

# Current status of and challenges posed by autism spectrum disorders in China: Prevalence, legal issues, and public awareness

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**SUMMARY** Over the past 30 years or so, the body of research on autism spectrum disorders (ASD) in China has grown steadily. With the tireless efforts of government agencies and private organizations, the legitimate rights and interests of children with ASD have been initially guaranteed through a series of education and rehabilitation reforms, yet there are still many challenges to overcome. Many quality studies on the prevalence of ASD have been conducted in recent years, but China has lacked official census data until now. Moreover, there is a general lack of awareness of ASD even among the groups that directly interact with individuals with ASD, namely parents/caregivers, teachers, and doctors. Despite that fact, ASD should be brought to the attention of professionals and policymakers so that they can take appropriate measures, which include *i*) early comprehensive screening and diagnosis of ASD, *ii*) improvement of the corresponding policies and regulatory system, and *iii*) promotion of public awareness of ASD.

**Keywords** autism spectrum disorders, prevalence, legal issues, public awareness

## 1. Introduction

Autistic spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent deficits in social interaction and communication, as well as restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities (1). Although the disorder is closely related to genetic factors, there is no form of prenatal screening for ASD like there is for Down syndrome (2). Therefore, perinatal care for pregnant women, and especially women of advanced maternal age, is crucial to reducing the risk of ASD onset (3). Globally, 0.76% of people worldwide suffer from the disorder (4), resulting in a heavy economic burden for both families and society as a whole. Research on ASD was initiated relatively late in China, so the first case in a child was not diagnosed and reported until 1982 (5). Since more attention is being devoted to autistic children in China, research on ASD has tended to increase in recent years. Statistics indicate that the number of articles published by Chinese scholars on the topic of "autism" increased from only 9 in 1993 to 5,674 in 2021. The current review summarizes the recent trends in prevalence, national

policy, and public knowledge of ASD over the past few decades, and it offers recommendations to professionals and policymakers on how to better help individuals with ASD.

## 2. Prevalence of ASD in China

So far, there are no official statistics on the prevalence of ASD in China (6), but a meta-analysis summarized the prevalence of ASD in 26 studies published from 2000 to 2016, yielding an estimated prevalence of 0.3% on the Chinese mainland (6). Due to the use of non-standard methodologies (7), the prevalence reported in China is regrettably believed to be underestimated (8,9). A point worth noting, however, is that recent studies have identified and sought to remedy these flaws, leading to more accurate figures. Currently, the largest epidemiological study conducted in eight cities estimated the prevalence of ASD nationwide to be 0.70% (8), which is closer to global estimates of its prevalence (4). Details on representative epidemiological studies on ASD in China over the past few years are shown in Table 1. However, the vast

**Table 1. Summary of representative epidemiological studies published since 2019 in China**

Year	Region	Prevalence /1000 (95% CI)	Screening tools	Diagnostic criteria	Age (years)	Sample size	Ref.
2019	Jilin	10.8 (8.7, 13.5)	CAST	ADOS; ADI-R; DSM-IV-TR; DSM-5	6 to 10	6,149	(9)
	Shenzhen	4.2 (2.0, 8.9)				20,802	
	Jiamusi	1.9 (1.0, 3.8)				15,663	
2020	Nationwide	7.0 (6.4, 7.4)	MC-ASRS; WISC-C; MINI-kid	ADOS; ADI-R; DSM-5	6 to 12	125,806	(8)
2021	Wuhu	4.11 (2.8, 4.9)*	CARS	DSM-5	2 to 6	12,657	(27)
2021	Inner Mongolia	2.66 (1.6, 3.5)*	CABS; ABC	DSM-5	3 to 14	15,817	(28)

\*Prevalence estimates and/or 95% CIs calculated from information reported in the original papers. Nationwide: Shanghai, Guangzhou, Changsha, Harbin, Beijing, Chongqing, Chengdu, Wenzhou. ABC, Autism Behavior Checklist; ADI-R, Autism Diagnostic Interview-Revised; ADOS, Autism Diagnostic Observation Scale; CABS, Clancy Autism Behavior Scale; CARS, Childhood Autism Rating Scale; CAST, Children Autism Spectrum Test; DSM-IV-TR, Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> Edition, Text Revision; DSM-5, Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Edition; MC-ASRS, modified Chinese version of the Autism Spectrum Rating Scale; MINI-kid, Chinese Mini International Neuropsychiatric Interview for Children and Adolescents-Parent Version; WISC-C, Wechsler Intelligence Scale for Children in Chinese.

majority of the population with ASD living in remote or backward areas still tends not to be diagnosed due to the shortage of medical personnel, public ignorance, and parental concealment (6), implying a higher level of prevalence. The speculation is that the number of patients with ASD exceeds 10 million in China, more than 2 million of whom are children (10). The increasing prevalence of ASD has attracted the attention of the government.

### 3. Laws, regulations, and policies on ASD in China

China enacted a slew of legislation since the mid-1980s with the goal of helping the disabled, and especially through special education. In 1986, the government adopted the Compulsory Education Law, providing disabled individuals with access to public education, and then "Suiban Jiudu", literally learning in regular classrooms, became the dominant form of special education in 1988 as a result of the influence of foreign "inclusive education" (11). The Law on the Protection of the Disabled promulgated in 1990 further emphasized the necessity of protecting the right to education of the handicapped. With the help of the 1994 Regulations on the Education for the Disabled, more detailed regulations and distinctions have been made in terms of methods of instruction and curricula. Eventually, the aforementioned laws and regulations promoted comprehensive universal basic education for all children, including those with disabilities (11).

Regrettably, early legislation only described principles and it provided very general and spotty protections for the mentally disabled. There is no specific policy guaranteeing an education to children with ASD, who are often turned away from government-run public schools, including special education schools (12). Nevertheless, once autism was included as a mental disability, the state specifically proposed education for children with ASD for the first time in 2009, reflecting the country's particular attention to their compulsory education (12). At present,

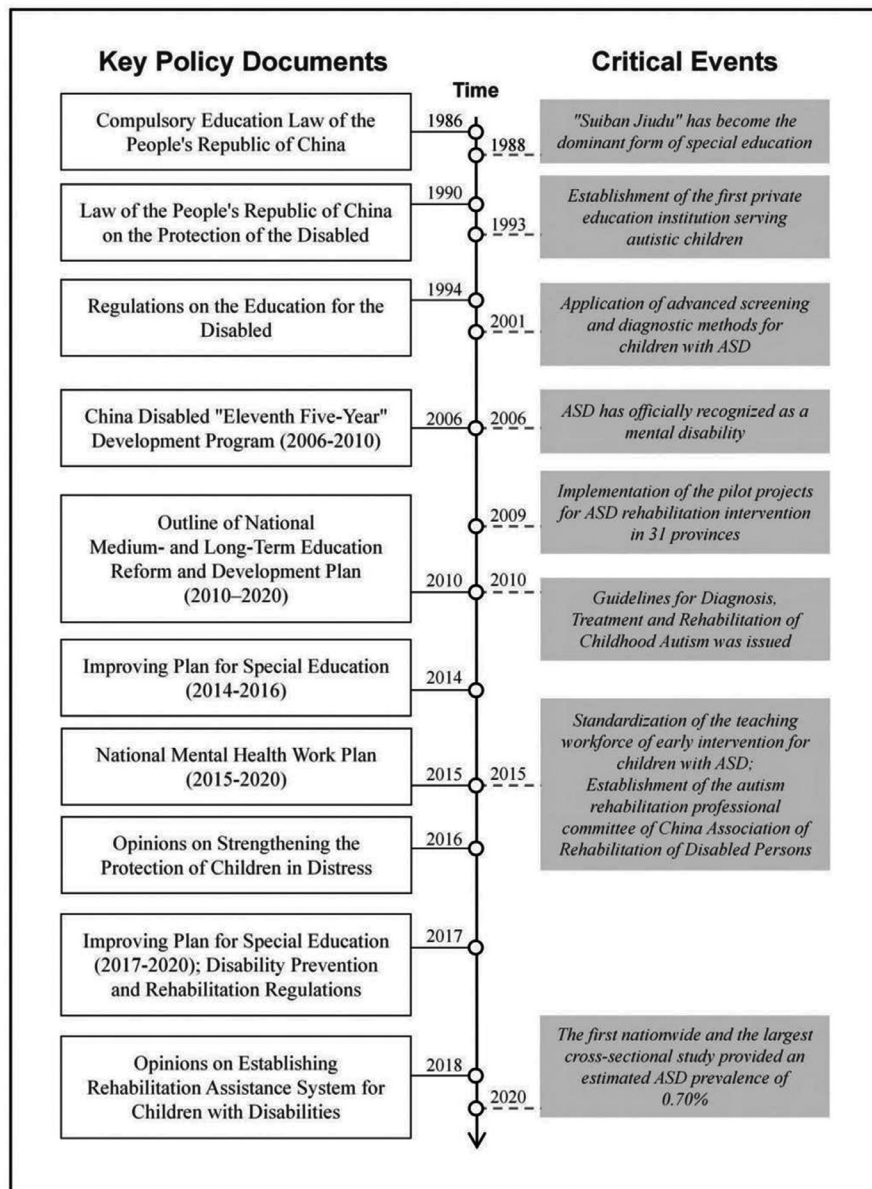
special education has entered a new phase. Relevant departments additionally launched two phases of a plan to promote special education, ultimately resulting in an enrollment rate among children with disabilities of more than 95% and an enrollment in special education (including children with ASD) of 149,046 by the end of 2020 (13). To ensure the development of rehabilitation in conjunction with education, a series of guidelines and rehabilitation policies were successively promulgated, gradually creating a national system of rehabilitation assistance for disabled children (14). Figure 1 shows a timeline of major events and milestones in the development of China's laws, regulations, and policies on ASD since the 1980s.

### 4. The public's knowledge, attitudes, and perceptions towards ASD in China

There has been speculation that a lack of public awareness of ASD might contribute to an insufficient understanding of the disorder in China (7,9,15). Described below is the current status of ASD awareness among three main groups of Chinese: parents/caregivers, educators, and medical personnel.

#### 4.1. Parents/caregivers

In general, Chinese parents of children with ASD lack basic knowledge about the condition (16). They often suffer from great psychological pressure and social discrimination because of negative media portrayals and social stigmatization (6,16-19), resulting in the reduced likelihood of seeking diagnosis, intervention, and support (16,19). Worse still, these parents usually prevent their children from interacting with outsiders to hide what they consider to be the shameful truth (16). Moreover, approximately 40% of families of children with ASD face heavy indebtedness after incurring rehabilitation costs are (6), and almost 60% of families experience interpersonal conflict and job loss because of parenting



**Figure 1.** Brief timeline of China's ASD strategy since 1986. Key policy documents are mainly related to education and rehabilitation. Major national initiatives or landmarks are cited as critical events.

demands (20). Increasing expenses for education and rehabilitation have made families more vulnerable, affecting their well-being in a substantial way (21), which explains why most parents feel hopeless and pessimistic about their children's future.

#### 4.2. Educators

Teachers with knowledge of ASD have been in short supply in China's education system for a long time (6,15). A recent study indicated that the majority of teachers were not familiar with the general situation of and interventions to deal with ASD, reflecting a lack of training in special education (15). Although experience working with disabled children might compensate this deficit, paradoxically the reason for children with ASD are most often denied school admission is the lack of experienced teachers to work with them (22). Notably, some teachers are reluctant to accept autistic children

in their classes, but most teachers are eager to teach children with disabilities and would like to do more to help students with disabilities, including ASD (15). Accordingly, some scholars have proposed the concept of pre-service and post-service teacher training, which may lead to a more optimistic future for children with ASD in China (23).

#### 4.3. Medical personnel

An absolute lack of ASD-related knowledge among medical personnel prevailed on the Chinese mainland. Doctors at community clinics and local hospitals have little education or professional training in child psychiatry (7), so most children with ASD are diagnosed only at tertiary hospitals in large cities (24). On the one hand, child healthcare workers are relatively young, with comparatively little work experience (25); on the other hand, they have relatively low levels of education

(25), and even highly educated or pediatricians also have minimal training in child and adolescent psychiatry (7). Thus, the fact that they know little or even less than parents of children about ASD is not surprising. More alarmingly, there is still an acute shortage of pediatricians and pediatric psychiatrists in China (7,26). They are concentrated in relatively developed areas such as Beijing, Shanghai, and Guangzhou, resulting in an uneven distribution and vast disparity in levels of care (26).

### 5. Suggestions and outlook for the future

Despite some progress and achievements, there are still some deficiencies and urgent issues that need to be addressed: *i*) Expanding the coverage of screening for children with ASD. The prevalence of ASD in China needs to be monitored continuously at the national level to obtain accurate data about its incidence to understand the course of the disorder; *ii*) Improving assistance and treatment for children with ASD; and *iii*) Raising public awareness of ASD. Research on ASD should be publicized in a comprehensive manner to garner society's attention and awareness, and an understanding of ASD should be promoted among key groups to ensure a good environment so that children with ASD can integrate into society.

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