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**TOWARDS AN
INCLUSIVE FUTURE:
ACHIEVING QUALITY
SUPPORT FOR
CHILDREN WITH AUTISM
IN BEIJING**

Prepared in October 2021

Project Background

Autism, also known as autism spectrum disorder (ASD), is a lifelong developmental disability characterized by impairments in social interaction, problems with verbal and non-verbal communication and restricted, repetitive behaviour, interests, and activities. It usually manifests itself during the first three years of life.¹ Up till now, there is no scientific research that verified the specific causes of autism,² nor is there a known cure for it. Appropriate support, accommodation and acceptance of this neurological variation allow those with autism to enjoy equal opportunity, and full and effective participation in society.³ In 2007, the United Nations General Assembly highlighted the need to help improve the quality of life of those with autism so they can lead full and meaningful lives as an integral part of society.

Although children irrespective of gender, race, or socio-economic status could be affected by autism, there are some differences among different genders: as of 2016, autism was 4.3 times as prevalent among boys as among girls in the United States, whereas the percentage of those with an intellectual disability⁴ was higher among girls than boys (39% versus 32%).⁵ Though without nationwide statistics, it is believed that the situation of children with autism (CWA) is similar in China.⁶

Since the first autism case was diagnosed in 1982, China has become the country with the world's largest population with autism (over 10 million), including more than 2 million girls and boys aged 0-14.⁷ In the seven types of disability⁸ recognized in China, autism is categorized into mental disabilities. Most children diagnosed are of moderate or severe autism, whereas most with milder symptoms live unidentified and undiagnosed. There is no official statistics of CWAs in Beijing.

China lacks the education and training for professionals working in schools, rehabilitation organizations, and health system that can provide support and service including screening and diagnosis, appropriate rehabilitation, tailored education approaches in both special education schools and regular schools. These result in difficulties in providing quality and comprehensive support for CWAs and their families. Therefore, many parents of CWAs and/or professionals

¹ United Nations General Assembly. 2008. *Resolution adopted by the General Assembly on 18 December 2007 – 62/139. World Autism Awareness Day.* <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N07/472/11/PDF/N0747211.pdf>, accessed September 2021.

² Autism results from a neurological disorder that affects the functioning of the brain.
Ibid.

³ United Nations. *Background – World Autism Awareness Day.* <https://www.un.org/en/observances/autism-day/background>, accessed September 2021.

⁴ About 1 percent of the general population is thought to have Intellectual Disability, and about 10% of individuals with Intellectual Disability also have a diagnosis of Autism Spectrum Disorder (ASD) or autistic traits. However, a much higher percentage of individuals on the autism spectrum have Intellectual Disability.

<https://www.carautismroadmap.org/intellectual-disability-and-asd/>

⁵ United States Centers for Disease Control and Prevention. 2020. *Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years -- Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016.* <https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm>, accessed September 2021.

⁶ Wucailu Autism Research Institute. 2019. *China Autism Education and rehabilitation Industry Development Status report III.* http://www.china.org.cn/chinese/2019-04/12/content_74673984.htm (in Chinese), accessed September 2021.

⁷ Wucailu Autism Research Institute. 2019. *China Autism Education and rehabilitation Industry Development Status report III.* http://www.china.org.cn/chinese/2019-04/12/content_74673984.htm (in Chinese), accessed September 2021.

⁸ China's Criteria of Disabilities are based on the World Health Organization's International Classification of Diseases (ICD) and the International Criteria of Functions, Disabilities and Health (ICFDH). Disabilities were accordingly divided into seven categories: visual, hearing, speech, physical, intellectual, mental, and multiple.

founded autism organizations to explore their own way of supporting CWAs. But there is a **lack of regulation of the service quality, nor systematic programme for staff capacity building**. These autism organizations⁹, usually registered as civil society organizations (CSOs) or private companies, have become the backbones of studies, surveys, research, training of professionals, and interventions in the country. However, these organizations offer interventions and trainings based on different methodologies and are not always equipped to teach students with special needs.¹⁰ Their services are provided with varied cost, but generally higher than affordable for many families.

Parents play a vital role in CWAs' early identification, diagnosis, rehabilitation, education, and development, but they **face daunting challenges** as a result of the above-mentioned situation:

(1) Heavy financial burden, which sometimes throw families back to poverty. The family structure is usually seriously affected by the diagnosis, hence reduces the family income.¹¹ The *Revised Regulations on Disability Prevention and Recovery of the Disabled*¹² asked to establish a national rehabilitation system for children with disabilities (CWDs), with the goal of providing free rehabilitation devices and services to CWDs aged 0-6, including CWAs. The Beijing municipal government provides subsidies for all autistic children with or without a Disability Certificate,¹³ as long as they have been diagnosed by a qualified medical institution. However, the amount of financial support remains fractional to the expenses.

(2) Insufficient knowledge and information: Many parents do not know where to find quality and reliable services and organizations for their children. At the early stage, many parents disbelieve that their children have autism, hence miss the prime window of opportunity for rehabilitation (commonly recognized as 0-6 years old); and then tend to misbelieve that autism could be completely cured, transferring among different autism organizations across China, which causes increasing costs and additional pressure. Many even peddle untested medications and other quick fixes that promise a "cure" for autism – most are ineffective or even harmful for their children.¹⁴

(3) Insufficient and unbalanced resources for adolescents and youth with autism. This group is often too old to attend autism organizations (primarily for children from 0 to 7 years old) but are not prepared for work. According to a 2016 report on Chinese families with autism, adults with autism had an employment rate of less than 10% in the country.¹⁵ In a survey in

⁹ In 2019, there were 1,811 autism organizations in China, with over 50,000 staff.

Wucailu Autism Research Institute. 2019. *China Autism Education and Rehabilitation Industry Development Status Report III*. http://www.china.org.cn/chinese/2019-04/12/content_74673984.htm (in Chinese), accessed September 2021.

¹⁰ In 2019, there was no colleges or universities in China that trains professionals ready for frontline intervention. Ibid.

¹¹ Many parents of CWAs (or at least one parent) had to give up their full-time job to support their children. Many couples are divorced after diagnosis or during formidable rehabilitation.

¹² The State Council of the People's Republic of China. 2018. *Revised Regulations on Disability Prevention and Recovery of the Disabled*, http://www.gov.cn/gongbao/content/2019/content_5468953.htm (in Chinese), accessed September 2021.

¹³ The Disability Certificate is an identification document given to a person with disabilities by the China Disabled Persons' Federation, a national official organization that safeguards the rights and interest of persons with disabilities in China. In principle, all benefits related to persons with disabilities, such as living subsidies, aids for job searching, etc. are only provided to those with a Disability Certificate. In reality, many parents of CWAs are reluctant to apply for a Certificate for their children for the fear of discrimination.

¹⁴ Wall Street Journal. 2015. *China's Uncounted Children with Autism*. <https://www.wsj.com/articles/chinas-uncounted-children-with-autism-1431963548>, accessed September 2021.

¹⁵ Xinhua News Agency. 2021. *China Focus: Chinese families strive to improve lives of children with autism*. http://www.xinhuanet.com/english/2021-04/02/c_139854492.htm, accessed September 2021.

2014, 69.3% of the parents think there is a lack of attention on employment skills training for older CWAs; and 72.7% worries about their children's future after their passing away.¹⁶

Last but not least, **an enabling environment** is yet to be fully established. Autism is a complex and inadequately understood disability with a wide range of manifestations. In addition to the daily challenges of their disability, CWAs and their families must also cope with the negative attitudes of society, inadequate support for their needs and, in some cases, blatant discrimination.

This project will be Save the Children China's first pilot to focus on a particular type of disability and improve the quality of support for CWAs by autism organizations and parents. Among the above-mentioned bottlenecks and gaps, this one-year pilot will focus on **capacity strengthening of pilot autism organizations, support for parents of CWAs to build their knowledge and skills, as well as improvement of an enabling environment of inclusion and non-discrimination**. The project also aims to identify gaps in current policy implementation, knowledge, and capacity, to lay a solid foundation for project design of the next phase (2-3 years) to better support families of CWAs, improve social services, and inform policies and regulations.

Project Goal & Strategy

Project Goal:

Girls and boys with autism (after identification up to 18 years old) receive improved support from autism organizations and parents on rehabilitation and social integration to fulfil their development potential in Beijing, China

Project Strategy:

- Strengthening the capacity of autism organizations based on a better understanding of the context and needs of CWAs and families
- Improving the knowledge and skills of parents of CWAs through online and offline capacity building modules
- Raising stakeholders' awareness of CWAs to create a supporting environment

Target Group and Location

This project will work in Beijing to target:

- Girls and boys with autism (after identification up to 18 years old);
- Parents of CWAs; and
- Staff of autism organizations supporting families with CWAs.

Specifically, the project will directly benefit **100 CWAs** (subject to the actual number of CWAs in the selected pilot organizations and surrounding communities) and **around 2,600 adults**. Indirectly, the

¹⁶ China Association of Persons with Psychiatric Disability and their Relatives. 2014. *Blue Papers on Needs of Parents with Autistic Children in China* (in Chinese). The sample size of the survey was 3,581.

project is expected to reach **additional 1,000 CWAs** through strengthened capacity of autism organizations and parents.

Project Outcomes and Key Activities

Outcome 1. The capacity of autism organizations is strengthened

Output 1.1 A situation analysis is conducted to understand current situation of CWAs, policies, and challenges

- *Key activities include: a situation analysis will be conducted to understand the current situation of CWAs, including the education, rehabilitation, employment, and development of CWAs; the way of work and methodology of autism organizations; and challenges facing parents of CWAs in Beijing.*

Output 1.2 The support model by autism organizations is improved, with one or two autism organizations as the pilot

- *Key activities include: support for daily operation and capacity building for one or two autism organizations, and exploration of ways to better support CWAs.*

Outcome 2. The knowledge and skills of parents of CWAs are improved

Output 2.1 Capacity of parents of CWAs is improved through online courses, offline training and exchange sessions

- *Key activities include: online course development for parents based on successful experience, training and exchange sessions for parents and CWAs.*

Output 2.2 Interactive activities are conducted for CWAs to practice socialization skills

(*Potential opportunities for donor employee engagement)

- *Key activities include: Project team will work together with the partnering autism organisations to facilitate interactive activities for parents and CWAs to develop the socialization skills of CWAs.*

Outcome 3. The supporting environment for CWAs is improved

Output 3.1 Stakeholders' awareness of inclusion and challenges of CWAs is improved

- *Key activities include: policy advocacy based on pilot, and awareness raising activities in communities. On one hand, CSOs should join hands for policy advocacy to address common challenges that parents of CWAs are facing. On the other, efforts should be made to enhance the understanding and acceptance of autism and awareness of inclusion, especially for parents of children without disabilities. In this way, CWAs can benefit from the supportive environment they need to reach their full potential and contribute to society.*

Output 3.2 Project experiences are documented and shared among multi-stakeholders to inform policy implementation

- *Key activities include: the establishment of an exchange platform for CWAs and parents, policymakers, researchers, and autism organizations to share experience.*

Project Duration & Budget

Duration: 1 year

Budget: USD 200,000