an alliance network. These centers teach parents how to use evidence based practices which they can then apply in their home setting. Parent centers also provide parents with factual information about autism while simultaneously correcting misperceptions, such as the mistaken belief of finding a “cure.” Most successful parent centers have programs and networking activities that are designed to ensure transparency and legitimacy with the Chinese government and are heavily dependent on overseas aid. The need for services in a vast nation such as China is great, and most parent centers have long waiting lists for training sessions (McCabe, 2007; Wong et al., 2004).

**HUMAN AND SOCIAL CAPITAL: EDUCATIONAL IMPLICATIONS**

The development of educational policies in China may be understood through the concepts of human and social capital. Enlarging human capital, the intellectual competencies of a nation’s individuals, raises a country’s ability to compete on an economic plane with other countries (Alkire, 2002; Lanzi, 2007). Developing the compulsory educational system in place since the end of China’s Cultural Revolution (1978) is an example of an attempt at enlarging human capital.

**Generating Economic Growth through Human Capital**

Post-Maoist China has had to develop policies that would generate economic growth quickly, and the government focused on the education of individuals who could raise the economic and technological level of the country. Although the government of China has been gradually developing and improving society for all citizens, this process has been very rapid for individuals who can raise human capital through contributing in economic areas, but has progressed more slowly in areas which do not directly affect economic development, such as potential contributions of people with ASC (Rawski, 1980). Goals for education and the rights of individuals with disabilities outlined in the National Human Rights Action Plan of China, 2012–2015 (2012) are encouraging signs that the Chinese government may have accumulated sufficient human capital to focus on the improvement of all members of the society, including children with disabilities and their parents who, by default, are no longer contributors to economic development in their full-time caregiving and teaching roles.

**Influence of Social Capital**

Human capital is directly linked to social capital. Social capital is “the ability of people to work together for common purposes in groups and organizations” (Fukuyama, 1995, p. 10). Social capital develops through networking among groups with common interests (Cordini, 2010). Social capital influences human capital by operationalizing the knowledge base of social norms; for example, parental interest in their children’s learning can create human capital in the next generation (McNeal, 1999; Sun, 1999; Wu, Palinkas, & He, 2010). Social capital can be developed and maintained through informal structures that increase opportunities for information exchange and through formal organizations, which act as social anchors (Bridger & Alter, 2006; Putnam, 2000, Perkins, Hughey, & Speer, 2002).

In China, parent centers for autism can be considered social anchors that support the development of parents' social capital, characterized by: “strong social networks . . . strong social norms, and mutual trust and reciprocity among their members” (Clopton & Finch, 2011, p. 72). Recognizing that children with autism are typically bypassed in the development of human capital, parents can find a network of support through the services of parent training centers. The development of social capital is one of the significant functions of parent training centers. Parents of children with autism have a common social perception of the importance of education and its capability for producing human capital. Parents also share
the potential of rejection from school due to their children’s disabilities, and common interests related to the responsibility of learning how to provide their children with the best possible education they can. Isolation and the feeling of shame often experienced by parents with children with disabilities can be reduced when parents come together for training. By participating in the programs of the parent centers, the parents can find a means to increase their social capital through interaction with others with similar experiences.

THE AUTISM CENTER

This study took place in the Autism Center, (pseudonym) located in a suburban neighborhood in a major city in China. This center was the first parent training center in China and was selected because of recognized contributions to leadership in service to parents. The center focuses on parent training because it has the potential of reaching more children than delivering direct service would, given the shortage of services for ASC.

The center’s program focuses on clarifying concepts for parents related to the condition of autism and instructing parents in Applied Behavior Analysis (ABA) techniques (Maurice, Green, & Luce, 1996). ABA has the strongest degree of research support in the field of autism (National Autism Center, 2009). The Autism Center provides four, 11-week training sessions per year to approximately 50 families per session. The children accompany their parents to the Autism Center, and both participate in daily small group parent-child classroom sessions using demonstration, hands-on instruction, and skills practice. Parents also attend weekly lecture based and discussion classes led by the director. The Center offers scholarships for low income families, which are reimbursed retroactively based on family resources and completion of the training.

The 11-week course begins with two weeks for observation and assessment, after which a written educational plan is developed for each student. This educational plan is patterned after the Individual Educational Program (IEP) used in the United States or the Statement of Educational Needs (SEN) in the United Kingdom. This educational plan is basically a set of goals and recommendations to be implemented during the training program and is not a legal document. The next 8 weeks cover training in ABA techniques. Parents practice instructional strategies in small groups with their children, within the context of scheduled time for language, fine motor, music, art and sport activities. Parents are consulted on their progress in implementing ABA techniques at the end of each week. The final week (Week 11) covers student evaluation and individual family program development. The family plan is patterned after the individualized family service plan (IFSP) in the United States wherein goals for the child and strategies for the caregiver are outlined.

The training provided by the Autism Center is especially important because the knowledge provided is the basis for bringing harmony into family life, teaching parents how to respond appropriately to their children by reinforcing positive behaviors. The training also helps parents learn strategies for teaching their child at home. Training may enable some parents to cling to the hope of their child being accepted in a school. Appropriate behavior, self-help skills, verbal language skills and basic pre-academics are all skills that are prerequisites for school attendance (McCabe, 2007). If able to demonstrate these skills, a child can enroll in a general public school. Often, parents will hide or minimize the fact that the child has autism, just so that the initial enrollment in school is not questioned. The longer the child can maintain appropriate behavior, the probability of staying increases, especially for those with higher functioning ASC (Sun et al., 2013).

Given the importance of the training for these parents, the Autism Center sought a greater understanding of how parents perceived their needs relative to the current curriculum. Although the curriculum was based on the most recent instructional practices designed for individuals with ASC, development has typically been the province of instructors with little input from the parents.

METHODOLOGY

In this investigation, an informal questionnaire was used to determine perceptions of training needs provided by a group of parents attending the program at the Autism Center. Parents responded to 37 questions regarding their perceived training needs and their attitudes towards collaboration. Parents also had the opportunity to add additional comments regarding training or perception of services for autism.

Participants and Context

Participants were 55 parents of children with autism who were attending the Autism Center. Five fathers and fifty mothers voluntarily took part in the study. Their children ranged in age from 3–8. None of the children were currently enrolled in school, and their parents were their primary educational providers. Each of the parents paid tuition in advance of the training and, due to demand for these services, had experienced at least a 12 month wait from the time of application to the scheduled training.

Instrument

The second author designed an informal questionnaire based on concepts from the literature which commonly address curriculum practices for children with ASC: communication skills, behavior supports, self-help skills, and basic pre-academics. Collaboration was another major topic found in the literature. This was included in the questionnaire because research from the United States has
demonstrated that collaboration between parents and teachers plays a significant role in the education of children with ASC. Historical accounts related to parent access to services were also collected.

Questionnaire items were composed of short stems with a modified Likert type format in two areas: 14 items for Family Needs and 16 items for Collaboration. The parent could check one of more of the following: a) This topic is a very important priority for my family, (b) I would like more information, (c) This topic is not a priority at this time, but may be important in the future and (d) No, I do not need information about this topic. Historical accounts consisted of 7 simple statements with the option of a yes or no response, e.g., “Were you referred to a specialist for further assessment?”

Parents had opportunities in each section for other comments or open-ended remarks. Analysis of parental responses offered a view of the impact on the development of human and social capital for families who are raising and educating a child with ASC.

The questionnaire was initially composed in English and was translated into written Chinese. Parents responded in written Chinese, which was then translated into English. In order to assure that the questionnaire and parent responses were appropriately translated, the documents and responses were translated by the center staff and then reviewed independently by two native speakers and readers of Chinese with no affiliation to the Autism Center.

The first author and the director of the Autism Center presented the questionnaires to the parents. The director translated any questions the parents had and clarified the process. Parents completed the questionnaire immediately after a weekly parent meeting, at the mid-point (week five) of the training program. All parents enrolled in the program completed the questionnaire. Their participation was voluntary and responses were anonymous; no names or other descriptive information was requested.

Table 1 lists the items from the questionnaire, and the response choices for the categories of access to referral services, parent needs, and desired collaboration activities. Parents were not required to respond to all items and could respond to more than one choice for an item (e.g., “very important” as well as “would like more information”) based on their personal perception.

Data Analysis

Referral services. For each item in this section of the questionnaire (e.g., referral to a specialist, etc.), the number of yes and no responses were counted, and a percent of yes responses and a percent of no responses were calculated from the total responses. The 27 open ended responses and additional comments were translated and sorted into categories.

Parent needs and collaboration sections. For each item in these sections of the questionnaire, total responses for each choice (important priority, request more information, not a priority, not needed, and no response) were summed. From these totals, the percent for each choice per item was calculated. Responses that included more than one choice were included in item totals. As in the referral services section, open ended responses and additional comments were translated and sorted into categories.

RESULTS

Access to Referral Services

Most children were between the ages of two to three years when the parents were first given the diagnosis of autism, although two children were four years of age and one child was five years old. Upon initial diagnosis, 57% of the parents were referred to a specialist for treatment, 25% were referred to a specialist for further assessment, and 19% were given another appointment with a doctor. These parents were seen originally by a general practitioner and the referrals were for further medical services, which was basically the extent of the help they were given. Some parents were referred to literature about autism (36%), but only eight percent received a referral to a parent support group and only six percent were told of educational services for very young children.

A few parents made additional comments about their experiences and thoughts during that time. Their written statements suggested the need for a bridge to the social networks of others. One parent wrote, “The doctor told the parents to buy books from his colleagues (the doctor’s coworkers) in the hospital.” Another complained about access, “In addition, we especially need support and help from government and the law, but we do not know how to get the supports or how to promote.” Essentially, the parents reported being left on their own to find help for their child, that the doctors “were no help” in determining what was needed. Others relayed a more independent approach: “We only received a diagnosis, the rest is up to us to become educated and find connections,” and “There is very little help in reality, we must depend on ourselves.”

Parental Training Priorities

The areas of communication, behavior support, self-help, and academic support are important skills for school acceptance. Parents identified additional training needs that could be incorporated into the program of the Autism Center, such as asking for things the child wants, sharing conversation, or establishing daily routines. Items listed as high priority and where further information was requested are listed in Table 2.

Communication. While all areas of communication were a high priority, the ability for the child to express
when sick or hurt was indicated most often (57% and 51%, respectively). Also listed as a high priority (49%) was teaching children how to play with others, sharing conversations with their child (48%), and the ability to ask for what is wanted (46%). Parents’ open-ended comments also reflected the need for communication and related social skills, as indicated in the following characteristic responses:

“[My] Hope [is] these children can express their needs even in the simplest ways.”

“[My] Hope [is] these children can express their needs even in the simplest ways.”

“[My] Hope [is] these children can express their needs even in the simplest ways.”

“What can we do to reduce his speech to himself?”

“How can we improve his motivation for communicating with others?”

“How can I help my child when he is in contact with typical children, and help typical children to accept my child?”

“My child is quiet; are there any good methods to help the child become more motivated and excited?”

Table 1
List of Items from Parent Questionnaire

<table>
<thead>
<tr>
<th>Access to Referral Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>After receiving a diagnosis of autism, what sort of information or services did you receive?</td>
</tr>
<tr>
<td>Please answer ‘yes’ or ‘no’ to the following items</td>
</tr>
<tr>
<td>Another appointment from a doctor or a specialist</td>
</tr>
<tr>
<td>Referral to a specialist for treatment</td>
</tr>
<tr>
<td>Referral to a specialist for further assessment</td>
</tr>
<tr>
<td>Referral to services for very young children</td>
</tr>
<tr>
<td>Referral to support groups for parents</td>
</tr>
<tr>
<td>Referral to websites, literature such as brochures, information books</td>
</tr>
<tr>
<td>Other (Please specify)</td>
</tr>
</tbody>
</table>

Family Needs

Families of children with autism may need additional training or support in order to get their child the help that is needed. Which of these topics are of interest to your family? Please rate as (1) very important for my family, (2) I would like more information, (3) this topic is not a priority at the time, but may be in the future, or (4) no, I do not need information about this topic.

A. Communication skills

Asking for things he/she wants
Expressing when he/she is sick
Expressing when he/she is hurt
Sharing conversation
Playing with others
Behavior support. Establishing daily routines was an important skill for these parents, with 55% indicating this was very important and another 25% asking for more information. Other highly rated needs were teaching the child to be obedient, (46% very important and 16% wanting more information), and paying attention to the parent and others (42% very important and 37% wanting more information). Training on reducing inappropriate behavior was a lesser priority, (36%) most likely due to the successful nature of the ABA training that the parents were in the process of learning. Showing affection was the least selected, with only 21% indicating this as very important and 36% wanting more information. This section of the questionnaire received only one comment, which was stated as a question, “What can I do when my child’s odd behavior draws others’ attention in the community?”

Self-help skills. Self-help skills continued to be a topic of concern for some parents, but were not as high a priority as communication skills and behavior support. Approximately one-third of the parents still saw these areas as very important for additional training. They did not offer any additional comments or questions in this area.
Academic support. Learning to read and write was of the least importance to the parents, but several parent responses (33%) requested more information. Although they did not make any additional comments related to academic supports, their later responses at the end of the questionnaire indicated the desire for their children to be able to attend school.

Collaboration

Parents considered most of the suggested collaboration activities to be very important. As shown in Table 3, all of the suggested activities related to school-based collaboration were rated as very important by more than 50% of the respondents. Even though none of their children were enrolled in school, 70% gave a designation of high importance to receiving information from teachers about working with the child at home. Collaboration activities with teachers and activities in the school (e.g. observing, volunteering) took precedent over family and community collaboration, such as meeting with a family support group (52% considered this important), or receiving more information about autism or medical conditions. These responses show the high importance that parents place on communicating with teachers, and their willingness to participate in activities that would support collaboration.

Other parental concerns

After each section and at the end of the questionnaire, parents wrote open ended comments and described concerns they had about any topic related to their children. Concerns that were not directly related to the questionnaire include the following.

Parenting skills. As one parent stated, “Being a parent of a child with autism is not easy.” A large area of concern was the challenge that autism placed on their parenting.
skills. The parents wrote about the pressure they felt, and wondered what they could do to feel happy with their child. They questioned their capabilities—“I can’t help punishing him every time I see him doing something wrong. I can hardly find a chance to reinforce him. What is wrong with me?” and “I feel very confused when I see that my whole life will be occupied dedicated to my child with autism. How it is possible to rescue my personal life? Am I a bad mother thinking about this?” They described themselves as feeling helpless, unqualified, and yet encouraged, “I am trying to learn as quickly as possible!” But other comments were reflective of the broader issues of life with a child with autism: “How can I maintain the passion of being the educator of my autistic child?”

Need for services. Some parents acknowledged the difficulty in obtaining services but remained somewhat hopeful, as indicated by these comments.

“I hope that when my child is of the age to go to school, he can enter a normal school and obtain special assistance from the teacher. That would be ideal. If that is not possible, I hope that there will be a special education school.”

“My child is about the age to go to school. I cannot find an appropriate school for him. I hope to obtain help from a school and from society. No one is in the same situation as me in my neighborhood, and I have no way to connect with others.”

Others confirmed what the literature reflected—a dire need for services on both the national and local levels.

The future. Perhaps most poignant were the heartfelt questions and comments related to the future of the children with autism. “Do you suffer with worries about the future care of your child, when he is left [alone] one day? Who will support him?” is reflective of the concerns of many of the parents. Coping with the challenge they faced with China’s one child policy was also worrisome. “Would it be possible that the second child could be also disabled? Chinese families have only permission for one child, the ‘One Child Policy,’ but if the first child is declared disabled, one can have permission for another child.” Parents are seeking information about the possibility of having another child with autism in order to assist them with making family planning decisions. Given the lack of services, the emerging burden of having to train and educate their child themselves, and the uncertainty about their children’s futures, these responses are not surprising.

**DISCUSSION AND RECOMMENDATIONS**

The participants in this study were limited to a select group of parents—those who were fortunate enough to have heard about the center, endured a year-long waiting list for services, had the financial resources to invest the 9,600 Yuan fee for training, and were able to take 11 weeks out of family and work life to attend day-long training sessions with their child. Although these parents were typical of those served by the Autism Center, this sample may not be representative of other parents of children with autism in China and results may not generalize to other organizations serving similar populations. In order to broaden the participant base, further research could tap additional families, perhaps through the alliance network of parent centers in China. The use of an informal questionnaire further limits the generalizability of this data. Considering
these results as an initial baseline, a more comprehensive investigation of the needs of parents in the areas of communication development and collaboration strategies would be beneficial.

Nevertheless, these results show that this sample of parents were left on their own to find information and were inadequately served, indicating minimal progress from earlier reports on policy analyses (Clark & Zheng, 2005) and perspectives of parents (McCabe, 2008). The experiences of these families highlight the need for the development of coordinated policies and support systems in the area of autism. Although China’s national laws are continuing to evolve, moving towards revising the regulations on education for children with disabilities, articulation of national intent to provinces, cities, and villages continues to be underdeveloped (National Human Rights Action Plan of China, 2012–2015). For now, education for children with autism is not yet state supported, local schools still have the autonomy to admit whomever they wish (or not), and parents remain with limited access to services (Cook, Gerber, Hong, Mannan, & Zhang, 2012).

Questionnaire results and open-ended comments indicated the importance of developing communication strategies, primarily those associated with language development and related social skills. This identified need for developing communication skills points to a larger issue, however. The Autism Center does not have access to a speech-language pathologist (SLP) who could guide the parents in developing these skills. Indeed, SLP services are in short supply throughout the nation. China has an estimated 1,000 SLP’s to serve a population of over 1.3 billion people, and most are affiliated with hospitals, not school or center based programs. Researchers estimate that a 250,000 newly trained SLP’s are needed to adequately serve China’s enormous population (Meyer, 2011). With only three universities offering coursework in this area, the shortage of speech therapists is not likely to be resolved in the near future.

**RECOMMENDATIONS TO POLICY MAKERS**

Chinese parents spend a great deal of time and money advocating for their child with autism by seeking information, schooling, and ultimately providing much of the education themselves. Although some successes in obtaining services are emerging, these efforts are overwhelming for most parents. The families appear to be seeking the best possible educational services available at this time, and desire additional educational support, but are often at a loss as to what action to take. Collaboration with teachers is also

### Table 3

**Collaboration Activities Important to Parents**

<table>
<thead>
<tr>
<th></th>
<th>Very Important</th>
<th>Request more information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A. School related collaboration</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receiving information from teachers about how to work with my child at home</td>
<td>70%</td>
<td>13%</td>
</tr>
<tr>
<td>Collaborating more with teachers</td>
<td>65%</td>
<td>19%</td>
</tr>
<tr>
<td>Sending reports of child’s progress to teachers at least once a week</td>
<td>64%</td>
<td>16%</td>
</tr>
<tr>
<td>Help to design an instructional program for my child</td>
<td>63%</td>
<td>16%</td>
</tr>
<tr>
<td>Meeting with a team of teachers to determine the progress of my child</td>
<td>63%</td>
<td>15%</td>
</tr>
<tr>
<td>Receiving written reports from the teachers at least once a week</td>
<td>61%</td>
<td>19%</td>
</tr>
<tr>
<td>Volunteering at school</td>
<td>59%</td>
<td>19%</td>
</tr>
<tr>
<td>Observing my child at school</td>
<td>60%</td>
<td>18%</td>
</tr>
<tr>
<td>Meeting with teachers at least once a week</td>
<td>58%</td>
<td>19%</td>
</tr>
<tr>
<td>Knowing my child’s teacher better</td>
<td>54%</td>
<td>22%</td>
</tr>
<tr>
<td>Receiving home visits from the teachers</td>
<td>52%</td>
<td>22%</td>
</tr>
<tr>
<td><strong>B. Community collaboration</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning more about the educational system for children with autism</td>
<td>61%</td>
<td>23%</td>
</tr>
<tr>
<td>Meeting with experts in the field of autism to discuss your child’s needs</td>
<td>54%</td>
<td>24%</td>
</tr>
<tr>
<td>Receiving more information about the condition of autism</td>
<td>47%</td>
<td>30%</td>
</tr>
<tr>
<td>Receiving information about my child’s medical conditions</td>
<td>42%</td>
<td>25%</td>
</tr>
<tr>
<td><strong>C. Family collaboration</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meeting with a family support group</td>
<td>52%</td>
<td>23%</td>
</tr>
</tbody>
</table>
a high priority for parents. Adding autism awareness and successful strategies to teacher training programs could help to support conditions in which collaboration begins to be possible.

**Working Collaboratively for Educational Options**

Future actions could focus on working collaboratively with the government to establish more educational options for children with autism. These options could include invitations to organizations with established programs to provide professional development for parent and teacher training in public and special schools, especially in the area of ABA.

**Instructional Support for ABA.** Through the efforts of the Autism Center and other similar centers, parents are taught to apply the principles of ABA to work with their children at home. Follow-up with ABA training, a highly complex process of instruction, is critical to the continued development of the education received by these parents. To become proficient in utilizing ABA principles addressing language development, for example, requires far more than an eight week equivalent of an introductory course. Mentorship by Board Certified Behavior Analysts (BCBA) could be solicited or invited by the Chinese government to provide support and determine the efficacy of parental efforts on the performance of their children.

**Use of Technology.** Further opportunities for intervention services are possible through online instruction. Given the high quality of interaction being provided through the internet, teachers and parents could both participate in online education. With the use of desktop video conferencing programs (either using a web 2.0 tool such as SKYPE or more secure proprietary software), observations of student progress in their homes can be monitored and feedback provided by professional educators within China and other countries. As parents and teachers become more sophisticated in delivering services to children with autism, parent mentorship programs could also be developed, providing peer support and training. Parent mentorship, similar to the Parent to Parent program in the US and Pacific Rim countries (Singer, Hornby, Park, Wang & Xu, 2012) could reduce the cost of services and increase the availability of instructional options in China.

**Human Capital, Social Capital and Education.** Further implications relate to the interaction between educational policy and development of human and social capital. First, the parent training centers serve multiple functions for parents of children with autism. Not only do they provide a structure in which knowledge can be exchanged, but they also serve as places where parents can share their feelings in a socially acceptable manner with others who have similar experiences with raising children with autism, providing the social anchor which permits an exchange of feelings in an environment where others have experienced similar pressures and stresses. Previous researchers have outlined the concerns of parents in China who have children with autism (McCabe, 2008; Wong et al., 2004). Their stress levels from raising children with autism are reported to be higher than for any other disability (Wang, Michaels, & Day, 2011). By expressing their needs and concerns in the supportive environment of the center, parents may begin to view their own social capital as an important factor in educating their children.

Second, as more information is learned about the skills possessed by individuals with autism, China has the opportunity to extend educational services that can build upon the intellectual capacity of its citizens. Many individuals with autism have strengths that with proper education can be used to develop human capital. Meticulous thinking, extensive long-term memories, ability to follow and be comfortable with utilizing rules, and an affinity for analyzing intricate patterns in the social and physical worlds are characteristics that can be nurtured and celebrated (Robertson, 2010). Effective educational services would allow both children and their parents to be more productive members of society, benefiting China economically and socially.

Third, the parents’ desire for collaboration with educators, along with the knowledge that this is possible elsewhere, may point to a readiness to turn their involvement into advocacy. In the United States, parent advocacy was the primary factor leading to the current system of free and appropriate public education in inclusive settings for children with disabilities. Today in China, parents are beginning to address the right to an education for their children of different abilities, the same issue that parents in the United States addressed more than 40 years ago (Sun et al., 2013). In the United States, parents were able to address this issue through the courts, although that approach may not work, since advocacy for reform is difficult in China, with its strong central government. Citizens must show respect and civil obedience in order to function and develop social capital (Dickson, 2004). This respect and civil obedience is no less true for parents of children with autism. They must be cautious in demanding support for the development of human capital for their children. Nevertheless, the parent centers, functioning as social anchors, serve to strengthen parents’ resolve to acknowledge the educational rights of their children, to set priorities for their education, and to seek further autism-specific services, encouraging the development of social capital in this area.

**CONCLUSION**

Addressing the needs and concerns of families of children with autism in The People’s Republic of China is a necessary element in developing the human and social capital of a
rapidly advancing world power. Information reported in this paper indicates that although parent centers are providing instruction and support to families, their needs cannot be solved through short term training alone. We found many of the same situations as did McCabe (2007), whose extensive research on perceptions of raising children with autism described extremely dedicated parents who faced discrimination, rejection, and lack of schooling opportunities. Comments from parents indicated that they realized that not much outside help was available and that they must do whatever they could personally to teach and advocate for their children. These sentiments echoed those found by McCabe and Tian (2001), and point to the fact that in the intervening years little has changed for children with ASC and their parents.

What is needed is national-level policy that will provide long term educational services to all families, regardless of location. China’s recent change in leadership has signaled a willingness to focus on the improvement of the lives of its citizens, indicating renewed opportunities for dialogue on educational policy. Acknowledging the parental needs and concerns for their children with autism offers hope that their voices will one day be heard.

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