

NEEDS OF CHINESE FAMILIES OF CHILDREN WITH AUTISM

By

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Abstract

This study examined the needs of Chinese families of children with autism from 40 parents' perspectives by conducting an adapted version of Family Needs Survey (Bailey & Simeonsson, 1988) and two focus group interviews. Results showed that the most frequently reported needs of Chinese families of children with autism centered around three categories: needs for information, needs for support, and needs for community services. Two specific service needs were identified as areas that require immediate support. First, families need more information regarding autism and how to handle their children's behaviors. Second, families need support and advocacy for their children to get services in public schools. Given the unique social and cultural contexts, parents and professional should cooperate to take the initiatives of making changes. Systematic training and support programs for parents and paraprofessionals may be one strategy to meet these needs in the short run. Government should also take responsibilities for establishing quality school-based services for children with autism.

Keywords: family needs, service, autism, China

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Chapter 1

Introduction

There are two important barriers that are impeding the development of the current special education service system in China toward a more effective and comprehensive direction. First, existing services tend to focus primarily on children with autism as the unit of service rather than on the family, which causes these services to center on the interventions for children with autism, rather than providing a full range of services needed by the child and family. Second, the resources and expertise of parents have not been used. Parents' valuable insights to evaluate services and make recommendations for changes as consumers of services tends to be ignored. Therefore, it is important for professionals and policymakers to make changes in the current service system so as to empower parents and better meet their family needs. Involving parents in service planning and evaluation by listening to their voices and tailoring services accordingly should be the first step of the changes. Although there are several studies related to family service needs of individuals with autism, most of the studies focused on the situations in western countries. Consequently, very little is known about what parents of children with autism considered as their family needs in the unique historical, cultural, and societal context in China. This study examined the needs of Chinese families of children with autism from 40 parents' perspectives and provided realistic recommendations for possible changes in the current service system.

Background

Under the influence of historical and cultural factors, the service provision for families of children with autism in China can be described as nascent and facing multiple challenges.

Children with autism were not diagnosed in China until 1982, when Tao (1987) gave the official diagnosis of autism to 11 children in Nanjing Brain Hospital, almost four decades later than western countries. Closely following Kanner's first use of term autism to describe the withdrawn behavior of several children in 1943 in the U.S., great professional attention and governmental support began to take place in western countries. However, it was not until 2006 that autism for the first time appeared in the Chinese government's official document and was mentioned as a disability covered by the Chinese Law on the Protection of Persons with Disabilities (CLPPD). Specifically, there are five categories of disability covered by CLPPD, and Autism was included in the psychiatric disability category in the Second National Sample Survey on Disabilities. Therefore, there has been a long period of time in Chinese autism service provision history when there was no official recognition and acknowledgement of autism, no policy from the government to provide support to children with autism and their family, and no regulations to supervise and monitor the autism-related service system. Consequently, children with autism were often rejected from public schools and much of the intervention for children with autism has been taking place in non-governmental, private rehabilitation centers or in state-run medical institutions (McCabe, 2007; Sun et al., 2012).

These organizations are often times the only accessible service options for children with autism in China. Since these organizations function as a substitute of service vacancy caused by the lack of nation-wide education services for these children in public school, it is not surprising most of the services will just focus on providing interventions for children, rather than parents. Moreover, without governmental level support and professional guidance, the incomplete understanding of the multifaceted and pervasive impact of having a child with autism on the

family, as well as the incomplete understanding of the consequent family needs further hindered efforts to provide comprehensive services to meet the needs of entire family.

Confucianism, which concentrates on properly ordered social relationships, benevolence, and harmony among people, was part of the feudal dynasties for more than 2000 years and still influences people's perspectives. Under the influence of Confucian traditions and socialist ideology, Chinese people have been taught to respect authority, obey rules and maintain harmony. The obedience in social norm discourages parents from advocating for their children and their family or challenging the existing implementation of service systems, which results in great neglect of valuable parents' opinions and recommendations throughout service planning and evaluation. This is against the widely accepted family-centered philosophy in special education, which believes the family is in the best position to determine the needs and well-being of the child (Dempsey & Keen, 2008). The lack of input and feedback from parents further restricted the capability of current services to comprehensively meet family needs of children with autism and decreased the quality of life of these families.

Purpose

Given the severity of the problems and lack of collaborations with families, it is important to actively engage Chinese parents of children with autism into service planning by studying the distinct service needs of their families. Listening to parents' voices about their service needs may be an effective way to enhance families' control over the services and provide insightful analysis of the current system and inform future development.

Therefore, we examined the needs of Chinese families of children with autism from the perspectives of 40 parents through web-based survey and focus group interviews in this study. The results of this study will help service providers to better acknowledge and understand the

unique and broad service needs of these families. Furthermore, the data gathered from parents serves as information needed to provide realistic recommendations for possible changes in two levels. First, the intersection of the frequently reported needs, unmet needs, and reported important needs indicated the specific direction for immediate changes and generated the outlook for service transformation in China. Second, for future service providers, the results of the study will work as a checklist for them to start their business by creating a more comprehensive supports for families in the priority order shown in the results (i.e. the ranking of the importance of the needs).

Furthermore, that this study will contribute to increasing the breadth of the research on the needs of Chinese family of children with autism also justified the rationale for this study.

Chapter 2

Literature Review

Opposed to the limited research in China, a great amount of research has been conducted to date on service needs of families of children with autism in western countries. Several studies have sought to obtain the perceptions of parents of children with autism about services their children received. The reason to obtain input from parents is that unique position of parents as consumers of services enable them valuable insights to evaluate services and make recommendations for changes (Dymond et al., 2007). The purpose of these studies were to understand parents' perceptions of need and priorities for services for their child (Fong et al., 1993; Whitaker, 2002), to acquire recommendations from parents for improving school and community-based services (Dymond et al., 2007), and to explore overall, best, and worst met service needs from parents' perception (Hodgetts et al., 2014; Siklos & Kerns, 2006). Methods for obtaining information have included interviews, surveys, and focus groups. Some conclusions drawn from this research include: many parents experienced difficulty accessing needed services (Fong et al., 1993), most frequently identified overall and unmet service needs were information on services, family support, and respite care (Hodgetts et al., 2014), and increased individualization of and accessibility to services is suggested (Dymond et al., 2007).

Despite the great amount of research conducted to date, few studies focused on service needs of family of children with autism specifically in China. It is reasonable to assume the needs of Chinese families of children with autism may differ from the previous studies results due to its distinct social and cultural context. For example, one of the unique features in China is that most children with autism receive their services in non-governmental, private rehabilitation centers or in state-run medical institutions instead of from schools (McCabe, 2007; Sun et al., 2012), because they are often rejected by public schools in China (McCabe, 2007). This is

contrary to what studies showed in the U.S that schools provide the central site, or backbone, of services for autism around which a wide range of outside services occur. And school services were identified as among the best, and most frequently used services by families (Tomas et al., 2006).

The lack of school services for children with autism at various functioning levels in China may be closely related to the lack of clear clarification of accountability and the ambiguous status of laws and policies (Huang and Wheeler, 2007; McCabe, 2003), because it provides local authorities flexibility and excuses not to carry out these policies (Deng & Guo, 2007). For example, Article 22 of Law of the People's Republic of China on the Protection of Disabled Persons states that “Ordinary primary schools and junior high schools must accept children or juveniles with disabilities who are able to adapt themselves to life and study there; ordinary senior high schools, secondary polytechnic schools, and institutions of higher learning must accept students with disabilities who meet the state admission requirements and shall not deny their admission because of their disabilities; in case of such denial, the students concerned, his family members or guardians are entitled to appeal to relevant authorities, and the latter shall instruct the schools concerned to enroll the student.” (National People’s Congress, 2008). This article fails in explaining the requirement for enrollment and does not specify who is responsible for enforcing the law, which indirectly offers schools the power and freedom in defining a student with autism’s eligibility for enrollment and causes parents great difficulties fighting against the denial because the so-called “relevant authorities” for appealing is not specified either.

Furthermore, China is still far from being a culture that involves wide acceptance and awareness of disability. Under the influence of Confucianism, people with disabilities occupied

the lowest social status under the hierarchical feudal pyramid of roles that dominated China for 2000 years (Deng et al., 2001). The capability of people with disabilities and rights they deserve have been underrated and neglected. It was not until the late 19th century, when European and U.S. missionaries entered China and founded the first special schools was the idea of educating children with disabilities, rather than keeping them at home, slowly accepted by the general public. Therefore, cultural norms of how these people are supposed to act and behave had been formed and was so deeply rooted that they still hinder people's understanding and acceptance of autism. Children with autism are often perceived as patients with a disease that needs to be "cured" instead of students that can be "educated" and deserve good quality of life.

Several studies have demonstrated the uniqueness of the service delivery system and current states of families of children with autism in China (McCabe, 2007, 2009, 2012). Parents have mentioned the situations they are facing such as lack of support, facing open discrimination, and great financial burden. Rather than through systematic assessment that focuses exclusively on their perception of service needs, these themes emerged from parents' broad descriptions of their experiences as parents of children with autism.

To date, there are limited Chinese studies focusing on identifying parents' perceived needs. Wong and his colleagues (2004) conducted four focus group interviews with 23 Chinese parents of children with developmental disabilities and identified five categories of needs: parental, informational, attitude towards the child, coping and support. Wang and Michaels (2009) assessed the needs of 368 Chinese families of children with severe disabilities (37% with a diagnosis of autism (n=137)). They found that the Chinese families of children with severe disabilities perceived the need for more community services, information, and family/social support. Families of children with autism tended to report greater needs for information and

supports than parents of children with intellectual disability or physical disabilities. However, neither of these studies focused exclusively on the specific needs of families of children with autism nor did they provide enough specific recommendations in how to meet family needs of children with autism.

In summary, parents are considered valuable sources of information about service improvement. Several research studies were conducted in western countries focusing on assessing parents' perception of the services they receive and their own service needs. Results indicate information on services, family support, and respite care may be needed for some families of children with autism (Hodgetts et al., 2014), and increased individualization of and accessibility to services is suggested (Dymond et al., 2007). The concepts and methods of these research studies may be applicable, but due to different cultural and social context, results of these studies are likely to vary in China. Nevertheless, this research illustrates the necessity to identify needs of Chinese families of children with autism so as to guide appropriate changes on current service system for improvement.

Research Questions

This study investigated the needs of Chinese families of children with autism from the perspective of parents. Our aim was to try to find answers to the following two questions: First, what do Chinese parents of children with autism consider as the current needs of their families? This covered three types of information: the overall needs, unmet needs, and important needs for families of children with autism. Second, based on these identified needs, what may be possible directions for changes in the current service system in order to adequately serve these families both in the short term and long run?

Chapter 3 Method

Study design and setting

Both quantitative research methods (online survey) and qualitative (focus group interview) were conducted to seek answers to the two research questions stated above.

Participants were directly recruited from Dalian Aina Autism Service Center, a Non-Governmental Organization which provides support and advocacy for families of children with autism. This organization is located in Dalian, China, an economically developed city.

Participants

Participants are parents of children with autism from Dalian Aina Autism Service Center. There are several reasons to recruit participants from this organization. First, it is one of a minority of organizations in China that were founded by parents of children with autism which aims at providing platforms for parents to support and advocate for their own family needs. As members of this organization, these participants had experience discussing their needs and working together to support each other. Therefore, they may be more aware of their needs and the existing service options. In addition, children of these participants are from broad age range (3 to 18 years old) and receiving services in various settings (e.g. school, private centers, home). The sample was diverse in terms of child autism characteristics and types of services these families received.

A total of 46 parents accessed the online survey and 43 of them successfully completed and submitted their answers. Out of the 43 participants, three participants were excluded from the study because the respondent's child was older than 18 years old. 30 out of these 40 parents participated in one of two focus group interviews. Table 1 summarizes characteristics of the participants and their families.

Table 1

Demographic Information

Participant parent characteristics (N=40)						
Gender	Male		Female			
	5 (12.5%)		35 (87.5%)			
Age:	30-40		40-50		50+	
	14 (35%)		25(62.5%)		1(2.5%)	
Education level	Middle school	High school	Associate college	Bachelor	Master	Doctor
	1 (2.5%)	3 (7.5%)	13 (32.5%)	16 (40%)	5 (12.5%)	2 (5%)
Employment status	Unemployed		Part-time		Full-time	
	14 (35%)		4 (10%)		22 (55%)	
Family monthly income	0-4000		5000-10000		10000+	
	8 (20%)		22 (55%)		10 (25%)	
Participants' children characteristics						
Gender	Male		Female			
	40 (93%)		3 (7%)			
Age:	3~5		6~12		13~18	
	4 (9.3%)		20 (46.5%)		16 (37.2%)	
Current receiving service	Special School	Special classroom in regular school	Regular classroom (academic performance included)	Regular classroom (academic performance not included)	Private autism center	Home other
	7 (17.5%)	1 (2.5%)	4 (10%)	18 (45%)	19 (47.5%)	6 (15%) 1 (2.5%)

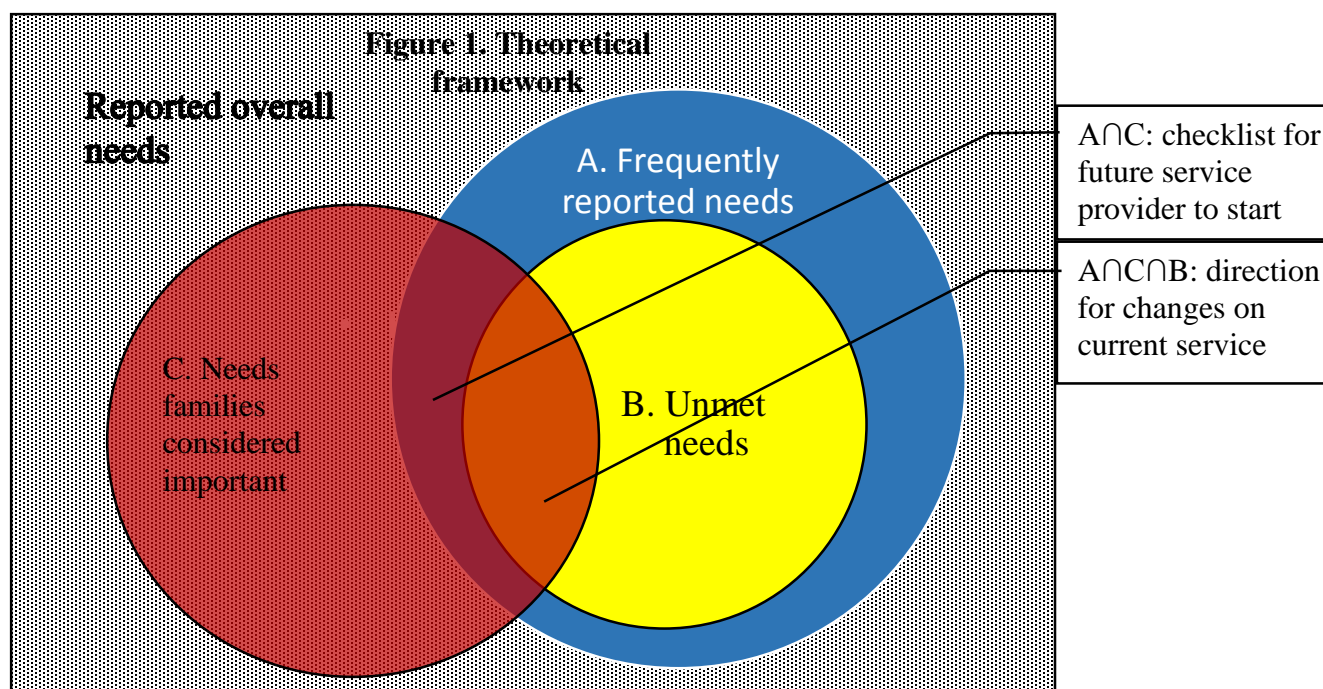
Instruments

All participants were asked to complete the online survey, which consisted of a Demographics Information Form and an adapted version of **Family Needs Survey** (Bailey & Simeonsson, 1988).

Demographics Information Form. A 12-item demographics information form was placed at the beginning of the online survey assessing gender, age, employment status, monthly family income, and education levels of the parents as well as gender, age, and current service conditions of their children.

Family Needs Survey. The Family Needs Survey (FNS; Bailey & Simeonsson, 1988) was developed by Bailey and Simeonsson to assess the functional needs of parents of young children with disabilities. It consists of 35 items and one open-ended question. Each of the 35 items is a statement that begins with a phrase such as “I need more...”, which reflects the parents’ perspective on specific needs for services. The rating is from 1 to 3, with 1=*I definitely do not need help with this*, 2=*not sure*, and 3=*I definitely need help with this*. The 35 items were grouped into six sections – “Need for Information, Need for Support, Explaining to Others, Community Services, Financial Needs, and Family Functioning”. This survey has been used in studies with children with different disabilities across a broad age range. Wang (2009) modified and translated the FSN to assess the overall service needs of families of children with severe disabilities in China. Hodgetts and his colleagues (2014) modified the survey by adding one choice of the scale (i.e. changed the original option from “Yes, I definitely need help with this” to “Needed, already provided” and “Needed, not provided”) to assess the overall needs and unmet needs of families of children with autism in Canada. This study tried to identify the overall needs, unmet needs, and important needs for families of children with autism in China

and based on this information to provide recommendations on the direction for changes on current service systems as well as guidance for future service providers. The theoretical framework of this study can be summarized in Figure 1.



We made several modifications to the original Family Needs Survey in order to obtain information specific to the needs of families of children with autism within Chinese social and cultural context. First, item 13 “I need to talk more to a minister who could help me deal with problems” and item 25 “I need help in getting appropriate care for my child in our church or synagoguo nurse during church services” were not included because religious activities are not considered as common and popular social activities in China and asking this question was deemed to be inappropriate (Wang & Michaels, 2009).

Second, due to the different family structure, item 17 “I need more help in explaining my child’s condition to either my spouse or my spouse’s parents” was slightly reworded as “I need more help in explaining my child’s condition to my relatives (including child’s grandparents, aunts, and uncles)”.

Third, seven new items were added in the survey. The new questions were chosen based on a review of the literature, clinical experience working with the families of children with autism, and from discussions with members of some of those families. Four of the new items were categorized into *Needs for information* section including: I need more information about how to set realistic goals (short-term & long-term) for my child; I need more information about how to make good decisions in choosing or changing services for my child; I need to have information regarding my child's therapeutic or educational progress (Waaland et al., 1993); I need more information about the latest policies and laws related to my child. One new item was categorized into *Needs for support* section: I believe study in public school with other regularly developing children is best for my child's development and I need someone to support and advocate for my child to get the service. One new item was categorized into *Explaining to others* section: Becoming willing to let other people know my child has autism. One new item was categorized into *Community services* section: I need for my child to have social activities other than with his/her own parents and siblings (Siklos & Kerns, 2006).

Fourth, in order to obtain information regarding how well the identified needs were met, we imitated Hodgetts and his colleagues' way of modifying the scale (Hodgetts et al., 2014) by changing the original option "Yes, I definitely need help with this" to "Needed, already met" and "Needed, but not met".

Fifth, a ranking question was placed at the end of each section, written as "Please choose up to 4 items you considered as important needs from items in this section and rank the items. Leave blank if not applicable." This was used to calculate the weighted mean of each item within six sections. Therefore, we can obtain the relative importance of all the items within each section by comparing their weighted means. This modified FNS is a 40-item questionnaire that provides

information regarding the degree to which an item was identified as needed, how well these needs have been met as well, as the ranking of relative importance of items within each section. All items were translated into Chinese by the author and were proofread by Chinese Ph.D. students who have great proficiency in both English and Chinese as well as a special education professional background.

The psychometric properties of this new measure were examined using Cronbach's alpha. All items of the adapted version of FNS appeared to have good internal consistency with a Cronbach's alpha = .875. George and Mallery (2003) provide the following rules of thumb: “ $\alpha > .9$ – Excellent, $\alpha > .8$ – Good, $\alpha > .7$ – Acceptable, $\alpha > .6$ – Questionable, $\alpha > .5$ – Poor, and $\alpha < .5$ – Unacceptable” (p. 231). Therefore, all items of the adapted version of FNS appeared to be worthy of retention: the only increase in alpha would come from deleting item 14 and 37 (which were from the original scale), but removal of these two items would increase alpha only by .003 and .001. Cronbach's Alpha if Item Deleted were summarized in Table 2.

Table 2
Internal Consistency of the Instrument

Item number	Cronbach's Alpha if Item Deleted	Item number	Cronbach's Alpha if Item Deleted	Item number	Cronbach's Alpha if Item Deleted
11	0.872	21	0.868	31	0.872
12	0.875	22	0.867	32	0.873
13	0.874	23	0.867	33	0.871
14	0.878	24	0.867	34	0.87
15	0.873	25	0.868	35	0.87
16	0.875	26	0.874	36	0.872
17	0.873	27	0.87	37	0.876
18	0.87	28	0.872	38	0.873
19	0.873	29	0.872	39	0.871
20	0.868	30	0.875	40	0.874

The original open-ended question “Please list your five greatest needs as a family” was replaced by focus group interviews through video conference software. The reason for this is

focus group can be used to provide meaning to a questionnaire with a forced choice format by examining the reasons and motives behind people's behavior (Heary & Hennessy, 2002).

Procedure

Emails with a recruitment letter and a link to the online survey were sent to the administrators of Dalian Aina Autism Service Center. The recruitment letter included the purpose and procedure of the study, information about confidentiality, a clarification that participation is voluntary and can be terminated by participants at any time, and contact information of the investigator in case of questions concerning the survey. The link led to the 40-item anonymous online survey described above at SurveyMonkey.com where data was stored in a password protected electronic format. The administrators then forwarded the email to all the participants. Participants were required to complete the questionnaire by themselves within 20 days of receiving the email and were instructed not share the link to others. At the end of the survey participants were invited to participate in an additional 1-hour focus group interview through video conference software. The exact time was sent to administrators of Dalian Aina Autism Service Center and they then forwarded it to all the participants.

Two focus group interviews were organized and conducted through Tencent QQ video conference software. Aina Autism Center established the online video conference platform through Tencent QQ and included all the participants into the platforms. During the focus group interviews participants were first shown the data analysis of the survey results and then were led to talk about why they considered certain services as needs, their current situation related to these needs, and why they considered certain needs important. The needs could be the items listed in the survey as well as newly reported items. The investigator of this study hosted and moderated

the entire interview progress through video conference software connected to his personal computer at home in Lawrence, US. Notes of the discussion was taken by the author.

Analysis

Statistical analyses were completed using Excel 2016. The original answers were downloaded from SurveyMonkey and were entered into Excel and screened for accuracy by the author prior to analysis. The *Overall needs* for individual items (i.e. the degree to which an item was identified as needed, regardless of whether that need was met) were determined as follows. We first coded 0= Not needed (i.e. all the item options “Not sure” and “No, I definitely do not need help with this”), 1= Needed (i.e. all the item options “Needed, already met” and “Needed, but not met”). We then calculated the percentage of participant reported need for each item. The *Unmet needs* for individual items represents the percentage of participants who identified that item as a need and reported “Need, but not met” (as opposed to “Needed, already met”). Therefore, needs unmet is proportional to participants who identified that item as a need and allows us to determine which needs were and were not being met. The weighted mean of each item was calculated to determine the *Relative importance of items in each subcategory* using the data collected from the ranking questions. In this study, we asked participants to choose up to 4 items from each section and rank the item based on their importance. We first assigned weights to each ranking as follows. Weight of Rank#1= $W_1=4$, Weight of Rank#2= $W_2=3$, Weight of Rank#3= $W_3=2$, Weight of Rank#4= $W_4=1$. Since a higher ranking denotes more importance, it was assigned higher weight. We then counted the number of responses for each ranking of each item. X_1 = response count for Rank#1, X_2 = response count for Rank#2, X_3 = response count for Rank#3, X_4 = response count for Rank#4. The weight mean of each item was then calculated as follows. Weighted mean = $(W_1 * X_1 + W_2 * X_2 + W_3 * X_3 + W_4 * X_4) / (X_1 + X_2 + X_3 + X_4)$

For example, item “Support and advocate for my child to get service in public school” was ranked #1 important by 24 participants, ranked #2 important by 3 participants, ranked #3 important by 2 participants, and ranked #4 important by 1 participant. Therefore, for this item, its weighted mean = $(W_1 * X_1 + W_2 * X_2 + W_3 * X_3 + W_4 * X_4) / X_1 + X_2 + X_3 + X_4$

$$= (4 * 24 + 3 * 3 + 2 * 2 + 1 * 1) / 24 + 3 + 2 + 1$$

$$= 3.67$$

In order to identify the exact service needs that required immediate support and efforts, we filtered the data based on a combination of three criteria: 1. Over half of the participants reported the item as needed; 2. More than half of the participants indicated the need was unmet; and 3. The weighted means of the needs were among the top four in each category. We then further divided the original data into two groups based on the age of the participants’ children so as to explore the possible differences between the two groups in terms of needs that required immediate support. Group1 included 24 respondents whose children aged from 3 to 12 years old. Group2 included 16 respondents whose children aged from 13 to 18. We followed the same methods described above to calculate the *Overall needs*, *Unmet needs*, *Relative importance of items in each subcategory* (i.e. Weighted mean) and determined the needs that required immediate support in each group. The author then coded the notes taken from focus groups to identify common themes across focus groups.

Chapter 4 Results

Overall needs

Table 3 summarizes responses for each FNS item. The average number of needs reported on the FNS was 28 (out of 40 choices; $SD = 6.298$). Two families indicated a need for help on all items (range 15-40 items). The most frequently identified needs were for information on the services that are presently available for their children (100% of participants; $n = 40$). The majority of respondents also indicated the need for more information on how to play with or talk to their children (97.5% of participants; $n = 39$) and the need for more time to talk with their children's teacher or therapist (97.5% of participants; $n = 39$) as well as the need for their children to have more social activities other than with their own parents and siblings ((97.5% of participants; $n = 39$). There are 28 of the 40 items that more than 50% respondents identified as an area of need. These 28 items are considered as the frequently reported overall needs of the family and are highlighted in red in Table 3. Needs based on the FNS subcategories ranged from 70% to 100% as follows: 100% of participants ($n = 40$) need information, professional and social support, and community services; 82.5% ($n = 33$) needed help explaining to others; 75 % ($n = 30$) needed help on family functioning, and 70% ($n = 28$) need financial support.

Table 3
Frequently reported overall and worst-met needs by adapted version of Needs Survey items (N=40)

Section	Item	Needed ^a	Need unmet ^b	Weighted mean ^c
Needs for information	About services that are presently available for my child	100%	90%	2.46
	How to play with or talk to my child	98%	82%	2.13
	About the services that child might receive in the future	95%	92%	2.68
	How to set realistic goals (short-term & long-term) for my child	95%	89%	2.62
	How to make good decisions in choosing or changing service for my child	95%	87%	1.80
	About ASD	95%	84%	3.25
	My child's therapeutic or educational progress	95%	84%	2.60
	How to teach my child	95%	82%	2.84
	How to handle my child's behavior	90%	83%	3.33
	Latest policies and laws related to my child	90%	72%	1.55

	How children with autism grow and develop	85%	82%	2.00
Needs for support	Talking with my child's teacher or therapist.	98%	59%	2.68
	Meeting and talking with other parents of children with autism	85%	47%	1.95
	Support and advocate for my child to get service in public school	75%	70%	3.67
	Family members to talk more about problems.	75%	60%	2.45
	More time for myself	70%	79%	2.16
	Material about other parents of children with autism	68%	67%	1.70
	Meeting more regularly with a psychologist to talk about problems.	65%	85%	2.47
	More friends to talk	60%	58%	2.67
Explaining to others	Helping spouse in understanding and accepting our child's condition	58%	43%	2.93
	Explaining my child's condition to other children	55%	95%	2.96
	Knowing how to respond when friends, neighbors, strangers ask questions about my child	48%	79%	2.76
	Explaining my child's condition to my relatives	43%	59%	2.46
	Explaining my child's condition to his or her siblings	38%	60%	2.06
	Becoming willing to let other people know your child has autism	33%	23%	3.09
Community services	Social activities other than with his/her own parents and siblings	98%	77%	2.43
	Locating a doctor who understands me and my child's needs	95%	84%	2.96
	Locating a place for my child's weekend and after-school activities	95%	68%	2.74
	Locating a dentist who will see my child	75%	70%	2.31
	Locating babysitters or respite care providers for my child	68%	81%	2.96
Financial needs	Paying for education, therapy, day care, or other services my child needs	68%	93%	3.42
	Paying for expenses such as food, housing, medical care, clothing, or transportation	50%	90%	3.32
	Paying for babysitting or respite care	45%	94%	2.36
	More counseling or help in getting a job	38%	93%	1.62
	Paying for toys that my child needs.	35%	100%	1.71
	Getting special equipment for my child's needs	30%	92%	2.67
Family functioning	Help our family discuss problems and reach solutions	70%	79%	2.4
	Deciding on and doing recreational activities	45%	89%	0.73
	Help our family learn to support each other during difficult times	45%	83%	1.75
	Deciding who will do household chores, child care, and other family tasks	30%	83%	1.35

a Percentage of total respondents who indicated area of need (Needed, already met" + "Needed, but not met").

b Proportion (%) of previous column who responded "Needed, but not met".

c Between 0 and 4

Unmet needs

There are 37 of the 40 items that identified an area of need that more than 50% of respondents reported unmet. Among these 37 unmet needs, 26 were also frequently reported overall needs (i.e. More than half of respondents reported as needs). These 26 were highlighted in blue in Table 3. They were related to all the six subcategories of Family Needs Survey. All of the items in the section of information and community services were frequently unmet; 7 out of 8

items in the needs for support section were unmet. The worst-met needs in each section are information about services that are presently available for my child (90% unmet; 36/40 respondents, *Information*), meeting more regularly with a psychologist to talk about problems (85% unmet, 22/26 respondents, *Needs for support*), explaining my child's condition to other children (95% unmet, 21/22 respondents, *Explaining to others*), Locating a doctor who understands me and my child's needs (84% unmet, 32/38 respondents, *Community services*), Paying for education, therapy, day care, or other services my child needs (93% unmet, 25/27 respondents, *Financial support*), and Help for our family to discuss problems and reach solutions (79% unmet, 22/28 respondents, *Family functioning*).

Relative importance of items in each subcategory (Weighted mean)

We used weighted means to determine the relative importance of items in each subcategory. The higher the weighted mean was, the more important this item was to the family compared to other items in that section. We identified the top four important items in each subcategory of the adapted version of FNS as well as the ranking of these items. They were highlighted in yellow in the Table 3. The most important need in each section reported by participants are: How to handle my child's behavior (*Information*); Support and advocacy for my child to get service in public school (*Support*); Becoming willing to let other people know your child has autism (*Explaining to others*); Locating a doctor who understands me and my child's needs (*community services*); Paying for education, therapy, day care, or other services my child needs (*Financial support*); Help our family discuss problems and reach solutions (*Family functioning*).

Needs that required immediate support

Needs that required immediate support were identified following three criteria: 1. Over half of participants reported the item as needed; 2. More than half of participants indicated the needs remained unmet; 3. The weighted means of the needs were among the top four in each category. Results of the entire participant group were highlighted in green in Table 3. Results of the two age groups were summarized in Table 4. By comparing the results, we found that there were great similarities and several noticeable differences between the groups.

First, a majority of the needs were centered around needs for information and needs for support and community services. Regardless of the children's age, all participants indicated the same needs related to information about ASD; information about how to handle my child's behavior; Needs for Support and advocacy for my child to get service in public school; Need more friends to talk; Locating a doctor who understands me and my child's needs; Locating babysitters or respite care providers for my child; Paying for education, therapy, day care, or other services my child needs; Help our family discuss problems and reach solutions. These identified needs were consistent with the results of entire participant group. Therefore, it provided insights into gaps of current service structures and systems and informed the specific direction for changes.

Second, no needs were identified by parents of older children in the subcategory of explaining to others. This may be well explained by the statement made by one participant during the focus group "Explaining my child's condition to others has already become one part of my life, through years of interaction and experience, I can already tell at what situation my explanation may affect the listener and at what situation my explanation is just in vain. And no matter how others react, I won't feel embarrassed anymore".

Third, the results indicated participants of younger children need more information regarding educating their children at the present (i.e. How to teach my child; My child's therapeutic or educational progress) while participants with older children focused more on information related to their children's future (i.e. How to set goals for my child; Information about the services that child might receive in the future). In addition, participants of older children reported more needs in helping them with family functioning (i.e. Help our family learn to support each other during difficult times; Deciding on and doing recreational activities).

Common theme across focus groups

The needs identified during focus group interview centered around several items that were already identified in the survey. Specifically, (1) information on methods to handle child's problem behavior; (2) information about available services; and (3) support and advocacy related to public schools.

Information related to methods to handle my child's problem behavior and strategies to teach my children. Quotes related to this theme include:

“My kid often bites others. I need to know how to solve this problem.”

“He always throws tantrum when I asked him to finish his homework. I really need to know how to teach him”

“There are all kinds of information online, but not from authoritative resource. I don't know which one to believe. “

Information related to available services for my child. Quotes for this them include:

“My child just got the diagnosis of autism few months ago, I am now totally lost. I don’t know where to get help for my child.”

“My child is now 14 years old, I really worry about his future. I don’t know what services are available for him to offer him a job.”

Need for support and advocacy for my child to get educated in public schools.

Exemplar quotes for this theme include:

“I go to school with my child as his paraprofessional. Although we were in school, my child’s teacher treated us like we were not there. I basically teach him by myself.”

“I don’t really know the progress of my child at school. When I ask my child what happened in school, he just answered with few words. I need more opportunities to talk with my child’s teacher. If there were a better communication between parents and school, I think my child probably will make more progress.”

“There is no specific system and process for school to include and teach my child. Inclusion is still at a theoretical level rather than practical implementation.

Table 4
Frequently reported, important, worst-met needs

Parents of younger children (3~12 years old), N=24					Parents of older children (13~18 years old), N=16			
Section	Item	Needed	Need unmet	Weighted mean	Item	Needed	Need unmet	Weighted mean
Needs for information	About ASD	100%	92%	3.17	About ASD	88%	71%	3.50
	How to handle my child's behavior	92%	91%	3.43	How to handle my child's behavior	88%	71%	3.20
	How to teach my child	100%	83%	2.83	How to set goals for my child	88%	79%	3.33
	My child's therapeutic or educational progress	100%	88%	2.57	About the services that child might receive in the future	100%	88%	3.09
Needs for support	Support and advocate for my child to get service in public school	79%	79%	3.78	Support and advocate for my child to get service in public school	69%	55%	3.50
	More friends to talk	58%	57%	2.67	More friends to talk	63%	60%	2.67
	Talking with my child's teacher or therapist.	96%	65%	2.47	Meeting more regularly with psychologist to talk about problems.	69%	82%	2.71
	More time for myself	71%	88%	2.38	Material about other parents of children with autism	81%	54%	1.75
Explaining to others	Knowing how to respond when friends, neighbors, strangers ask questions about my child	58%	79%	2.92				
	Explaining my child's condition to other children	58%	100%	3.07				
Community services	Locating a doctor who understands me and my child's needs	96%	83%	3.20	Locating a doctor who understands me and my child's needs	94%	87%	2.69

	Locating babysitters or respite care providers for my child	58%	93%	2.93	Locating a dentist who will see my child	75%	67%	2.38
	Locating a place for my child's weekend and after-school activities	92%	77%	2.86	Locating babysitters or respite care providers for my child	81%	69%	3.00
	Social activities other than with his/her own parents and siblings	100%	75%	2.58	Locating a place for my child's weekend and after-school activities	100%	56%	2.62
Financial needs	Paying for expenses such as food, housing, medical care, clothing, or transportation	54%	85%	3.45	Paying for education, therapy, day care, or other services my child needs	81%	92%	3.43
	Paying for education, therapy, day care, or other services my child needs	58%	93%	3.42	Paying for babysitting or respite care	56%	100%	2.25
Family functioning	Help our family discuss problems and reach solutions	67%	81%	2.25	Help our family discuss problems and reach solutions	75%	75%	2.63
					Help our family learn to support each other during difficult times	56%	78%	2.38
					Deciding on and doing recreational activities	63%	100%	1.69

Chapter 5

Discussion

Due to the influence of historical and cultural factors, the current service system in China is unable to provide a full range of services needed by Chinese families with children with autism and parents' perspectives are seldom taken into consideration through service evaluation and development. In addition, contrary to the great amount of research conducted on family needs in western countries, very little is known about the needs of families of children with autism in China. Therefore, this study systematically examined the needs of Chinese families of children with autism from 40 parents' perspectives using the adapted version of Family Needs Survey and focus group interviews.

We have discovered that the frequently reported needs of Chinese families of children with autism center around “needs for information”, “needs for support”, and “needs for community services”, which is consistent with previous research on the Chinese family needs of children with severe disabilities (Wang & Michaels, 2009). Out of these frequently reported overall needs, we further filtered the data and identified specific service needs that require immediate efforts based on the unmet extent and relative importance of the needs. Under the category of needs for information, results suggested families reported a strong demand for information regarding knowledge of autism, ways to teach their children, and how to handle their children's behaviors, which is consistent with previous research (Wong et al., 2004; Wang & Michaels, 2009). One possible contributing factors could be the lack of available authoritative information resources. Participants reported that they were actually exposed to great amount of

information related to autism from a variety of sources. However, they couldn't verify the reliability and quality of the information, which caused them more confusion about what to do.

This finding represents an urgent need for government and professionals to cooperate together to establish a reliable information dissemination platform to guide families with children with autism. Furthermore, results indicated great needs related to information about current available services as well as services that child might receive in the future. This corresponded with McCabe's suggestion that there is a need for more comprehensive referral system so parents automatically are given direction on where they might access appropriate assistance (McCabe, 2008).

In addition to the need for information, needs for "support and advocacy for my child to get service in public school" also stood out. On the one hand, this indicated the eager hope of Chinese families for their children to obtain education. On the other hand, this need reflected the brutal reality that children with autism are still often rejected by public schools in China (McCabe, 2007). Even though many participants reported progress is being made in that schools are more willing to accept the children if families could provide necessary support such as paraprofessionals to guarantee their children's appropriate behaviors, little intervention and education is individually planned and implemented on the children.

Influenced to a large degree by culture and social context, it will take a long time for the Chinese government to react to the current situation. Given the urgency of these needs as well as the reality of the current situation in which the government is not likely to provide these needs in the short run, immediate changes have to come from Chinese families and dedicated

professionals in this field. Based on the needs analysis, there are two strategies that may serve as possible solutions.

First, in terms of needs for providing information, systematic parent training and support programs should be regularly held by experienced parents of children with autism as well as dedicated professionals. Professionals should take the responsibility of teaching and guiding parents. Parents could share their problems and experience of raising their children with each other, which will help them feel more supported and lower their stress. Identified items from this study could serve as the potential topics in such training including (a) understanding the characteristics of children with autism, (b) how to set realistic goals for their children, (c) how to handle their child's behavior, (d) evidence-based practices to teach their children, (e) how to monitor my child's progress, (d) basic coping strategies, and (f) how to make good decisions and choose services for their children. Professionals and parents should try to make good use of the fast growing media technology (e.g. long distance teaching) to make the training accessible to more families from different regions. The material of these training could also be stored for future use and shared online through social media so as to raise social awareness of autism.

Second, given the critical position paraprofessionals are holding in terms of educational services for children with autism, similar training programs should be created to train more skilled paraprofessionals. Currently, paraprofessionals are playing an important role as the only bridge between school and families. They are giving direct instruction to children with autism in public schools. Their teaching skills as well as their ability to handle children's behaviors will directly influence the child's progress as well as whether the child can stay in public school.

These two recommendations should only work as an expedient before the bigger service changes from government took place. After all, it is the government's responsibility to provide appropriate education and welfare services to its citizens regardless of their physical conditions. The identified needs of this study will also provide guidelines for the government to monitor service development. In the long run, the government should provide children with autism with school-based services. It will lower the financial impact on parents, and the services, if provided appropriately, will improve the quality of life not only for children with autism but also for parents of children with autism. Private sector agencies and family support groups will provide auxiliary services only. By that time, families of children with autism will no longer ask for the provision of services but rather the improvement of quality of those services.

Limitations

The findings reported here do not completely capture the complexities of the needs of families of children with autism in China. A limitation of this study was that all respondents were gleaned from families who have already received services and most of them live in Dalian, an urban city in China. The needs of those families who are not receiving services, like those in rural and underdeveloped regions in China, remain unknown. Future research should strive to include participants from other rural or underdeveloped cities to better understand the needs of Chinese families of children with autism.

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Appendix

Adapted version of Family Needs Survey

题目 Item	是的, 而且已经满足 Needed, already met	是的, 但是没有满足 Needed, but not met	不确定 Not sure	不是 No
1. 我需要更多关于我孩子自身的状况或障碍的信息。I need more information about my child's condition or disability.				
2. 我需要更多关于如何应对我孩子行为的信息。I need more information about how to handle my child's behavior.				
3. 我需要更多关于如何教导我孩子的信息。I need more information about how to teach my child.				
4. 我需要更多关于如何与我孩子玩耍或者交流的信息。I need more information on how to play with or talk to my child.				
5. 我需要更多关于如何为我孩子设立实际的(短期和长期)目标的信息。I need more information about how to set realistic goals (short-term & long-term) for my child.				
6. 我需要更多现有的可供我孩子使用的服务的信息。I need more information on the services that are presently available for my child.				
7. 我需要更多有关如何在为我孩子选择或更换服务时做出更好决定				

的信息。 I need more information about how to make good decisions in choosing or changing service for my child.				
8. 我需要关于我孩子治疗或教育进展的信息。 I need to have information regarding my child's therapeutic or educational progress (Waaland et al., 1993)				
9. 我需要更多关于我孩子未来可能会接受到的服务的信息。 I need more information about the services that child might receive in the future.				
10. 我需要更多最新的关于我孩子的法律和政策的信息。 I need more information about the latest policies and laws related to my child.				
11. 我需要更多关于自闭症儿童如何成长的信息。 I need more information about how children with autism grow and develop				
<p>在以上提到的需求中，请选择出最多四个对您来说最重要的信息，并根据其重要性来排序，若无符合可不填。 Please choose up to 4 items you considered as important needs from items in this section and rank the items. Leave blank if not applicable</p> <p>1. 2. 3. 4.</p>				
12. 我相信在公立学校中和其他孩子一起学习是最利于我孩子发展的并且我需要有人来为我孩子得到此服务进行援助和倡导。 I believe study in public school with other regularly developing children is best for my child's development and I need someone to support and advocate for my child to get the service.				

13. 我需要家庭成员中有人能够让我可以倾诉更多的问题。 I need to have someone in my family that I can talk to more about problems.				
14. 我需要更多的朋友让我倾诉。 I need to have more friends that I can talk to				
15. 我需要有更多的机会同其他自闭症孩子家长见面交流。 I need to have more opportunities to meet and talk with other parents of children with autism.				
16. 我需要更多与我孩子老师或治疗师交流的时间。 I need to have more time just to talk with my child's teacher or therapist.				
17. 我愿意更定期的和心理医生见面倾诉问题。 I would like to meet more regularly with a psychologist to talk about problems.				
18. 我需要关于其他自闭症儿童家长的阅读材料。 I need reading material about other parents who have a child similar to mine.				
19. 我需要更多的时间留给我自己。 I need to have more time for myself.				
<p>在以上提到的需求中，请选择出最多四个对您来说最重要的信息，并根据其重要性来排序，若无符合可不填。 Please choose up to 4 items you considered as important needs from items in this section and rank the items. Leave blank if not applicable</p> <p>1. 2. 3. 4.</p>				
20. 我愿意让他人知道我的孩子有自闭症。 I need help to become				

willing to let other people know my child has autism.				
21. 我需要更多帮助来向我孩子的兄弟姐妹（亲的）解释他的障碍。 I need more help in how to explain my child's condition to his or her siblings				
22. 我需要更多有关如何向我亲戚（孩子的祖父母，姑姑，舅舅等等）解释我孩子障碍的帮助。 I need more help in explaining my child's condition to my relatives (child's grandparents, aunts and uncles etc.)				
23. 我的爱人需要帮助来理解并接纳我们孩子现在的状况。 My spouse needs help in understanding and accepting our child's condition				
24. 我需要帮助来了解如何回应我朋友，邻居或是陌生人关于我孩子障碍的询问。 I need help in knowing how to respond when friends, neighbors, or strangers ask questions about my child's condition				
25. 我需要帮助来向其他同龄孩子解释我孩子的障碍。 I need help in explaining my child's condition to other children				
<p>在以上提到的需求中，请选择出最多四个对您来说最重要的信息，并根据其重要性来排序，若无符合可不填。 Please choose up to 4 items you considered as important needs from items in this section and rank the items. Leave blank if not applicable</p> <p>1. 2. 3. 4.</p>				

26. 我需要帮助找到能了解我和我孩子需求的医生。I need help locating a doctor who understands me and my child's needs				
27. 我需要帮助找到能够接待我孩子的牙医。I need help locating a dentist who will see my child				
28. 我需要帮助找到愿意并且有能力照顾我孩子的保姆或者临时看护人员。I need help locating babysitters or respite care providers who are willing and able to care for my child				
29. 我需要帮助找到一个能为我孩子提供课外及周末活动的场所。I need help locating a place for my child's weekend and after-school activities				
30. 我需要我的孩子有除和他父母, 兄弟/姊妹之外的社会交往活动。I need for my child to have social activities other than with his/her own parents and siblings				
<p>在以上提到的需求中, 请选择出最多四个对您来说最重要的信息, 并根据其重要性来排序, 若无符合可不填。Please choose up to 4 items you considered as important needs from items in this section and rank the items. Leave blank if not applicable</p> <p>1.</p> <p>2.</p> <p>3.</p> <p>4.</p>				
31. 我需要更多的帮助来支付家庭的生活费用, 如食品, 住房, 医疗, 穿衣或者交通费用。I need more help in paying for expenses such as food, housing, medical care, clothing, or transportation.				
32. 我需要更多帮助为我孩子购买特殊器械用品。I need more help in				

getting special equipment for my child's needs.				
33. 我需要更多帮助来支付我孩子的教育, 治疗, 日间护理等与他/她相关的服务。I need more help in paying for education, therapy, day care, or other services my child needs				
34. 我或者我的爱人需要更多的辅导来找到工作。I or my spouse need more counseling or help in getting a job.				
35. 我需要更多帮助来支付保姆或孩子的临时看护费用。I need more help paying for babysitting or respite care.				
36. 我需要更多的帮助来支付孩子需要的玩具。I need more help paying for toys that my child needs.				
<p>在以上提到的需求中, 请选择出最多四个对您来说最重要的信息, 并根据其重要性来排序, 若无符合可不填。Please choose up to 4 items you considered as important needs from items in this section and rank the items. Leave blank if not applicable</p> <p>1.</p> <p>2.</p> <p>3.</p> <p>4.</p>				
37. 我们家庭在如何一同探讨并解决问题方面需要帮助。Our family needs help in discussing problems and reaching solutions.				
38. 我们家庭需要帮助来学习如何在困难时期彼此扶持。Our family needs help in learning how to support each other during difficult times.				
39. 我们家庭需要帮助来决定由谁承担家务活, 护理孩子和其他家庭				

<p>任务。 Our family needs help in deciding who will do household chores, child care, and other family tasks.</p>				
<p>40. 在决定和实施我们一家人的娱乐活动方面，我们家庭需要更多的帮助。 Our family needs help deciding on and doing recreational activities.</p>				
<p>在以上提到的需求中，请选择出最多四个对您来说最重要的信息，并根据其重要性来排序，若无符合可不填。 Please choose up to 4 items you considered as important needs from items in this section and rank the items. Leave blank if not applicable</p> <ol style="list-style-type: none"> 1. 2. 3. 4. 				