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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.

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Introduction

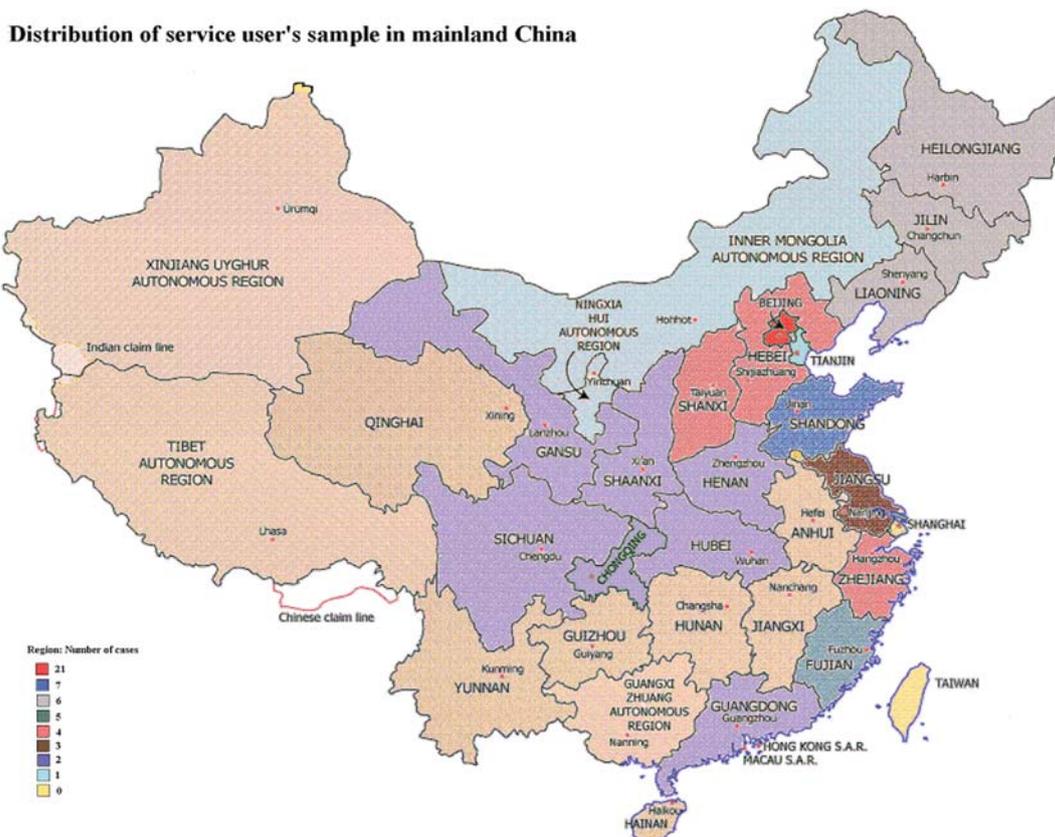
The media have highlighted Autism Spectrum Conditions (ASC) as an "epidemic" (Dales, Hammer, & Smith, 2001). The prevalence of ASC was reported to be as high as 157/10,000 (1 in 64) in the UK (Baron-Cohen et al., 2009) and 113/10,000 (1 in 88) in the US (Centres for Disease Control and Prevention, 2012). 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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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

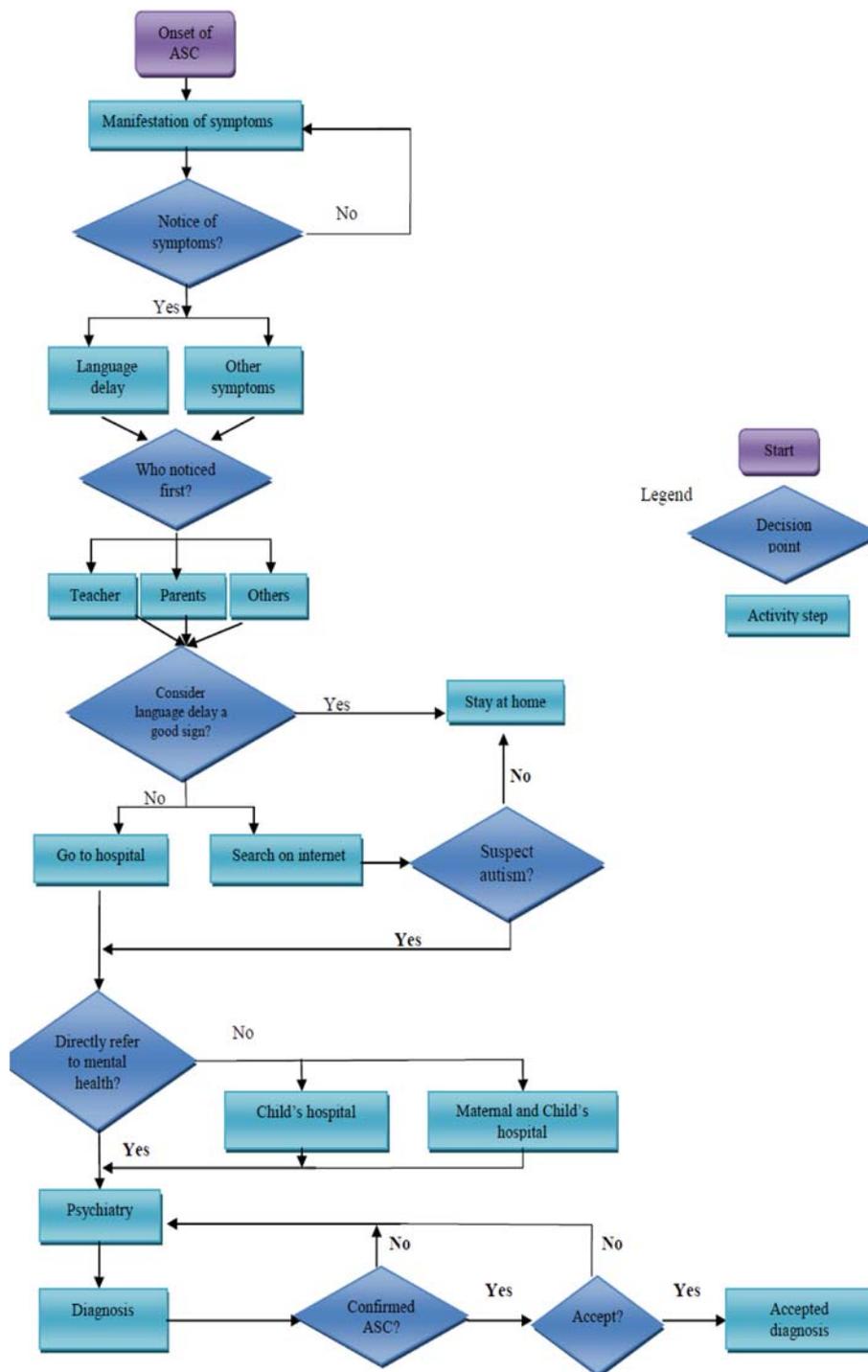


Fig. 2. Flow chart of healthcare pathway—from onset to diagnosis.

(10) General information about the parents. [Supplementary material](#).

Data collection and analysis

All of the interviews were recorded by hand without audio taping, as requested by the parents. The transcript was read by the first author, and a framework approach was used to systematically identify themes (Pope, Ziebland, & Mays, 2000; Ritchie & Spencer, 1994). The framework approach includes 1) familiarization—reading transcripts and studying notes; 2) identifying a

thematic framework—identifying key issues, concepts and themes to condense data into manageable segments; 3) indexing—applying the thematic framework to the transcripts by annotating them with numerical codes; 4) charting—regrouping data according to their place in the framework and creating charts; 5) mapping and interpretation—using charts to convey concepts and convey the essence of phenomena, followed by interpretation (Pope et al., 2000). This approach provides a detailed examination of parents’ understanding and allows the researcher to focus on pre-determined objectives (Calzada, Pistrang, & Mandy, 2012; Pope et al., 2000). To ensure the research quality, guidelines for the best

Table 1
Results of findings of first symptoms to diagnosis from interview.

Questions	Categories	Number	(%)
Symptoms of first concern	Language delay	33	(48)
	Little eye contact/response	18	(26)
	Lack of love to parents	4	(6)
	No peer relationships	13	(19)
	Stereotyped or odds behaviors	1	(1)
Who raised first concern	Family members	40	(58)
	Teachers	20	(29)
	Doctors	8	(12)
	Others	1	(1)
Consider language delay a good sign	Yes	9	(13)
	No	60	(87)
Direct to mental health	Yes	46	(67)
	No	23	(33)
Use of internet	Yes	38	(55)
	No	31	(45)
First referral hospital	Children's care/research hospital	33	(48)
	Maternal and children's care	14	(20)
	Psychiatric hospital	22	(32)
	Other	0	(0)
	No response	0	(0)
Second referral hospital	Children's care/research hospital	16	(23)
	Maternal and children's care	1	(1)
	Psychiatric hospital	26	(38)
	Other	0	(0)
	No response	26	(38)
Third referral hospital	Children's care/research hospital	3	(4)
	Maternal and children's care	2	(3)
	Psychiatric hospital	9	(13)
	Other	1	(1)
	No response	54	(78)
Diagnosis	Autism	24	(35)
	Tendency of autism	36	(52)
	Other or no diagnosis	7	(10)
	Asperger Syndrome	1	(1)
	No response	1	(1)

practices in qualitative research were followed, including triangulation, respondent validation, clear exposition of data collection and analysis and reflexivity (Mays & Pope, 2000; Pope et al., 2000). Quantitative analysis was conducted in STATA 10.0 (StataCorp, College Station, Texas, USA) using Mann–Whitney tests to compare the mean ages of independent groups. Systematic modeling was used to map the service pathway (Jun, Ward, Morris, & Clarkson, 2009).

Results

There were 55 (80%) boys and 14 (20%) girls. They were born in Beijing and 18 other provinces within mainland China, and 90% lived in urban areas. Most of them (63/69, 91%) were the only child in their family. The mean age was 4.6 years old (range: 2.2, 11). The geographical distribution of this sample is shown in Fig. 1.

Time delay from diagnosis to intervention

The mean age of the children when their parents first became aware of their features of ASC was 2.2 years old (range: 0.5, 6). The mean age for diagnosis was 2.8 years old (range: 1.7, 6.8), and the mean age of initial intervention was 3.3 years old (range: 1.3, 7). The mean amount of time between first awareness and diagnosis was 7.1 months (range: 0–30 months). The mean amount of time between diagnosis and initial intervention was 6.5 months (range: 0–48 months). The pathway from first awareness to diagnosis is shown in Fig. 2.

Service pathway

The condition was recognized mostly by family members (58%), teachers (29%) and doctors (12%). The most obvious autistic characteristic that led to primary concern was language delay (48%). Among the 33 parents who sensed that their child developed speech later than other children of the same age, nine (16%) considered their child's language delay to be a good sign since many stories of ancient Chinese heroes had language delay in their childhood. Thus, the parents considered it as an indication of future success and did not take immediate action. When asked about possible causes of ASC, 34% of the respondents (13/38) identified

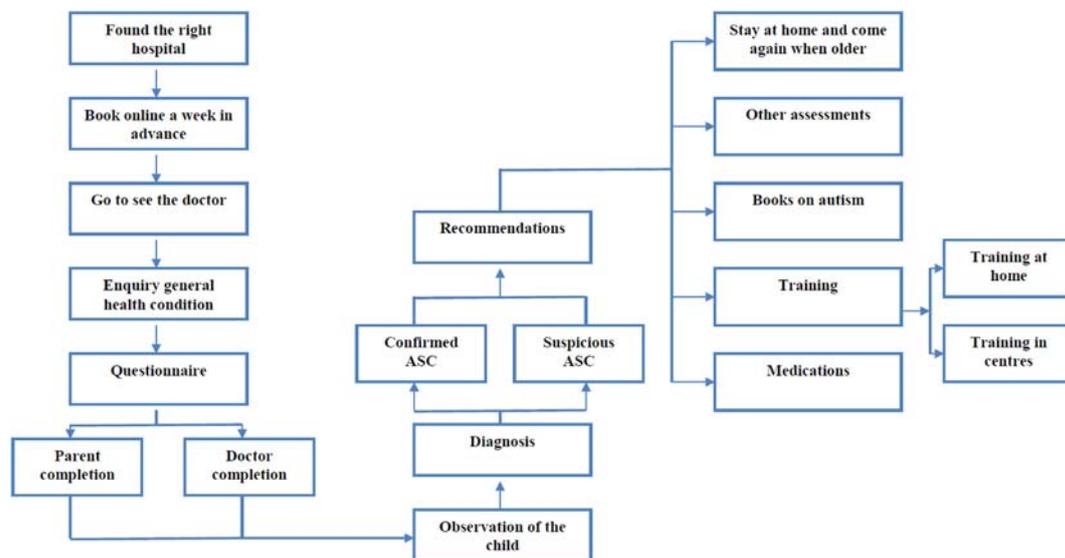


Fig. 3. Flow chart of diagnostic process.

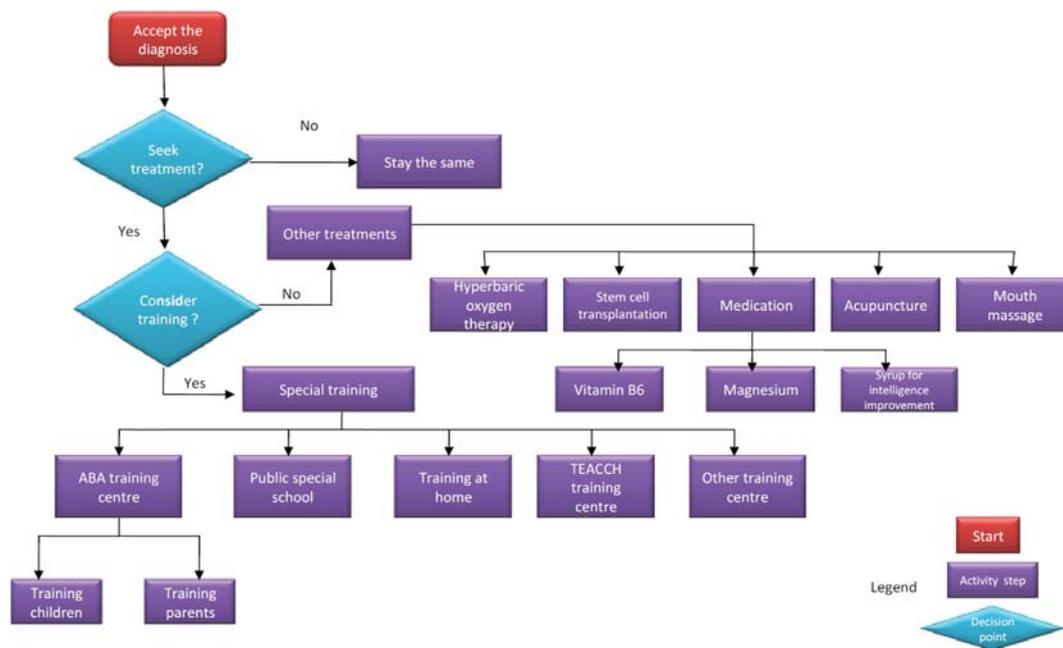


Fig. 4. Flow chart of healthcare pathway—from diagnosis to treatment.

depression, anxiety or anger during pregnancy as a possible cause of their child's condition.

After their first concern, 55% of the respondents (38/69) used the internet to seek medical explanations for their child's behavior, which led to further hospital referrals. Parents reported seeking care at three types of hospitals: children's hospitals or research centers, maternal and children's health hospitals and psychiatric hospitals. After an initial diagnosis, many parents took their children to other hospitals for a second opinion before accepting the diagnosis.

Many parents took their children across regions to see well-known psychiatrists for diagnosis. At first diagnosis, 35% of the children were diagnosed with autism, and 52% were diagnosed with "a tendency towards autism or a possible case of autism". For most participants (70%), the diagnostic process took less than 30 minutes and usually included a general health inquiry, completion of an autism questionnaire and direct observation of the child. The pathway from first symptoms to diagnosis is shown in Table 1, and the diagnostic process is shown in Fig. 3.

Following diagnosis, the doctor usually recommended sending the child to a special rehabilitation center for intervention. Approximately 70% of children in this study had attended intervention programs based on the Applied Behavior Analysis (Granpeesheh, Tarbox, & Dixon, 2009; Hilton & Seal, 2007) and/or the Treatment and Education of Autistic and Related Communication Handicapped Children (Panerai, Ferrante, & Caputo, 1997). Of the remaining children in this study, 23% received sensory integration or auditory integration training, and the rest did not receive intervention (7%). About 46% attended two or more centers. Generally, parents apply for a place for their child in a center and waited an average of 8 months until a place became available.

The mean time period between entering a center and parents seeing a noticeable improvement in their child's social and self-care ability was 4.5 months, and 64% of parents reported their child's greatest improvement was speech. The pathway from diagnosis to treatment is shown in Fig. 4.

Cost and local policy for ASC

The mean monthly expense for intervention and care for one child with ASC was £850 (¥8500) in Beijing and £697 (¥6790) in Qingdao. Overall, 90% of the families spent £700–£1000 (¥7000–¥10,000) per month on supporting one child with autism. Most costs were paid by parents. Approximately 30% of parents stated that they were unable to sustain this financial burden for an extended period. The interview results are shown in Table 2.

In China, individuals with disabilities can apply for a disability certificate from local branches of the China Disabled Persons' Federation (CDPF). This enables health authorities to keep records on such individuals and provide support accordingly. Parents from seven provinces reported knowing that they can receive an allowance from the local government if they have a disability certificate. However, only 12% had applied or wanted to apply for this certificate, while the rest did not express a willingness to apply because they did not want it on their child's records for the rest of their lives. The parents from Beijing ($n = 21$, 30%) reported that completing the certification application took time because it involved the local branch of the CDPF, the local community, a confirmed diagnosis from an authorized hospital and an evaluation of the child's condition.

Many young mothers expressed their desire to have another child. The revised one child policy allows a couple to have a second child if both parents are the only child of their families (People's Republic of Ninth National People's, 2002). In some provinces, if a child is disabled, parents can make a request to the local family planning committee to have another child. The committee then seeks evidence of a confirmed diagnosis and sends a professional team to evaluate the child. In some provinces, a confirmed diagnosis of autism is sufficient, while a disability certificate is also required in other provinces. One mother reported that the local requirements for having another child also included a mother's age and a low IQ score for the firstborn child. Because requirements for having a second child vary across regions, this situation can easily trigger a sense of unfairness among parents.

Discussion

The service pathway: from first awareness to intervention

Most parents in the sample had never heard of autism prior to their child's diagnosis. It took them a long time to get their child diagnosed. In some cases, although the parents noticed an abnormality, they denied it at first. Some parents sought hospital referral, but their suspicions were sometimes dismissed by doctors who were not familiar with ASC. This dismissal created a sense of false reassurance among some parents. In such cases, the pathway to care was delayed until the child was diagnosed by a well-known pediatrician or psychiatrist, at which point the diagnosis was accepted. Most parents sought intervention once they accepted the diagnosis. Doctors often recommended special intervention centers

to parents directly after diagnosis. Their options were clear, but given the lack of unified standards for such centers, many parents wanted their children to enter the most well-known centers. This led to long waiting times and intervention delays. Because these centers are private businesses, parents must pay a substantial amount of money to support their child. The costs of attending such centers are a burden even to middle class families in mainland China.

Old beliefs and the early detection of autism

There is an old saying in Chinese culture related to language delay. It says that a child who speaks late during childhood will turn out to be more intelligent than others in the future. This ancient belief has a long history in China and spans generations. Thus, if a child, especially a boy, cannot speak at the time when he/she should have acquired speech, grandparents may remind young parents of this old belief. In this sample, almost half of the children (48%) showed obvious language delay and over a quarter of the families interpreted it as a positive sign. This finding has previously been reported in China (Liu & Wen, 2006). A similar belief exists in India and has been reported as potentially delaying the diagnosis of autism there (Daley & Sigman, 2002).

Stigmatization

Stigma is considered as a possible factor that delays treatment-seeking and adherence for individuals with mental illness, which, in turn, causes significant social and economic burdens for families (Shrivastava, Johnston, & Bureau, 2011). Because psychiatrists categorize autism as a mental disorder, many parents considered their child's diagnosis to be undesirable. In Chinese families, having a child with a disability may be viewed as a source of shame and failure (Wang et al., 2012). Due to limited knowledge about autism, the existence of this condition and the behaviors of autistic children may be considered their parents' fault (Holroyd, 2003). Some parents preferred to keep their child's autism diagnosis secret, pretend there was nothing wrong with the child or refuse to consider their child's condition as a mental health problem. In such cases, a family may keep the child at home and avoid contact with others. This could impede the child's development and exacerbate the situation. When the surrounding community discovers the diagnosis, their perception of autism may lead to the stigmatization of the child and/or the whole family. This may be one of the reasons why families strive to keep it secret in the first place. Stigmatization of parents is an example of what Erving Goffman has termed "courtesy stigma" (Goffman, 1963). This means that the family members of autistic children experience stigmatization due to their association with the stigmatized child rather than any characteristics of their own (Gray, 1993). As the family members receive more courtesy stigma, they are more likely to experience negative self-evaluation, negative emotion and behavioral withdrawal (Corrigan & Watson, 2002). The experience of stigma among parents of children with autism is not specific to Chinese culture but also exists in Western cultures (Mays & Pope, 2000; Pope et al., 2000).

The one-child policy and the desire to seek intervention among Chinese parents

The one-child policy has been implemented in mainland China since 1980 as a strategy for birth control and long-term development (Sleeboom-Faulkner, 2008). Now, many young couples who were born in the 1980s and are the only child in their own family have become new parents. Their baby is therefore likely to be the only grandchild within the two extended families. This is called the

Table 2
Results regarding intervention and family burden from interview.

Questions	Categories	Number	(%)
Initial training method	Home training	5	(7)
	ABA	48	(70)
	Sensory/auditory integration/other	16	(23)
Number of centres attended	1	30	(44)
	2	23	(33)
	3	9	(13)
	4	6	(9)
	6	1	(1)
Waiting time	≤7 months	47	(68)
	8–10 months	14	(20)
	>10 months	8	(12)
Biggest improvement	Speaking	44	(67)
	Compliance to instructions/orders	13	(19)
	Play with others	3	(5)
	Concentration	0	(0)
	Stereotyped or odds behaviors	1	(1)
	Comprehension	5	(8)
Least improvement	Speaking	9	(13)
	Compliance with instructions/orders	7	(10)
	Play with others	14	(20)
	Concentration	12	(17)
	Stereotyped or odds behaviors	4	(6)
	Comprehension	15	(22)
	No response	8	(12)
Expense (£ per month)	≤700	32	(46)
	701–800	15	(22)
	801–1000	22	(32)
Degree of burden	Huge burden	21	(30)
	Certain burden	26	(38)
	Little burden	21	(30)
	No response	1	(2)
	Hypothesised causes of autism	Depression/anxiety during pregnancy	13
Exposure with computer		4	(6)
Early childhood disease		3	(4)
Parents' personality		5	(7)
Spoiled way of raising child		5	(7)
Chemical poisoning during pregnancy		9	(13)
No response		30	(43)
Disability certificate		Yes	8
	No	61	(88)

"4:2:1 Little Emperor Phenomenon" (Chen, 1994) and means that the child receives focused attention from both the parents and grandparents. In such families, the child's future embodies the future of the entire extended family. In mainland China, the large population contributes to a competitive environment for education and career development, so a child's academic performance, as illustrated by test scores, is considered an issue of enormous importance. However, most children with ASC cannot meet their parents' expectations. A child's inability to meet parental expectations may be perceived as a failure by the parents and could trigger further courtesy stigma. In this sample, most of the parents expressed concerns about the learning potential of their children. This concern led them to seek intervention. Most of the parents' efforts aimed at improving their children's level of functioning. The implications of having a child with a special condition are even more important in mainland China than other countries, given that each family normally has only one child.

Limitations and future research

Because convenience sampling was used, selection bias might have been introduced; the parents who did not participate might have made different decisions from those who did. The sample was selected from children who already had a diagnosis of autism and were already in special centers for intervention. These children could be considered at the extreme end of the autism spectrum in mainland China. Future studies should include children with other subtypes of ASC and families who do not have access to centers for various reasons. Because the findings were based on the memories of parents and the interviews were only recorded by hand, recall bias may have influenced this study. However, to minimize the effect of potential recall bias, the key points from interviews were re-checked with parent respondents at the end of each interview. Additionally, most of the informants were mothers. In future research, more male participants are needed to represent both parents' perspectives. Additionally, most of the children in this sample were between 3 and 6 years old, so the study only reflects the experiences of children who were diagnosed relatively recently. There are many children beyond this age range who might have different experiences of service provision. Thus, further studies should adopt multiple methods within a wider age range of children with ASC.

The healthcare and education system for autism has not been fully developed in mainland China. Most of the time, the parents in this sample initiated the service pathway without prior knowledge about or general guidelines for autism. In addition, there are many cultural issues relating to autism that might have added barriers to the service pathway. As a result, diagnosis and intervention are relatively delayed. There is a need to develop specific autism-related services with standard policies and regulations to cater to the needs of affected children and their families. Improving the public awareness of autism and increasing support from the government and society could reduce stigma and ultimately reduce some of the burden experienced by affected families.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <http://dx.doi.org/10.1016/j.socscimed.2013.08.016>.

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