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Service provision for autism in mainland China: Preliminary mapping of service pathways

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ABSTRACT

Few data on healthcare services for individuals with Autism Spectrum Conditions (ASC) are available from mainland China. This article is based on findings from 69 semi-structured interviews with parents of children with ASC in three intervention centres. The respondents are from 19 regions in mainland China. A service-mapping questionnaire containing 50 questions is developed and used as an interview schedule for service mapping. The pathway to diagnosis and intervention for children with ASC is presented according to parents' experience. The findings report considerable delay along the pathway which may be partly due to the under-developed service system. Several cultural issues are identified which may also contribute to the delay, such as the perception of mental illness, folk beliefs equating delayed development of language skills in early childhood with future high intelligence, and the state-imposed one-child policy. Delays in recognising ASC and a lack of support are also considered to be associated with the considerable financial burden placed on parents of children with ASC in mainland China.

Introduction

The media have highlighted Autism Spectrum Conditions (ASC) as an "epidemic" (Dales, Hammer, & Smith, 2001). The prevalence of ASC was reported to be as high as 157/10,000 (1 in 64) in the UK (Baron-Cohen et al., 2009) and 113/10,000 (1 in 88) in the US (Centres for Disease Control and Prevention, 2012). The increase in the prevalence of ASC in developed countries is a significant public health issue (Fombonne, 2005; Rahbar, Ibrahim, & Assassi, 2011). Western countries have been developing new strategies for healthcare practice, service delivery and system development to cope with the increasing needs of people with ASC and their families (Dover & Le, 2007; Estes et al., 2009; Jones, 2002; Le-Couteur, 2003). In the UK, the Committee of the National Institute for Health and Clinical Excellence (NICE) has issued a guideline on the recognition, referral and diagnosis of ASC (National Screening Committee, 2011). The NICE guideline proposes the establishment of a multidisciplinary autism team in each area in Britain, which includes a pediatrician and/or child and adolescent psychiatrist, a speech and language therapist and a clinical and/or educational psychologist. After diagnosis, individuals with ASC and their families should receive proper support for further referral and long-term treatment.

Mainland China has a large population of more than 1.37 billion. However, mental health care was not well offered through the national healthcare system until the first National Mental Health Plan (2002–2010), issued by the Ministries of Health, Public Security and Civil Affairs and the China Disabled Persons' Federation (CDPF) in 2002. It aimed to establish an effective system to provide services for individuals with mental health conditions (Liu et al., 2011). The CDPF is a unified organization that represents the 83 million people living with disabilities in China (Wikipedia, 2012). In 2004, a Proposal on Further Strengthening Mental Health Work was approved by the Ministries of Health, Public Security and Civil Affairs, and the CDPF to provide guidance about effective interventions for behavioral problems and mental disorders (Liu et al., 2011). This guidance is especially relevant to clinicians who diagnose and treat children and adults with autism because clinicians' understanding of autism varies across regions in China (The Chinese Autism Society, 2003). A previous study found that parents were more knowledgeable than physicians about the diagnosis of autism (Zhang et al., 2011). For a long time, children with severe disabilities were kept out of the

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Fig. 1. Geographical distribution of children with ASC in this sample.

mainstream educational system (Deng, Poon-McBrayer, & Farnsworth, 2001). This practice changed after the issue of the "*Suiban Jiudu*" policy, which recommended that all children with disabilities attend school in regular classrooms. However, because this policy is not mandatory, schools maintain flexibility in which students they admit (Huang & Wheeler, 2007). As a result, many children with autism in urban areas cannot enter ordinary schools but instead travel across regions to attend rehabilitation centers for intervention or training (Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2013, Sun, Allison, Auyeung, Matthews, et al., 2013; Xiong, 2010). Learning from parents' perspectives could provide both insight into the existing ASC services and feedback for policymakers. For this reason, this study aims to map the ASC service pathway based on parents' experiences.

Methods

Procedure

This study was approved by the Ethics Committee of Peking University First Hospital. Before this study, ten autism service providers in mainland China were interviewed. Through these interviews, contact information for several headmasters of special rehabilitation centers were obtained (Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2013, Sun, Allison, Auyeung, Matthews, et al., 2013). The head teachers of these centers were contacted, and two private (Centers 1 & 2) and one state-owned rehabilitation (Center 3) centre participated in this study from January to April 2010.

Convenience sampling was used to recruit participants. After gaining consent from the centers, children's parents were invited to participate. These centers require a caregiver to accompany the child throughout the day (Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2013, Sun, Allison, Auyeung, Matthews, et al., 2013). The interviews were conducted during daily one-on-one training sessions for the children, when parents did not accompany their children and were available for interview. Face-to-face interviews were arranged after consent was obtained from each parent.

Participants

Sixty-nine parents of children with an existing diagnosis of autism were recruited. There were a total of 45 children in Center 1 in Beijing, whose parents were contacted. Of these, 35 agreed to participate. The total number of children in Center 2 in Qingdao was 330, and the parents of 30 children were recruited. The other four interviewees were recruited from Center 3 in Beijing.

Semi-structured interviews

Each interview was conducted with one parent and lasted up to 1.5 hours. A topical interview guide with 50 questions was developed after the first seven interviews. The questions used in the interviews covered ten areas:

(1) General information about the child
(2) First signs of any difficulties
(3) Referral to hospital for diagnosis
(4) Diagnostic process
(5) Finding and entering special training centers
(6) Training courses offered at special training centers
(7) Burden on the family due to autism
(8) Local policy on autism
(9) Possible causes of autism