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## Research in Developmental Disabilities



#### 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

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