



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

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### ARTICLE INFO

#### Article history:

Received 4 June 2012

Received in revised form 14 August 2012

Accepted 14 August 2012

Available online 4 October 2012

#### Keywords:

Autism

Healthcare and education

Service provision

Service providers

Mainland China

### 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

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