



Service provision for autism in mainland China: A service providers' perspective

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ABSTRACT

Qualitative semi-structured interviews were conducted with service providers regarding the current healthcare provision and education services for children with Autism Spectrum Conditions (ASC) and their families in mainland China. 10 service providers described the current policy and identified unmet needs within current practice. Providers perceived that children with ASC were an important but under-served group in mainland China. Two levels of service provision related to ASC were identified: (1) healthcare services mainly provided by government authorities; (2) education services mainly provided by the parents of children with ASC. Little cooperation was reported between the two types of providers. The structure of service provision for ASC is under-developed. There is an important need to establish coherent healthcare and education policies to support children with ASC and their families.

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1. Introduction

There has been a marked increase in reported prevalence estimates of Autism Spectrum Conditions (ASC) in the West (Williams, Higgins, & Brayne, 2006). It has been suggested that the development in research methodology and more defined diagnostic criteria for ASC has partly contributed to an increase in the reported prevalence of ASC (Williams et al., 2006; Fombonne, 2009). This increase has led to more focus on healthcare provision and support for children with ASC (Brooks, Marshallsay, & Fraser, 2004). Since ASC was described first in the West, it has been widely investigated and understood by Western populations through various fields of autism research (Levy, Mandell, & Schultz, 2009). Many intervention and treatment programmes have focused on parental training and are family based, so parents in the UK and US are considered to be familiar and accepting of this condition (Edwards & Bristol, 1991).

China's population is approximately 1.37 billion. The reported prevalence of ASC is 1% in the general population in Western cultures (Baird et al., 2006; Baron-Cohen et al., 2009). If this is applicable to the Chinese population, 13.7 million people would be expected to have ASC. This would require a large financial input from the Chinese government. However, service provision related to ASC in mainland China has seldom been investigated. The small number of papers that have been

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published suggest that having a child with ASC in mainland China may lead to even more challenges than others elsewhere (McCabe, 2008a,b). One possible reason is that most families only have one child, parents usually put all their hopes into this child which contributes to considerable amount of disappointment and frustration of parents when they discovered their child has ASC (McCabe, 2008a).

Another possible reason is that autism is considered as one of the conditions of disability in mainland China. Disability is an issue not only involved individual's physical or mental status but also individual's social and economic status. Most different from the West is that in China it is also influenced by culture (McCabe, 2008a). In Chinese culture, mental conditions attract social shame, and denial may be preferable to seeking advice (Mak & Kwok, 2010). In addition, understanding and interpretation of the autistic features may also be influenced by culture. It has been suggested that social, cultural and ethnic background may determine the recognition of whether a specific behaviour could be considered as an indicator of autism (Wallis & Pinto-Martin, 2008). For example, the absence of eye contact is listed as a red flag for identifying ASC by the American Academy of Paediatrics (AAP). However, direct eye contact in China is not considered to be appropriate and is sometimes considered to be shameful (Wallis & Pinto-Martin, 2008).

Cultural influences may partly explain the lack of awareness about ASC in China that may in turns contribute to under-developed services. A policy for education inclusion for children with disability was not developed until the 1990s when the most comprehensive disability laws were issued: the law on the Protection of Persons with Disabilities (National People's Congress, 1990) and the Regulations on Education for Persons with Disabilities (Huang & Wheeler, 2007; McCabe, 2003). The existing literature on special education in China reported that children with more severe disabilities have long been rejected by both mainstream and special education provision (Deng, Poon-McBrayer, & Farnsworth, 2001; McCabe, 2003). The 'Suiban Jiudu' policy (Huang & Wheeler, 2007) (which means attending school in mainstream classrooms) was first developed as a major initiative to promote the implementation of nine-year compulsory education (supported by government) for all children in 1988. However, this policy is not mandatory and cannot guarantee an appropriate education for children with autism (Deng & Mansson, 2000).

There is an emerging awareness about ASC in China, and it is therefore important to assess current practice to improve services for affected children and their families. This study examined the currently available healthcare provision and education services for children with ASC and their families in mainland China. Service providers were interviewed in order to identify future challenges for improvements in policy making and autism research.

2. Methods

2.1. Preliminary identification of service settings: literature search

A literature search was conducted in two Chinese databases, the Chinese Web of Knowledge and Weipu database, to identify previous literature on service provision for ASC in mainland China. The following search terms were used: "Autism" OR "Autistic Disorder" OR "Autism Spectrum" OR "Pervasive Developmental Disorder" OR "Asperger Syndrome" AND "Healthcare" OR "Education". The inclusion criteria for study selection included: (1) the study must be an original report; (2) it must focus on mainland China; (3) it must focus on the healthcare service and education provision for ASC. Information about the main settings of service provision was summarized from the identified studies.

The five papers identified from literature search were used as a preliminary source to identify existing service settings (Chen & Zheng, 2008; Gao, 2005; Zhang & Ji, 2005; Liu & Wen, 2006). One paper described children with autism in a primary school in Beijing city (Gao, 2005). This paper suggested that pre-school children with ASC might be educated at home or in kindergarten. For school age children, there were four education settings: home, special education schools, rehabilitation centres and mainstream primary schools. Nine-year compulsory education (provided by the government) includes mainstream schools and state-owned special education schools (Chen & Chen, 2008). 62% of children with a disability received compulsory education in mainland China (Chen & Zheng, 2008). Of these, 3% were children classified as having a mental disability. 70% of these children received nine-year compulsory education (Chen & Zheng, 2008). No data were available for the percentage of children with ASC attending compulsory education. Two papers listed available intervention methods for autism and mental retardation (Lu, Zhang, & Liu, 2008; Zhang & Ji, 2005). These included: (1) hospital treatment: medication, surgical operations and physical therapy; (2) family treatment: intervention and training by parents or special therapists at home; (3) institution treatment: special therapy and training in a rehabilitation centre; (4) educational treatment: education in a nursery or a kindergarten or a mainstream primary school. Another study based on interviews with 30 parents of children with autism from rural areas in China suggested that rehabilitation and education services for autism in rural areas were less available compared with urban areas due to the financial constraints and the lack of community support (Liu & Wen, 2006).

2.2. Procedure

Based on previous literature, healthcare service providers related to ASC included the government, hospitals and autism research settings. Educational service providers included state-owned special education schools, private rehabilitation or training centres and mainstream primary schools. Therefore, six service settings for ASC in mainland China were identified and five of them were selected for the current study. These settings included a research setting, a clinical setting, a

government authority, a special education setting and a rehabilitation setting. This study was part of a collaborative research project between the University of Cambridge, UK and the Peking University First Hospital, China. This programme of work was considered and approved by the Peking University First Hospital Ethics Committee.

2.3. Participants

In order to reach the appropriate informants within the identified settings, snowball sampling was used. This sampling method was used because the initial informants recommended further relevant participants (Cooper & Endacott, 2007; Cooper, O'Carroll, Jenkin, & Badger, 2007). Fig. 1 shows the process of identification of service providers in this study.

The first two informants from the provider community were identified through academic contacts. A total of 10 informants (see Table 1) were recruited as service providers.

The informants in special education and rehabilitation centres were informed about the design and procedure of this study and also informed that the content of the interview could be used to report on the current situation of service provision for ASC in mainland China. All interviews were conducted after consent was given by the institutes as well as the informants and they were assured confidentiality.

2.4. Semi-structured interviews

Face-to-face interviews were conducted. Written transcripts of the interviews were taken, however no audio recording of the interviews was conducted as requested by the informants. The semi-structured format guided informants through the key themes of enquiry but allowed for flexibility and responsive probing when different informant-prompted topics emerged. The informants in this study will be referred to as P1–10. The key themes of that guided the interviews were as follows:

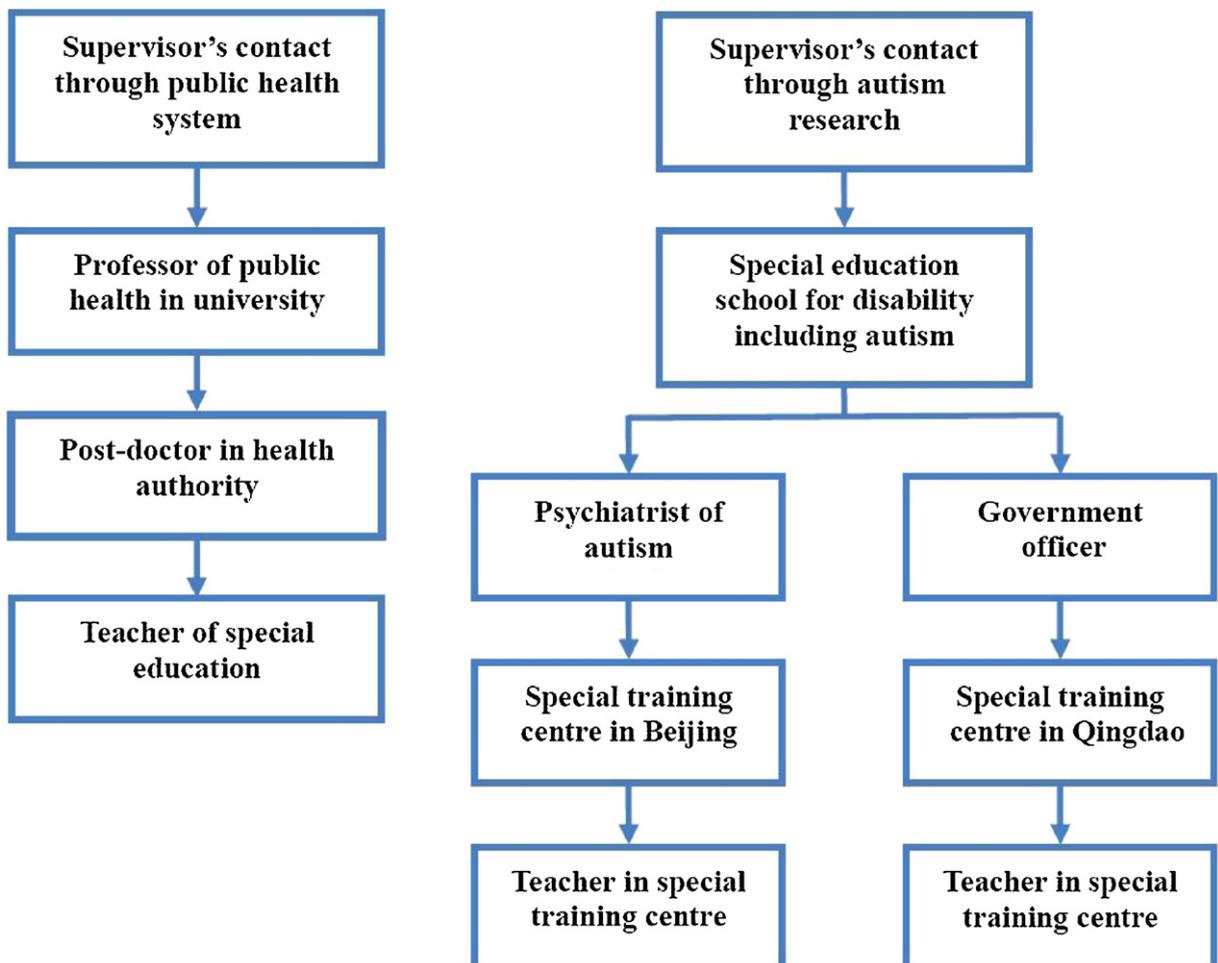


Fig. 1. Snowball sampling for informants as providers.

Table 1
Settings represented by the informants in the interview with providers.

Title of informant	Setting	No.	Setting for autism	Source provider represented	Years of experience related to autism
Professor of public health	Research institute in university	1	Research	University or medical school	30 years research experience in public health
Dean of special education school	Education	1	Intervention and education provision	Private owner	8 years special school for children with disability
Post-doctor in health authority	Health authority	1	Intervention and evaluation	Government-owned rehabilitation	7 years research experience in development of children with disability
Government officer	Policy Authority	1	Policy and service provision	Government	5 years experience in autism
Psychiatrist	Hospital	1	Diagnosis	Hospital/government	30 years experience in child psychiatry specialised in the diagnosis of autism
Headmaster of special centre	Special training centres	2	Intervention	Private owner	5 years experience in autism intervention
Teacher of special training centre	Special training centres	3	Intervention	Private owner	2–6 years experience in autism intervention

Note: The pathway of how the informants as service providers were identified and their related experience in autism in this study.

- (i) History of ASC in mainland China;
- (ii) National and local level health services for ASC;
- (iii) Key issues on current practice for ASC;
- (iv) Healthcare differences between regions;
- (v) Local educational settings for children with ASC;
- (vi) Advantages and disadvantages of the state-run and private educational services.

2.5. Data collection and analysis

A generic qualitative method was adopted. The method included participant recruitment, interviews, transcription, checking, reflection on the interviews and analysis via thematic coding (Robertson, Richards, Egan, & Szymlek-Gay, 2012). The hand recorded interview transcripts were the primary data. The researcher checked the key points of the transcripts with the informant first. Transcripts from each interview were summarized and sent back to the informants to check for accuracy. The informants' comments were incorporated into the transcripts. The transcripts were then read by the first author to note relevant ideas and identify possible text segments for further coding in Microsoft Word and Excel. The codes were either inductively drawn from the data or deductively and iteratively refined. The codes were rechecked by the first author after the first entry to ensure accuracy. In the next step, the coded data were categorized into meaningful patterns for further analysis and reporting. Qualitative analysis was conducted to make the experiences and personal dimensions reflect the current healthcare system for ASC (Russell, Kelly, & Golding, 2010).

3. Results

3.1. Context

All informants had a median of 7 years experience (range 2–30 years) working with children with ASC and their families. Their experience with ASC was established based on their role as service providers in different service settings in mainland China.

3.2. The introduction of autism in mainland China

Until now, there has been no available literature either in Chinese or English about how the term 'autism' was has been understood by Chinese psychiatrists. The psychiatrist indicated that the term 'autism' was likely to be introduced to China by a child psychiatrist named Tao Kuo-Tai in 1949. Tao Kuo-Tai went to America to study Child Psychiatry at the Institute of Psychiatry at the University of California in 1948, sponsored by a scholarship from the World Health Organization (WHO) (Tao, 1987). A year later, he came back to China in 1949 to develop the discipline of Child Psychiatry. He established the Nanjing Child Mental Health Research Centre on 1st June, 1984. Since then, much research on autism has been conducted with the support of this centre (Cheng, Ge, Sun, et al., 2009; Cheng, Ge, Xiao, et al., 2009; Jiao et al., 2010). There are two literal Chinese translations of the term 'autism' ("Gudu Zheng" and "Zibi Zheng") and both mean the disease of loneliness or self-isolation. It is described as a condition in which a person usually has difficulties with

communicating or forming relationships with others (Luo, Li, & Chen, 2000) and had a tendency to keep to him or herself. These two terms refer to the same condition and were used interchangeably in China (The Chinese Autism Society, 2003). In medical text books, autism as a diagnostic term was first included in Child Psychiatry in the 2nd edition of Chinese Psychiatry in 1989 with a description as a comprehensive developmental disorder (The Chinese Autism Society, 2003). Over recent years, the psychiatrists and researchers in the West have tended to adopt the terms 'autism spectrum disorders' or 'Autism Spectrum Conditions' to capture more subtypes of ASC, reflecting autism as a spectrum, with childhood autism at one extreme, and Asperger Syndrome at the other. In China, the term childhood autism has been used most frequently. Research on ASC has mainly focused on childhood autism in mainland China, rather than viewing autism as a spectrum (Ren, Duan, & Xu, 2003).

"The term 'Gudu Zheng' and 'Zibi Zheng' was probably generated as the translation of autism from the West by Professor Kao-tai Tao. . . He went to America for a year and studied Child Psychiatry and he was also the first doctor that reported the diagnosis of autism in mainland China, the terminology 'childhood autism' was used most frequently since we first heard about the existence of autism." (P1)

"Most studies of autism in mainland China have focused on childhood autism rather than the autism spectrum since we still don't have a very clear definition and diagnostic criteria for the spectrum." (P3)

3.3. *The development of research on autism*

The first research article about autism in mainland China was published by the child psychiatrist Tao Kuo-Tai in 1982 (Tao, 1982) reporting four cases of autism. The first publication in English about Chinese children with autism five years later was also written by Tao Kuo-Tai (Tao, 1987).

"... In China, the branch of developmental psychiatry has not been developed into an independent department yet, so there has been no specific research team for autism in universities. . . so the training of clinicians about autism largely depended on the autism referral rate to that particular hospital. . ." (P5)

ASC is a relatively new research topic in mainland China. Research on ASC can be found in various departments including Psychiatry, Psychology, Education, Social Science, Pathology, Genetics, Neuroscience, Public Health and Epidemiology (Liu & Wen, 2006). Medical training in mainland China for undergraduates does not include psychiatry. Therefore, clinicians who can give a diagnosis of autism in mainland China either learned from a graduate supervisor whose work was related to autism or s/he had experience in a psychiatric department in hospital in their career. Research on ASC in mainland China has mainly focused on aetiology, specifically concerning genetics (Cheng, Ge, Xiao, et al., 2009; Wang et al., 2008; Wu et al., 2005).

"... Medical training in China for undergraduates is five years, after which medical students need to pass a practitioner examination in order to become a registered doctor. However, in the basic five-year training, we usually do not have courses in Psychiatry, rather we have courses on Internal Medicine, Surgery, Obstetrics and Gynecology, and Paediatric. . . So most students may not have heard of autism. . . until they are at graduate level and learned from supervisors who had been involved in autism or mental health." (P1)

"When I was in medical school, I did not know about autism since we did not learn it. . . after graduation, I became a doctor in this hospital. . . I worked in the Paediatric department for a while when my attending physician was an expert of autism who was one of the earliest doctors in China that can diagnose autism. . . after many years, we were transferred to the psychiatry department and opened this out-patient clinic for autism." (P5)

Epidemiological research focusing on prenatal and perinatal risk factors (Zhang et al., 2010) and autistic characteristics has usually been carried out in hospital settings. According to the informants from research institute (P1) and health authority (P3), there were almost no epidemiological studies before the survey for autism conducted in 2000 (Luo et al., 2000).

"... there have been two national surveys of disability so far. One was in 1987 and the other was in 2006 (Chen & Chen, 2008; Chen & Zheng, 2008). In the first national survey, autism was not included as it was barely known about in China at that time (Chen & Zheng, 2008). . ." (P3)

"... in 2001, there was a survey for autism conducted in 12 cities in mainland China which was hosted by China Disabled Persons' Federation (CDPF), Ministry of Health and Ministry of Public Security. . ." (P1, P3)

"... in 2004, the Beijing CDPF hosted a survey on autism in 18 regions in Beijing using a clinical questionnaire without further follow-up assessments. . . the second national survey in 2006 included autism (Chen & Chen, 2008). . ." (P3)

3.4. *National and local policy for autism*

The informants from the health authority (P3) and special education services (P2) stated there was no unified national level policy for ASC, although many regions had their own local policy that varied across China. In some regions, families with children with autism are provided with an allowance from the government. However, the amount of the allowance differed among different regions.

Beijing (as the capital of China) is supposed to have a better political and economical environment than average regions in mainland China. Thus, a relatively better policy for children with special needs is to be expected in Beijing. Five informants indicated one requirement of having a certification of disability and allowance in Beijing is that the child is a legal resident of Beijing.

“...the local policy depends on whether the local population is familiar with this condition or not. . . I learnt this from the parents of children with autism from other provinces, they told me about their local policies on autism. . . the policies vary across regions. . . in Beijing, the Beijing China Disabled Persons' Federation (BCDPF) provides £50 monthly as an allowance for each child who both has a “Hu Kou” (residential identification) and a disability certificate. . . however, the allowance is not directly accessible to parents. They obtain the money once, at the end of year, by invoicing for the special training payments in rehabilitation centres. . . there are certain conditions of the reimbursement. . .” (P3)

“If the child is trained outside Beijing, the £50 cannot be used to compensate the payment in this case. . . in Beijing, the disability certificate requires the confirmed diagnosis from a well-known Psychiatric hospital and the “Hu Kou” (residential identification) in Beijing.” (P2)

When asked the main issues on autism from the policy making and management point of view, three informants stated that there has been increased awareness about autism as a result of the media publicity and the widespread information that is now available about autism via the internet. Usually, when parents become concerned that their child may have autism, they try to find information online prior to seeking a diagnosis.

“...there has been a marked rise in autism concerns since 2000 which requires recognition with more provision for children with autism and their families. . .” (P4)

“...much focus has been put on autism by the media since there have been many TV programmes about children with autism. . .” (P4)

“...there are many children who come from all over China to get into hospitals or institutes which have become well-known in this field to get a diagnosis. . . the parents usually can get this information through an internet search. . . or have heard from other parents. . .” (P5)

Although children with autism have been given more attention than in previous years, the system of service support from the government and society is still under-developed with limited resources that cannot fulfil the needs of these children and their families.

“...as there are few government supported special training and educational institutes for autism, many private institutes have been established by parents of children with autism. . . because of the lack of support, once diagnosed, it is usually the parents who have to pay the costs to support their child with autism. . .” (P6)

“...in each setting related to autism, people tend to work separately and independently. . . they seldom work together as a team, so there is little interaction and collaboration among Chinese researchers or officers to make any scientific or policy breakthroughs about autism. . . often the parents of children with autism are the ones that are suffering from this situation. . .” (P4)

3.5. *Current practice for autism*

The informant in the Psychiatric hospital described a general delay in diagnosis for autism because many parents did not seek diagnosis of their children for various reasons. Some parents did not realize there was a problem with their child until someone else pointed it out, while some parents may have noticed early on that there were issues but did not think it was something serious. Some parents were simply reluctant to accept the condition.

“There are many children who were diagnosed many years after their parents sensed there might be something wrong with the child. . .” (P5)

“Many parents have been reluctant to accept the diagnosis of autism when they were first given it. . . because this means their child has a mental disorder. . . this is especially difficult to accept if their child appeared to have typical development in early childhood, or if the child has high-functioning autism. . .” (P5)

Once the child was taken to a clinical setting for a diagnosis, the diagnostic process was relatively short due to limited resources and a lack of diagnostic instruments.

“The diagnosis for autism is usually no more than 30 minutes. . . it usually contains a time for parents to complete some questionnaires and coding. . . then the interview with parents. . . and an observation with the child by asking him or her to complete several tasks. . . actually in many cases by simply observing the child, you can tell whether he or she has autism or not. . .” (P5)

The questionnaires used in mainland China are old versions of questionnaires that were adopted from the West in the 1980s, such as Autism Behaviours Checklist (ABC) (Krug, Arick, & Almond, 1980; Yang, Huang, Jia, & Chen, 1993), the Clancy Autism Behaviour Scale (CABS) (Clancy, Dugdale, & Rendle-Short, 1969; Wang, Wang, & Wang, 2003) and the Childhood

Autism Rating Scale (CARS) (Schopler, Reichler, DeVellis, & Daly, 1980). These urgently need to be updated. The Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000) and the Autism Diagnostic Interview-Revised (ADI-R) (Lord, Storoschuk, Rutter, & Pickles, 1993) have not been well adapted in clinical or research settings in mainland China.

“There is no national screening programme for autism in clinical settings during routine developmental check-up for children... however in our psychiatric department we have adopted Chinese versions of Western screening questionnaires to initially evaluate the child at referral... after the parents fill in the questionnaires we calculate the score, and then we spend some time playing with and observing the child. On the basis of this, a decision about a suitable diagnosis is made...” (P5)

“We have translated the ADI-R and conducted a pilot study and validation... but it has not been generally used in clinical diagnosis since it is quite long...” (P5)

The informant also indicated that clinicians in China often felt frustrated since it seemed there was no medication or other treatment that could act to alleviate symptoms of autism.

“I felt quite sad and powerless when I saw some very severe cases and they came to diagnosis too late... following diagnosis, there is very little we can do to help the child other than recommending special training...” (P5)

3.6. Local level educational service for autistic children

Informants from the health authority and policy authority reported the availability of local educational services for children with autism.

“Children with an existing diagnosis of autism usually cannot enter mainstream primary schools, since their behaviours will be easily recognized by teachers and other children... It might be possible that children with autism with normal intelligence could stay in a mainstream school as long as their examination scores does not influence the overall academic performance of the class. But still very few of them could stay...” (P4)

“From the records in our department, most children who have been diagnosed and have a certificate of disability are not in mainstream schools. Some of them are in private training centres for autism, while some of them are in government-supported or private special education schools... I am not sure whether there are children that have been kept at home...” (P3)

During the interviews with the headmasters of two well-known private rehabilitation centres for autism, the general operation of these centres was described as follows.

“When the child enters the school, professionals in our centre will evaluate the ability of the child in the following domains: cooperation and reinforcement effectiveness, visual performance, receptive language, motor imitation, vocal imitation, requests, labelling, intra-verbal and spontaneous vocalization... all these abilities will be evaluated and updated daily by the teacher in the one-to-one training class for each child.” (P7)

“During daily training, each child has to have an adult to accompany him or her throughout the whole day”. (P7)

“During weekdays, the training usually takes place from 9am until 4pm... the training is like a primary school from Monday to Friday with Saturdays reserved for parental training.” (P6)

Courses in private centres included individual training in sensory integration, fine motor skills, music, video and sports. In one centre each class lasted about 45 min, while in the other centre it was 30 min. Each child had a fixed curriculum designed by the professionals following an evaluation. These two centres mainly used the Adaptive Behaviour Analysis theory (Hilton & Seal, 2007) (ABA), Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) (Panerai, Ferrante, & Caputo, 1997) and Relationship Development Intervention (RDI) (Gutstein, Burgess, & Montfort, 2007) as the theoretical basis for the training, adopted from the West. In general, three months was the minimum training period for each child required by private centres. There were also other training centres which offer training courses for sensory integration, fine and gross motor skills, and language skills but they are not exclusively for children with autism. These centres are privately owned and some of these centres have become chain business.

The two informants from the private centres also indicated that parents had concerns about current educational services.

“Our centre is only able to accept children who are between 3 to 6 years old. If they have reached primary school age, we have to let them go but many parents reported that they would end up nowhere to go and they wanted to come back...” (P8)

“The number of government-supported special schools is very limited. They do not provide special intervention for children with autism. So the parents were concerned that, if they send their child to such school after intervention in our school, their child might soon revert back to their original condition and therefore have wasted all the years of intervention...” (P8)

An interview was conducted with the Dean of a private special education school. Most of the children in the school were under 13 years old and were allocated into different grades according to their intellectual ability. The curriculum was similar to that in mainstream schools with special training lessons. One of the training lessons included making ceramics, which was adopted from Japan. When the teachers were confident about the learning ability of the child, they would recommend the

child progress to a higher grade to study. There was a mainstream primary school nearby. When the child was considered capable enough, the teacher would send him or her to this primary school to study with typically developing children. This was called the integration education programme. However, only a small proportion of the children in this special education school had autism.

3.7. *Advantages and disadvantages of state-run and private educational services*

3.7.1. *Lack of resources in state-run educational services*

The informant from health authority reported that the Beijing China Disabled Persons' Federation (BCDPF) has a state-run rehabilitation centre which provides several training courses for children with autism such as sensory integration, fine and gross motor skills, and the speech therapy. These courses were relatively cheap and their costs can be reimbursed from the government allowance. However, given the shortage of special teachers, there are a limited number of places available in such centres.

“The rehabilitation centre of BCDPF was small and has a limited number of therapists and special teachers. . . the intervention programmes are separate which are different from private centres where the programmes are all day long and comprehensive. . . we offer intervention as modules. . . for example, once or twice a week for fine motor or sensory intervention. . . we can only cater for a small number of children due to a shortage of resources. . .” (P3)

There was no such rehabilitation facility in the state-run Psychiatric hospital.

“We only provide diagnosis and basic examination to children in our clinic. We don't have therapists here, so after diagnosis, the parents need to find a rehabilitation centre for intervention or other educational settings. . .” (P5)

The informant from health authority indicated that there were state-run special education schools in Beijing.

“Generally, each district has one school run by the government which is relatively cheap. . . the tuition fee can be reimbursed by the government allowance if the child has a disability certificate. . . however, all of these schools are not specialised for children with autism. . . most children in those public special schools were children with other mental or physical disabilities. . . children in all age groups are mixed together. . . since each district only has one state-run special school, the number of children that can attend such school is limited, and thus not all local needs are catered for. . . many parents have to choose other private special schools like us in order to get their child educated. . .” (P2)

3.7.2. *A developing structure for special teachers and therapists in private centres*

Compared with the shortage of resources in state-run rehabilitation centres, certain private centres tried to develop their own structure of coordinated training and professional development for special teachers and therapists. Three informants who were teachers in two private centres reported that teachers in their special training centres were mainly recruited from special education colleges. In one centre, they were required to pay a training fee to join an ABA training programme, run by the centre. The training programme for teachers consisted of two parts: theory of ABA and ABA practice with children. All the trainers in the training centre were experienced special teachers of autism. There were usually 30–40 participants at the beginning of the training. However, after two examinations only 10–13 trainees actually became teachers in this centre. This maintained the quality and manpower of the intervention programme.

3.7.3. *Reported improvement of children with autism by intervention in private centres*

The most effective part of training was the individual training or ‘one-to-one training class’, according to the teachers. In one centre, this individual training must be carried out without the parents, while in the other centre, the training required the caregiver to be present. After each individual training class, the teacher reported progress to the parent. This included the improvements the child made that day and instructions on how to continue the training at home.

“The child with autism needs to be trained in order to foster basic daily routines. . . the training helps to improve the ability of the child and to make it easier for the parents to cope with their daily lives.” (P8)

“Most children made progress within three months, especially in speech. . . many children who were unable to speak when they first entered the training programme began to speak during their training. . .” (P9)

3.7.4. *Non-unified regulations on intervention among private centres*

Although teachers reported improvements of children with autism following intervention, the regulations and training strategy in private centres lack of coherence. They usually have different and sometimes contradictory theories regarding what is best for the child in terms of intervention. This makes it difficult for a child to adjust if the child has to be transferred from one centre to another employing a different strategy (e.g. the presence or absence of parents during individual training sessions).

“. . . we do request one caregiver to attend the one-to-one instruction training. . . because we want the parents to learn the methods and the purpose of training. . . only in this way, they can continue the training at home. . . only one hour one-to-one training session a day is less than adequate. . . the child needs to be trained during daily life, not only in class. . .” (P8)

“...we don't recommend the parent to be present during the one-to-one training...we found that many autistic child behaved differently in front of their parents...they become more difficult to teach when their parent is there...every teacher reports progress and gives instructions to parents after each class...” (P9)

4. Discussion

The main aim of this research was to learn the current situation of healthcare and education service for children with ASC in mainland China from the service providers' perspective. Interviews with several key informants from the health and education system were conducted. The interviews were guided by several key themed questions but not limited to these questions. The findings from each provider brought up several common issues on service provision in main settings for ASC.

4.1. Government settings

Unlike the UK and US (Johnson & Myers, 2007; Le Couteur, 2003), there has been no standardised national policy or strategy for ASC in mainland China. Different regions had local policies which usually included a disability certificate for autism and a monthly or annual allowance for the child. Government bodies such as the China Disabled Persons' Federation (CDPF) and their local branches were generally considered as the responsible authority to issue the disability certificate and the allowance. However, if the children did not have a disability certificate or they attend the rehabilitation centres outside their residence stated in their “*Hu Kou*” (residential identification), they could possibly not get the allowance from the government.

4.2. Research settings

Autism researchers are scattered across different settings. The network for sharing resources and collaborations has not yet been established, which has led to limited capacity for further research in autism. Most available studies were reports from the national survey for disability in 2001 and 2006. But those studies focused only on Childhood Autism and there had been almost no research about the whole autism spectrum (Chen & Chen, 2008). In the West, studies have been conducted across various research themes, such as epidemiology, genetics, neurobiology, psychosocial and pharmaceutical interventions. In mainland China, such a structure has not yet been established.

4.3. Clinical settings

ASC are not taught during medical training until graduate school. However, there are a limited number of psychiatrists or paediatricians with a special interest in autism, and therefore the traditional education pattern in medical schools limits the chance of becoming a health professional specialising in ASC. This has led to an uneven distribution of knowledge of autism across mainland China. Thus, people who live in a region with a high level of awareness about autism would benefit from the local policy than those who lived in a region without such awareness (The Chinese Autism Society, 2003).

In the Western clinical settings, there is generally a multidisciplinary team for diagnosis of ASC including a psychiatrist or paediatrician, a language therapist, occupational professionals, a developmental therapist and a nurse or teacher from the school (Dover & Le, 2007; Le Couteur, 2003). In mainland China, there is no unified department for the clinical diagnosis of autism. Therefore, children with autism are usually diagnosed by physicians, psychiatrists and paediatricians. Diagnosis usually depends on the judgement of the clinician to whom the child was referred to (Zhang et al., 2011).

4.4. Rehabilitation settings

The findings of this study confirmed previous studies which suggested that most children with a diagnosis of autism were educated mainly in special rehabilitation centres (McCabe, 2003, 2008b). Some of the centres were specific for training children with autism according to the ABA, TEACCH and/or RDI theories. There were also other centres providing training courses in specialised areas such as the sensory and audio integration, language therapy, fine and gross motor skills, which cater to the individual needs of children. The autism training centres were run as primary schools, which often require the parents to help for the entire day. Most of these centres are run as businesses and the parents are responsible for paying for the majority of the costs. The minimum training period was arbitrary (three months) and this was determined by the centres themselves. There was no scientific evidence to support the length of the training period. According to teachers from the special training centres, a large proportion of parents noticed improvements in their children within three months. In mainland China, parents refer to the programmes provided in such centres as ‘training’ or ‘rehabilitation’ programmes, whereas in the UK and the US, the terms ‘treatment’ and ‘intervention’ are used. This semantic difference may reflect important underlying cultural influences between the East and West.

4.5. Education settings

Most mainstream schools do not accept children with autism unless the child is high-functioning and has not been given a formal diagnosis (McCabe, 2002). There are special schools that provide integrated education by mixing the typically developing children with children with autism together. However, integrated education is relatively expensive and only exists in a limited number of schools. The state-run special education schools usually mix children with different disabilities together. These schools are generally not specific to autism and the number of state-run special schools is limited.

4.6. Early detection and intervention

It is suggested that early detection should be followed by strategies of early intervention which could potentially benefit the children with autism, which could be crucial in some cases (Baird et al., 2001; Tebruegge, Nandini, & Ritchie, 2004). The families with children with autism in the UK get more support from the government and community than in mainland China. Thus, a policy and strategy for early detection of children with ASC in mainland China is essential, which could include screening during routine check-ups.

In mainland China, the one child policy generally means that each family only has one child. Chinese parents usually have high expectations about their child's development and future prospects. The informants from the hospital and health institute reported the desire of the parents in mainland China to seek interventions for their child once they had accepted the autism diagnosis. However, the availability of well-established special training centres for autism is less than adequate. Since most of the established centres were privately owned businesses, the tuition fees are quite high which causes a great burden on families. Thus, there is an urgent need to have more publicly funded training centres for children ASC to cater to their needs in mainland China (Jing & Hong, 2004).

4.7. Implications for professional training and research

There is a lack of trained professionals in the field of recognition and detection of ASC in China which is partly due to a lack of education among medical students during their basic training. This would be improved greatly if psychiatry could be included in the medical training programme or become a branch of specialist training. Another option would be to include training about autism into the field of paediatrics. Without the basic knowledge and awareness among the clinicians, it will be difficult to implement early detection and diagnosis for ASC in mainland China. The improvement of knowledge would encourage more researchers and clinicians to conduct research on ASC. So far, research on ASC in mainland China is limited. It would be very valuable if a Chinese network for ASC research could be established to encourage collaboration and effective resource utilisation. This research highlights the gap in government support for children with autism and their families both in service provision and research. One of the obstacles for policy making might be the lack of data on the prevalence of ASC in mainland China. It will be difficult to estimate the needs of children with autism without validated screening and diagnostic instruments to help accurately determine the population prevalence of ASC. Without this information, policy making will be impossible. Thus, a prevalence study for ASC would be a good start for further research and policy making.

4.8. Implications for healthcare service provision

The lack of standardized diagnostic and assessment tools on ASC in mainland China was highlighted in this study. Government input could help with the introduction and adoption of more advanced assessment tools to improve the diagnosis of ASC by training professionals and developing a multi-disciplinary assessment team. The multi-disciplinary assessment model had been developed in the US (Johnson & Myers, 2007) and UK (Dover & Le, 2007; Le Couteur, 2003). It has also been adopted in Hong Kong (Fung & Wong, 2005). In a multi-disciplinary team, each health professional has their own role and responsibility. They contribute and coordinate together all of their knowledge and results from their individual evaluation of the child to make a diagnosis and to form an individual plan (Wong & Hui, 2008). In order to achieve this, the gap between research and clinical practice should be breached by applying standardised methodologies for diagnosis and advanced intervention in clinical settings. This would help to support clinicians and improve their confidence in the diagnostic decision making. Informants were aware of the time delay between the first concerns about ASC and an eventual diagnosis. Children with severe autism usually display typical autistic features around the age of 2–3 (Mandell et al., 2010). It would therefore be helpful to improve public knowledge about ASC in order to assist early recognition. There is a need to develop the healthcare system and put in place more resources in clinical settings for children with ASC and their families.

4.9. Implications for educational service provision

Most children who had been diagnosed with ASC in mainland China were not in mainstream education but in a private rehabilitation centre or a state-owned special education school. There were a limited number of state-run special education schools and most of them were not specific for children with ASC. This study highlighted the concerns from service providers in mainland China towards the education system for children with ASC. Previous research reported that many children with

autism attend mainstream schools because of personal connections (McCabe, 2003) rather than the implementation of the “Suiban Jiudu” policy.

In the UK, each school has a Special Educational Needs (SEN) register which monitors children who require access to additional support beyond the ordinary curriculum offered by schools (Baron-Cohen et al., 2009). Children on the SEN register can apply for a ‘Statement of Special Educational Needs’. This states a child’s needs and the help that they should receive at school. This statement is reviewed every year to make sure the required extra help has been provided (Baron-Cohen et al., 2009). Three decades ago, the inclusion of education for children with different abilities was achieved through a great effort from the parents in the US. It is possible that China is in the middle of a transition, previously experienced in the West (McCabe, 2003).

4.10. Limitations

This study has several limitations that should be acknowledged. The first is to question the reliability and generalisability of snowball sampling. The informants were approached mainly through academic links. The description of the healthcare service for autism is predominantly from their personal point of view. However, during these interviews the informants reported overlapping information, which provides some confirmation of reliability of the accounts. Second, although the sample size in the current study is considered as adequate for generating sufficient in-depth data in qualitative research (Strauss & Corbin, 1998), the number of informants in each service setting was limited. The informants in this study were professionals in specific fields that might limit the representativeness of the views of their field as a whole. Thus, future studies should recruit more informants within each service setting. Third, the sources of informants and the types of service settings in this review were limited; there may be other settings related to ASC that were not covered in this study. Fourth, the interviews were not audio-recorded, so the hand-written transcript did not capture every word reported by the informants. It is possible that some content was missed out. However, transcripts were sent back to the informants to check for accuracy, it is reasonable to assume that the major topics should have been covered. Fifth, although all the transcript and coding results were double-checked, the transcript and the coding was conducted by a single researcher. This might lead to a bias in the interpretation of content.

5. Conclusion

There are two types of health services for autism in mainland China. One is government-supported service that includes local government, the Chinese Disabled Person’s Federation, research institutes and hospitals. The other is parent and privately supported service which includes parent-established training centres and special schools for children with disabilities. In mainland China, these two seem to operate in parallel. Parents depend on government health services for obtaining a diagnosis. However, for intervention parents, largely depend on a service that is mainly provided and funded by their own. There is little connection between government and private services, resulting in a shortage of training centres and a huge burden for parents to support their children. There is an urgent need to establish a more developed healthcare and education service system for children with autism in mainland China.

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