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Review article

A review of healthcare service and education provision of Autism Spectrum Condition in mainland China

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ABSTRACT

Little is known about the current situation regarding Autism Spectrum Conditions in mainland China. Electronic databases and bibliographies were searched to identify literature on service provision for ASC in both English and Chinese databases. 14 studies and 6 reports were reviewed. The findings of identified papers on service provision were summarized according to four settings for ASC including healthcare, mainstream education, private special education, and state-run special education. The literature on the situation of the healthcare system and educational services for children with ASC in China was profoundly limited. There were great financial problems faced by the parents of autistic children which were partly due to the under-developed healthcare and educational system for ASC.

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1. Introduction

Autism Spectrum Conditions (ASC) are neurodevelopmental conditions leading to impairments in social interaction, communication alongside repetitive and stereotyped behaviours and narrow interests (WHO, 1993). ASC includes autistic disorder, Asperger's Disorder and Pervasive Developmental Disorder-not otherwise specified (PDD-NOS) (American Psychiatric Association, 2000)). Recent epidemiological studies from the UK and US suggest the prevalence of ASC is around 1% (Baron-Cohen et al., 2009; Kogan et al., 2009). Research on the epidemiology and prevalence of ASC in mainland China is still lacking. A review (Sun & Allison, 2009) reported that prevalence estimates for Childhood Autism in mainland China were much lower than recent studies in the West (Baird et al., 2006; Baron-Cohen et al., 2009; Rice, 2011). The population of China exceeds 1.37 billion. Therefore, there are likely to be 13.7 million individuals who have ASC (diagnosed or undiagnosed) and who may require support and services.

Children with ASC and their families require a range of assessments and support services (McLennan, Huculak, & Sheehan, 2008). In the UK, although there is no national screening or surveillance programme for ASC, various bodies developed a strategy of good practice, including the Autism Spectrum Disorders Good Practice Guidance (GPG) (McConachie & Robinson, 2006). The National Autism Plan for Children (NAP-C) and the more recent NICE guidelines provided recommendations for service structure on the identification, diagnosis and early intervention for ASC (Le Couteur, 2003; National Institute of Health and Clinical Excellence, 2011). In the US, practice guidelines for service provision of ASC have been published regularly since 1999 by the American Academy of Child and Adolescent Psychiatry (Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1999). The American Academy of Paediatrics (AAP) proposed a developmental surveillance and screening algorithm for paediatric preventive care visits for ASC in 2006 (Johnson & Myers, 2007).

After diagnosis, intervention programmes are recommended in both UK and US. The NAP-C (NAS 2003) recommended that intervention for autism should commence no later than 6 weeks following the diagnosis (Jones, 2006). In the US, several types of intervention programmes have been provided for children with ASC, such as speech therapy, social skills teaching, behaviour management programmes, and service coordination/case management (Bitterman, Daley, Misra, Carlson, & Markowitz, 2008; White, Scahill, Klin, Koenig, & Volkmar, 2007). The evaluation of service provision and delivery for individuals with ASC has been investigated in both the West and East (Golnik, Ireland, & Borowsky, 2009; Imran et al., 2011; Rahbar, Ibrahim, & Assassi, 2011; Ruble, Heflinger, Renfrew, & Saunders, 2005).

Mental healthcare in mainland China has been recognised as a significant problem (Park, Xiao, Worth, & Park, 2005). The development of service system for mental health has undergone many changes. Regarding the healthcare system, the communist government built strong collective healthcare and public health systems after 1949 (Park et al., 2005), aiming to provide universal healthcare access with relatively low costs. However, during the Cultural Revolution (1966–1976), the development of all critical domains such as the economy, health, education in mainland China was halted (McCabe, 2003). Following the introduction of 'Reform and Opening', the reform in the health system started in the 1980s. The reform reduced the central governmental support while expanding the functions of the market which privatized the health system (Huang, 2002; Park et al., 2005). However, a consequence of this reform was the exacerbation of inequality of healthcare access especially between urban and rural areas (Ho, 2010; Huang, 2002). Children with autism were first diagnosed in mainland China in 1982, when it was reported by Dr Tao in Nanjing (McCabe, 2008b, 2008a; Tao, 1982, 1987). Nowadays, in mainland China, ASC is categorised as a mental disability which comes under the monitoring and administration of a government body called the China Disabled Persons' Federation (CDPF). The CDPF is responsible for people with disabilities and also for issuing a disability certificate, which is a prerequisite for receiving a government allowance.

Similarly, the reform in the education began soon after the commencement of the Reform and Opening. The promotion of integration education for children with disability was launched in the mid 1990s (National People's Congress, 1986) through the introduction of a Law of the People's Republic of China to protect individuals with disabilities (National People's Congress, 1990) and Regulations on education for individuals with disabilities (State Council, 1994). Those laws achieved the implementation of a compulsory nine-year education for all children (McCabe, 2008b). In 1988, The 'Suiban Jiudu' (attending schools in regular classroom) policy was issued to encourage children with disabilities to attend mainstream school classrooms (Huang, 2002).

However, children with autism were reported to have been turned away from both mainstream and special education for a long time (McCabe, 2003) due to a lack of resources and knowledge about autism. Different types of educational

Box 1. Literature search strategy for review of health and educational service for ASC in mainland China**Search 1:****Weipu database** (searched on 27th December 2011)

Years (1989–2011)

Step 1: “Gu Du Zheng (Autism)”/[Key words] OR “Zi Bi Zheng (Autism)”/[Key words] OR “Gudu Zheng Pu Xi Zhang Ai (Autism Spectrum)”/[Key words] OR “Guang Fan Xing Fa Yu Zhang Ai (Pervasive developmental disorder)”/all [Key words] OR “Ai Si Be Ge (Asperger)”/[Key words]

Step 2: “Validation”/[Key words] OR “Screen”/[Key words] OR “Screening test” OR “Validity”/[Key words] or “Reliability”/[Key words] AND results in Step 1

China Web of Knowledge (searched on 27th December 2011)

Year (Until 2011)

Step 1: “Gu Du Zheng (Autism)”/[Key words] OR “Zi Bi Zheng (Autism)”/[Key words] OR “Gudu Zheng Pu Xi Zhang Ai (Autism Spectrum)”/[Key words] OR “Guang Fan Xing Fa Yu Zhang Ai (Pervasive developmental disorder)”/all [Key words] OR “Ai Si Be Ge (Asperger)”/[Key words]

Step 2: “Validation”/[Key words] OR “Screen”/[Key words] OR “Screening test” OR “Validity”/[Key words] or “Reliability”/[Key words] AND results in Step 1

Search 2:**Weipu database/China Web of Knowledge** (searched on 27th December 2011)

Year (Until 2011)

“Gu Du Zhen (Autism)”/[Key words] OR “Zi Bi Zhens (Autism)”/[Key words]

programmes were established to serve children with disabilities, which included special schools, special classes, and state-run special education of children with mild cognitive disabilities and sensory impairments who can function relatively well in the classroom. Since the early 1990s, several private and state-owned intervention programmes for children with autism were gradually developed (McCabe, 2003).

However, to date, little is known about how current service provision works for individuals with ASC in mainland China. This study reviews the available literature on service provision for people with ASC in mainland China, and to learn about the current situation regarding ASC and identify possible directions for improvements in future research and service planning.

2. Methods

2.1. Literature search

Literature searches were conducted in January 2012 in four databases (English databases: Pubmed and Web of Knowledge; Chinese databases: Weipu and China Web of Knowledge) for publications focusing on healthcare and education provision for individuals with ASC in mainland China. Literature searches were conducted with broad search terms in order to identify all available studies. The search strategy is shown in Box 1.

2.2. Data abstraction and inclusion criteria

After abstract searches, all possible relevant papers were read. The data in Chinese papers were extracted and translated into English to present in this review by the first author. In addition, ancestral searches were conducted during literature search where it was necessary to understand the contexts of those articles.

Inclusion criteria for this review included being an original report or a review paper focusing on the healthcare, educational services for individuals with ASC in mainland China. The selected papers were categorised into several groups according to different ASC service settings that were described in the papers.

2.3. Materials from other source

In June 2011, the first summit conference for autism in mainland China was hosted by the CDPF. Six out of 10 provinces reported their achievements in mental health rehabilitation during the “Eleventh Five-Year programme” (2005–2010) and described the current situation with regards to autism in their provinces for the first time (China Disabled Persons’ Federation, 2011). The contents of the reported constitute an unpublished official summary of the mental healthcare situation and achievements of service provision in ten provinces within mainland China. These reports were provided to the first author by the CDPF.

2.4. Data analysis

The healthcare and education systems provide services for individuals with ASC throughout their natural history of this condition from onset to treatment. In order to better understand the service provision in general, the following key topics served as guideline for data analysis.

2.4.1 Healthcare: diagnosis and recognition

- (1) How are individuals with ASC diagnosed in mainland China?
- (2) Under current practice, have all individuals with ASC been identified thoroughly?
- (3) The awareness and knowledge among clinicians and parents about ASC.

2.4.2 Education: intervention and education inclusion

- (1) What happens after initial diagnosis?
- (2) Which settings can provide intervention for ASC? Can all diagnosed children receive intervention?
- (3) What do these identified intervention settings provide?
- (4) What are the providers' qualifications?
- (5) Implementation of education inclusion for children with ASC

2.4.3 Perceptions on service provision from teachers and parents

- (1) Teachers' and parents' attitude towards education inclusion
- (2) Parents' perceptions on service provision

2.4.4 The service costs on ASC.

3. Results

3.1. Study identification

Six papers were identified from two English databases and eight papers from two Chinese databases, as well as six reports from the CDPF regarding the situation in six provinces. The results are provided in [Table 1](#). Seven papers focused on the healthcare system, of which five were original studies, one was a summary report and one paper only had an English abstract. Seven studies were identified for education provision, of which six were original studies and one was a review. Six reports obtained from the CDPF reported both on healthcare and education service provision on ASC in mainland China.

3.2. Study methodology

Of 14 studies identified from the literature, 11 conducted interviews with various informants: a total number of 724 parents were interviewed in 11 studies; 295 physicians were interviewed in two studies; 54 teachers either in mainstream schools or special schools were interviewed in three studies; 36 school headmasters were interviewed in two studies. Two studies were general summary or recommendations on service provision of ASC in mainland China, and one study used previous hospital records to investigate the referral on ASC.

3.3. Diagnosis of ASC

One study found that hospital referrals for autism were mostly initiated by parents in mainland China ([Ming, Hashim, Fleishman, West, & Chen, 2007](#)). One study reported that 66.7% of parents chose a paediatric or a women and children's hospital for diagnosis while the remainder chose a psychiatric hospital or a neurological hospital ([China Disabled Persons' Federation, 2011](#)). In another study of 100 families, 74 children were diagnosed in a hospital while the remaining were diagnosed in a rehabilitation centre ([Ming et al., 2007](#)).

Regarding the accuracy of initial diagnosis, one study interviewed 60 parents of children with autism in Jiangxi province. It reported that 75.9% of children were correctly diagnosed with autism initially while 24.1% were first misdiagnosed as other mental conditions. Prior to receiving a diagnosis of autism, 75.6% of parents had no knowledge about autism ([China Disabled Persons' Federation, 2011](#)).

From CDPF reports in 2011, there were approximately 6000 children with autism and 72 mental health hospitals in Hunan province. In Jiangxi province, the reported prevalence estimate of children with autism was between 2 and 5 per 10,000, and the total number was approximately 40,000. In Guangdong province, the prevalence of autism was estimated to be 5 per 10,000 and the total number was 19,000. In Fujian province, the total number of children with autism was estimated to be 35,000 ([China Disabled Persons' Federation, 2011](#)).

3.4. The awareness and knowledge among physicians and parents on ASC

Recognition of autism among physicians varied across different regions ([Tao et al., 2011](#)). It can partly depend on the familiarity of this condition in the local area. Since the first diagnosis of ASC was given by Dr Tao in mainland China ([McCabe, 2008a, 2008b](#)), the Neurological and Mental Illness Prevention hospital (the Brain hospital) he established was receiving many children's referrals for autism. The Brain hospital therefore gained a positive reputation and many doctors followed Dr Tao's footsteps and began to specialise in the diagnosis and assessment of autism ([McCabe, 2008c; The Chinese Autism Society, 2003](#)).

One study investigated the awareness among community physicians, paediatricians in comprehensive hospitals and parents who were referred to these settings in Wuxi city ([Guo, 2012](#)). This survey used a self-completion questionnaire that included 22 items related to the concept, diagnostic features, aetiology, assessment and treatment of autism. Results

Table 1
Selected studies for review of healthcare and education service of ASC in mainland China.

Source	No	Year	First author	Language	Focus	Region	Research method
Healthcare system	1.	2007	Ming (Ming et al., 2007)	English abstract	Parent initiated referral for ASC	Wenzhou city	Retrospectively using hospital referral records
	2.	2011	Xiong (Xiong et al., 2011)	Chinese	Healthcare and education support for autistic children	Jiangsu province	Interviews with various informants: 28 leaders in rehabilitation centres, 36 special teachers and 216 parents
	3.	2011	Guo (Guo et al., 2012)	Chinese	Social support system for autistic children	Jiangxi province	Interview with 100 parents
	4.	2011	Tao (Tao et al., 2011)	Chinese	Healthcare and education	Hubei province	Interviews with 60 parents
	5.	2011	Wu (Wu, 2011)	Chinese	Healthcare and education	Hunan province	General summary and recommendations
	6.	2011	Chen (Chen, 2011)	Chinese	Healthcare and education	Shanghai city	Interviews with 3 parents
	7.	2011	Zhang (Zhang et al., 2011)	Chinese	Acknowledge of autism among parents and health professionals	Wuxi city	Questionnaires from 201 parents, 197 community physicians and 95 paediatricians
Education	8.	2005	Gao (Gao, 2005)	Chinese	Status of autistic children in ordinary schools	Beijing city	Interviews with 7 head masters and 12 teachers in mainstream schools and 7 parents of autistic children
	9.	2003	McCabe (McCabe, 2003)	English	Inclusion education	General	Review of policy changing
	10.	2008	McCabe (McCabe, 2008c)	English	Intervention programme at private and state-run centres	Beijing and Nanjing city	Interviews with 43 parents or caregivers
	11.	2008	McCabe (McCabe, 2008b)	English	Intervention in a state-run rehabilitation centre	Nanjing city	Interviews with 1 director, 3 doctors, 6 teachers and 8 parents
	12.	2008	McCabe (McCabe, 2008a)	English	The influences of autism towards the parents and families	Beijing city	Questionnaires from 78 parents and then invited 13 parents for interview
	13.	2010	McCabe (McCabe, 2010)	English	Employment and perspective of mothers with autistic children	Beijing city	Questionnaires from 70 mothers and 12 mothers were invited for interview
	14.	2011	Xiong (Xiong et al., 2011)	English	Raising burden of children with autism and other disabilities	Beijing city	Interviews with 61 parents
CDPF reports	15.	2011	CDPF (China Disabled Persons' Federation, 2011)	Chinese	Healthcare and rehabilitation provision for autistic children	Provinces: Fujian, Guangdong, Jiangsu, Jiangxi, Hubei, Hunan	Governmental reports from provincial CDPF

indicated that overall, the hospital-based paediatricians knew more about the existence of autism than the community physicians and parents. However, parents were the most knowledgeable about the diagnosis of autism compared to paediatricians and physicians. The report concluded that there was a general lack of knowledge about autism among physicians and paediatricians in Wuxi city (Guo, 2012). It suggested that this result might be due to increased access to information about autism diagnosis from the Internet and media coverage about autism. Another study reported that 44% of parental knowledge about autism was from the Internet, 33% from other parents with children with autism and only 16% was from health or rehabilitation professionals (The Chinese Autism Society, 2003).

3.5. What happened after initial diagnosis

One study reported about one in five children with autism received intervention immediately after diagnosis while 65% received within one year post-diagnosis (The Chinese Autism Society, 2003). Another study reported, 51.4% of parents accepted the initial diagnosis straight away and began to seek an intervention for their child (Ming et al., 2007). In contrast, 48.6% of parents delayed seeking help for two main reasons. First, 23% of parents did not believe the diagnosis and took their child elsewhere for further assessments and diagnosis. Second, 12% of parents did not seek an intervention due to financial limitations in their personal circumstances (Ming et al., 2007).

3.6. Which settings provide intervention

One setting for intervention is the state-owned hospital such as the Brain hospital. In 1989, it began to provide language and life-skills training for children with autism. In 1994, the Rehabilitation Division of this Nanjing Centre established an intervention programmes for children with autism. Another setting is the private rehabilitation centres (McCabe, 2008).

In the CDPF reports, the available intervention services were summarized. In Hunan province, there were 16 rehabilitation centres for autism, and five of them were established by the Hunan CDPF. In Jiangxi province, there were 8 autism rehabilitation centres, of which one was established by the Jiangxi CDPF. The others were all private centres, three of which were the main sources for autism rehabilitation in Jiangxi. In Fujian province, 20 rehabilitation centres were supported by the provincial CDPF in 2010 (China Disabled Persons' Federation, 2011).

3.7. The coverage of intervention

Four studies investigated the coverage of rehabilitation services for children with ASC. One study focused in Jiangsu province (Xiong, 2010) conducted interviews with the persons in charge in all 28 rehabilitation centres for autism in this province. 36 teachers in mainstream schools as well as 216 parents of children with autism were also interviewed. Within the 28 centres, only five operated smoothly with independent financial affairs. A total of 5100 children received special intervention programmes in Jiangsu province, which accounts for less than one quarter of the provincial estimated number of children with autism (Xiong, 2010). The report commented that how private rehabilitation centres could fit into the health system was unclear, given that support from the government and society was limited.

From the CDPF reports, in Hubei province, there were 935 children with autism who received intervention in the last five years. In 2006, the autism rehabilitation centre in Hubei province was established in Wuhan which can serve 150 children. In Guangdong province, there were 67 rehabilitation centres, within which there were 593 special teachers/therapists and 1051 children with autism. It exceeded the maximum capacity of service provision which was 1000 children. In Jiangsu province, there were 72 rehabilitation centres serving 533 children. Approximately 3000 children were reported to have received intervention in Fujian province over the past three years until 2011 (China Disabled Persons' Federation, 2011).

3.8. Intervention programmes

The intervention programmes in the state-run rehabilitation centres such as the intervention in Brain hospital included one-on-one instruction, sensory integration therapy, group music therapy and game classes. The centre was set up for children aged 3 to 10 with autism and required the presence of one caregiver as an observer during the classes. The one-on-one instruction was attended by all children in the centre which was comprised three modules: fine-motor tasks, language exercises and pre-academic skills. This study suggested that one of the main intervention strategies in Nanjing Centre was parents' involvement and learning from therapists by observation, which allowing parents to continue the intervention with their child at home (McCabe, 2008b).

The intervention programmes provided in private rehabilitation centres was identified by one study (Xiong, 2010) which included the following: (1) Comprehension therapy: Applied Behavioural Analysis (ABA) (Granpeesheh, Tarbox, & Dixon, 2009), Relationship Development Intervention (RDI) (Gutstein, Burgess, & Montfort, 2007), Floor time (DIR) communication development therapy (Wieder & Greenspan, 2003), Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) (Tsang, Shek, Lam, Tang, & Cheung, 2007), Mr Liu ability development therapy, Mr Liu scenario teaching method, PCI teaching method; (2) Singular therapy: sensory integration therapy, music therapy, picture exchange communication system (PECS) (Flippin, Reszka, & Watson, 2010), social story therapy, computer assistant therapy; (3) Other therapy: behavioural therapy, acupuncture and massage therapy (Yuan et al., 2009). All 28 centres adopted the ABA therapy, sensory integration therapy, music therapy, and PECS therapy. 21 centres (75%) used the TEACCH as a therapeutic method.

According to reviewed literature, there has been no specific intervention programmes or special assistant programmes provided in mainstream schools for children with ASC in mainland China. The intervention programmes employed in each setting are shown in Table 2.

3.9. Qualification of providers

One study reported (Xiong, 2010) the teachers and therapists in the rehabilitation centres were from one of the following educational backgrounds: pre-school education, special education, psychology, and social workers with the majority (71%) recruited from college graduates majored in pre-school education.

3.10. Implementation of education inclusion for children with ASC

One study reported on the policy of inclusive education for children with autism in mainland China (McCabe, 2003). It indicated children with more severe disabilities were still not in the mainstream or special education system (including

Table 2
Intervention programmes in different settings for ASC.

Setting	Details of therapy
Private rehabilitation centres	Applied Behavioural Analysis (ABA) Relationship Development Intervention (RDI) DIR Floor time therapy Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) Mr Liu's ability development therapy Mr Liu's Scenario therapy PCI therapy Sensory integration therapy Music therapy Picture exchange communication system (PECS) Social story method Computer assistant therapy Acupuncture and massage Behavioural therapy
State-run rehabilitation centre	Fine motor tasks Language exercises Pre-academic skills Sensory integration therapy Group music therapy Game classes
Mainstream schools	None special intervention or special assistant programme for children with ASC but have "Suiban Jiudu" policy to allow children with disability to attend regular class

mainstream and special schools) (Deng, Poon-McBrayer, & Farnsworth, 2001). Since the implementation of the 'Suiban Jiudu' policy, the situation has gradually changed. However, this policy is not mandatory but simply encourages the local government to provide nine-year compulsory education to all children.

One study found whether children with autism can attend a mainstream school and have educational opportunities does not depend on the implementation of the policy itself, but rather on parent's personal connections and the school's willingness and ability to accept a child with such condition (McCabe, 2003).

3.11. Teachers' and parents' altitude towards education inclusion

One study examined children with autism in mainstream schools in Beijing (Gao, 2005). Interviews were conducted with parents of children with autism ($n = 7$), the school head-teacher ($n = 7$), teachers ($n = 12$) and parents of typically developing children ($n = 7$) in 7 mainstream schools. Five out of 7 head-teachers (70%) agreed to integrate children with autism into their school. However, all the teachers interviewed were not willing to accept a child with autism in their class, but if it was imposed on them by the head-teacher then they had to accept it. The main reason why the teachers did not want to have children with autism in their classroom was because they believed that such child's behaviour would disturb their classes (Gao, 2005).

Another study focused on the acceptance of the 'Suiban Jiudu' policy by interviewing various informants (Xiong, 2010). All teachers ($n = 36$) considered that autistic behaviours were the primary reason why these children could not integrate into mainstream classroom or society in general. Only 1 out of 7 parents (14%) of typically developing children interviewed agreed with including autistic children into the mainstream classroom with their own child. All the other parents disagreed with such integration. Several parents of typically developing children expressed very negative attitudes towards the 'Suiban Jiudu' policy because they thought this would negatively influence their own child's education. All 7 parents of children with autism expressed their willingness to let their child attend a mainstream school and to try their best to cooperate with schools and the other parents. These parents considered that their child's social environment was more important than achieving good grades at school (Xiong, 2010).

Two studies reported the difficulties in integrating into mainstream education faced by children with autism (Wu, 2011; Tao et al., 2011). One study reported that 70% of parents would like their child to attend a mainstream school in the future (Tao et al., 2011). Another study focused on the situation in Changsha city conducted interviews with parents and teachers in a rehabilitation centre for children with autism. These two studies suggested that even when children with ASC were accepted into a mainstream school, the children were encouraged to leave once their autistic behaviours became apparent at school. Thus, children with autism aged 7 to 16 usually found themselves with no education provision due to the lack of special educational facilities (Wu, 2011).

3.12. Perceptions on current service provision

One study indicated the challenges for state-run intervention centres based on the experience of the Brain hospital (McCabe, 2008b). It concluded that there were two main challenges. The first challenge was financial support. As the

state-run centre was unable to make as much profit as the other divisions in the comprehensive hospital, the tuition fees increased. A second challenge was the limitation in the development and improvement of their intervention programmes. There was no ongoing learning programme available for therapists and special teachers, making it difficult to improve or update their intervention methods (McCabe, 2008b).

Challenges for private intervention settings were also indicated in reviewed studies: (1) a shortage of funding. This included unstable support from government and society which led to the imbalance between tuition paid for by parents and allowances from the government (Xiong et al., 2011); (2) the unstable structure of human resources for special teachers/therapists. The teachers and therapists in private centres may leave one centre for another one. This made it difficult to create or develop any kind of coordinated training and professional development within private centres (McCabe, 2002; Xiong, 2010); (3) cooperation between parents and the rehabilitation centres was not without difficulty due to a lack of knowledge about autism and the low social status of parents (Xiong, 2010); (4) a lack of a standard qualification requirement for teachers and therapists specialising in autism interventions.

One study in Jiangsu province suggested the integration into the society for children with ASC after intervention was still difficult. It indicated that less than 10% of children who received intervention were considered to be able to integrate into society, and less than 3% attended a mainstream school following participation in an intervention programme (Xiong, 2010).

Two studies suggested a long waiting period between receiving a diagnosis of ASC and entering an intervention programme in a rehabilitation centre. One study reported that the average time period was 10 months (Tao et al., 2011); the other study found that 77% of parents waited for more than 6 months to enter a rehabilitation centre after enrolling (Guo, 2012).

One study interviewed 216 parents of children with autism. The authors found that all the parents wanted better early detection and diagnostic systems for children with autism. Further, parents indicated that there was a huge financial burden on parents to provide education and intervention for their children with autism (Xiong, 2010). All parents expressed a desire for the availability of government-supported specialised institutions for diagnosis and intervention. Parents indicated that there should be a clear healthcare guideline for their children to follow. This study also found that parents were concerned about the future quality of life of their child with autism (Xiong, 2010).

Another study interviewed three parents of autistic children in Shanghai city. It suggested that receiving a diagnosis of autism can be very difficult for parents to cope, and if not managed properly, further difficulties within the family may prevail. They proposed that the Integration education in kindergarten should be encouraged in order to provide more opportunities for children with autism to interact with typically developing children during this time that may be the optimum period for implementing interventions.

3.13. *The cost of autism in mainland China*

One study interviewed 61 parents of children with autism. It provided estimates for the average annual costs for three service domains including rehabilitation, education and medical attention per child with autism. The estimated costs for those domains were £1919.80, £642.80 and £376.70 respectively, with the total cost as £2939.3 (Xiong et al., 2011). If basic living expenses were included, the cost rose to £4099.80. However, the average annual family income was £2056.9. Thus, the financial burden of raising a child with autism amounted to £2042.9 annually (Xiong et al., 2011). Another study interviewed 100 parents and found 56% of the children did not have a disability certificate from the government and another 30% did not know how to obtain one (Guo, 2012). As a result, 93% of the children in that sample did not receive an allowance. However, the parents who received an allowance reported that the allowance can only cover part of the fees for rehabilitation (Guo, 2012). The cost for rehabilitation varied from £150 to £500 monthly 96% of families had never received any financial support and 56% of parents wanted to get financial support in the future (Guo, 2012). One study investigated the employment experiences of mothers of children with autism, using questionnaires ($n = 70$) and face-to-face interviews ($n = 12$). The study concluded that mothers usually sacrificed their own career in order to accompany their child to the rehabilitation centres and to provide home-based intervention (McCabe, 2010).

In CDPF reports, the information on governmental support for ASC was provided. In Hunan province, 50 children with autism in low income families received financial support from the 'rescue programme' hosted by CDPF for disabled children aged 0–6 in 2010. In Jiangxi province, the government granted each centre with 80,000RMB (£8000) to help them operate in 2011. In Hubei province, The Hubei CDPF supported children in their identified centres with 500RMB (£50) each per year as an allowance and the Wuhan government supported each child in their identified centres with 3000RMB (£300) per year. In Jiangsu province, since 2007, the provincial financial department had distributed an allowance of 12,000RMB (£1200) annually to each child with autism in low income families. In Fujian province, since 2010, the provincial government began to support children with autism attending their identified rehabilitation centres with 5000RMB (£500) per child per year. In 2010, 20 rehabilitation centres were supported by the Fujian CDPF (China Disabled Persons' Federation, 2011).

4. Discussion

4.1. *Summary of findings*

This is the first review of service provision of ASC in mainland China. It has identified literature from both the West and China as well as directly from the government. The reviewed studies mainly based on interviews with service providers and

parents of children with autism. It provides a summary of crucial evidence on both healthcare and education service for children with ASC in mainland China. Governmental reports were also reviewed. Findings suggest that there are achievements as well as barriers within the health, government and education systems. There is a lack of knowledge in professionals and lack of awareness in the public on ASC. The healthcare and education systems are under-developed for ASC. The lack of support from the government and society resulted in substantial financial burden on parents of children with ASC in mainland China.

4.2. *Limitations and strength of this review*

There are several limitations that should be mentioned. First, this review is based on literature in two English and two Chinese databases, together with material from one other source. It is possible there may be papers focused on this topic that were not published in mainstream journals and thus were not identified in this review. However, the Chinese databases were two of the biggest databases in mainland China. The systematic search strategy with broad search terms and cross-checking in four databases should have kept publication bias to a minimum. It is unlikely the other unidentified papers could influence the results substantially. Second, the data were collected and analysed by a single researcher. This may lead to the language bias since most studies were published in Chinese. However, given the nature of this review, it is unlikely that key information would have been missed or misinterpreted. Third, most of the available English papers were by the same American author who is fluent in Chinese since these were the only studies that were available. However, similar findings were reported by other studies in Chinese language identified in this review. In addition, the representativeness of the findings should be noted since there was limited number of publications and a high degree of heterogeneity in study design. Caution must be applied when generalising these regional results to the population as a whole.

4.3. *Challenges for diagnosis of ASC*

This review indicated one obstacle for diagnosis is a lack of health professionals on ASC in clinical settings in mainland China. The physicians were found having little knowledge and experience of autism (Zhang et al., 2011). This is because in China, parents usually refer to paediatricians first when they suspect their children having ASC (American Academy of Paediatrics, 2001). However, diagnosis and management of ASC can be a challenge for physicians because diagnosis mainly depends on clinical judgement. It has been suggested the clinical judgement can be supplemented by adopting standardized assessment instruments such as the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview-Revised (ADI-R) (American Psychiatric Association, 2001). Thus, it would be helpful to introduce more standardized instruments and provide training to improve knowledge of ASC among health professionals in mainland China.

4.4. *Challenges for service delivery*

In reviewing the literature, there are many problems within the current system in mainland China: (1) an unclear pathway from diagnosis to intervention (Guo, 2012); (2) lack of standardised regulation of private training centres. It is difficult to integrate the private centres into either business services or public educational institutes. The lack of management and monitoring by the government, the quality of such services cannot be ensured (Xiong, 2010); (3) lack of educational facilities for older children with ASC. Current programmes mainly focus on children between 0 and 6 years old. There has been limited educational facilities available for children outside this age range (China Disabled Persons' Federation, 2011); (4) the links within the healthcare system among the government, institutes, schools, community and families are still weak and the cooperation between these settings are under-developed (Wu, 2011).

4.5. *Challenges in mainstream educational settings*

Children with ASC require not only healthcare services but also special education services (Bitterman et al., 2008). Many obstacles on the education pathway of children with autism were identified, including attending mainstream schools. First, the purpose of the 'Suiban Jiudu' policy was to encourage mainstream schools to accept children with special needs like autism, but whether accepting children with disability or not was up to the discretion of each school. Thus, there is still a long way to go to achieve a situation where children with autism can be accepted by mainstream schools (McCabe, 2003). Second, a lack of strategy and teaching methods for autistic children in mainstream schools led to the confusion and frustration within the school teachers as they did not know how to cope with the situation (Xiong, 2010). Third, there was a lack of awareness and knowledge about autism among the general public evidenced by the attitude of parents of typically developing children in mainstream schools (Xiong, 2010).

4.6. *The family burden of autism*

Autism has not been included in general health insurance, therefore most of the costs for rehabilitation and medical care are paid for by parents (Xiong et al., 2011). There has been limited support for families with children with autism. The annual expense for a child with autism in mainland China was £4099.80 (Xiong et al., 2011). This was a conservative estimate taking

into account that study also reported that the monthly tuition fees of private intervention centres ranged from £150 to £500 (Guo, 2012). In mainland China, the social stigma and misunderstanding on ASC might partly contribute to the lack of help and concern from society and the general public towards children with autism and their families. The amount of government allowance varied across regions and was not adequate to reimburse the parents for the true cost of supporting their child. In many families, one parent gave up their career to accompany their child in rehabilitation centre only served to increase the financial burden to the family due to this income loss (McCabe, 2010).

4.7. Conclusions and recommendations for future research

The volume of literature on healthcare systems and education services for children with ASC was profoundly limited. Parents of children with autism faced many problems, partly because of the under-developed service systems. The improvement of service provision could be achieved by the following strategy: (1) providing ASC related medical training for physicians especially integrating it into basic psychiatric training; (2) conducting epidemiological research focusing on the whole spectrum to understand the underserved needs of ASC in the general population; (3) providing systematic service pathway descriptions and practice guidelines on ASC with regulation for each setting in the system; (4) issuing evidence-based unified policies by the government in regards to the support for families with autistic children; (5) enhancing public education of ASC to improve awareness and acceptance of ASC in the general population; (6) thorough implementation of “Suiban Jiudu” policy to improve the education inclusion for children with ASC; (7) conducting further research on the service provision from both service providers' and users' perspective to provide feedback for service improvement.

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