

# Autism Spectrum Disorder in China: Challenges and Changes

## 自闭症 Zì bì zhèng

Elizabeth M. Starr, PhD.  
Faculty of Education  
University of Windsor



# Overview

- What is autism spectrum disorder (ASD)?
- The nature of ASD
- Causes of ASD
- ASD in China
- Challenges and Changes



# WHAT IS AUTISM SPECTRUM DISORDER?



# Autism Spectrum Disorder is...

- A developmental disability affecting many areas of a child's development
  - Impairments in communication and social development
  - Restricted and repetitive behaviour and interests (APA, 2013)
- First described in an article in 1943 by Leo Kanner
- Hans Asperger published article in 1944 in Vienna describing children with similar behaviour but higher functioning than those described by Kanner
  - Article not translated into English until 1981
  - "Asperger Disorder" or "Asperger Syndrome" became a possible diagnosis in 1994 with DSM-IV



# Autism Spectrum Disorder

DSM-5



~~Autistic Disorder  
Asperger Syndrome  
“High Functioning Autism”~~



# Facts and Figures

- Prevalence as high as 1/59 in the U.S. (CDC, 2018)
  - 4-5 boys for every girl (in China as high as 9:1)
- About ¼ develop epilepsy by adolescence
- About 38% have an intellectual disability as well
  - Those at the high functioning end of the spectrum do not have an intellectual disability but DO have challenges with understanding the social world
- Occurs in all racial, ethnic, and socioeconomic groups
- Children with autism grow up to be adults with autism
  - Autism is not “outgrown” but huge progress can be made even with low functioning individuals with education and early intervention

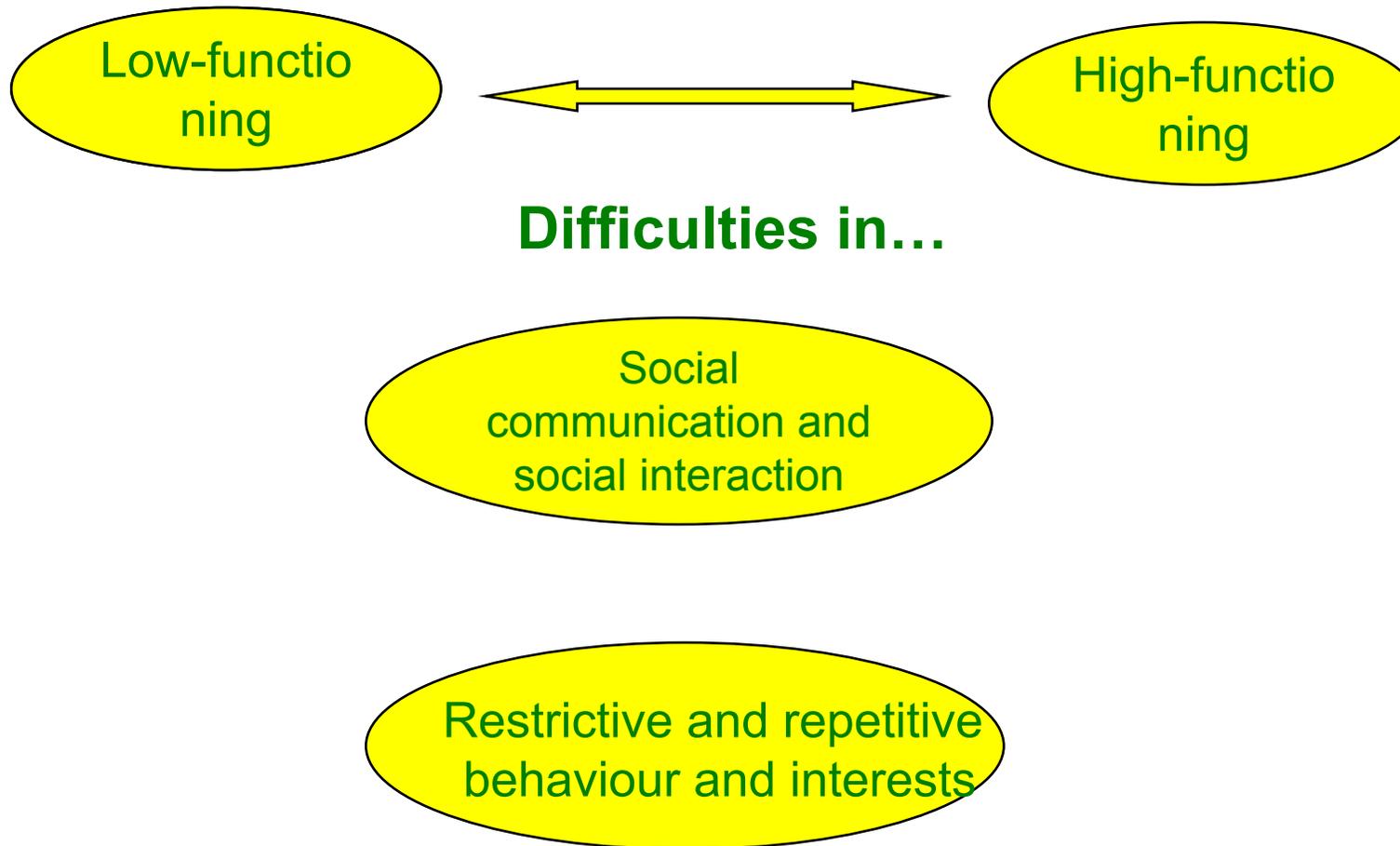
(Baio et al., 2018)



# THE NATURE OF ASD



# Commonalities



# Difficulties in social reciprocity

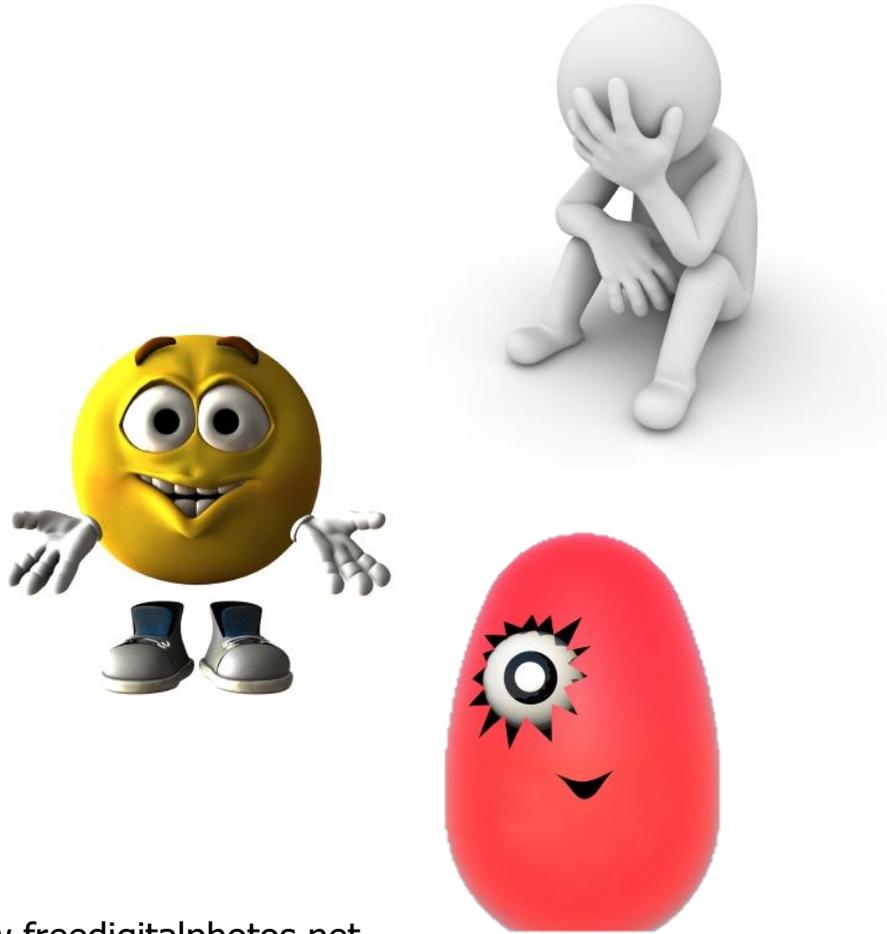
- Difficulties in social approach and having back and forth conversations
- Reduced sharing of interests, emotions or affect
- Failure to initiate or respond to social interactions
- Lack of perspective taking



(APA, 2013)



# Difficulties in Verbal and Nonverbal Communicative Behaviour



- Poor integration of verbal and nonverbal communication
- Abnormalities in eye contact and body language
- Deficits in understanding and use of gestures
- Lack of joint attention
- Limited or total lack of facial expressions and communication
- May not talk at all

[www.freedigitalphotos.net](http://www.freedigitalphotos.net)

(APA, 2013)



# Problems in developing, maintaining, and understanding relationships

- Difficulties adjusting behaviour to suit various social contexts
- Difficulties in sharing imaginative play or in making friends
- Absence of interest in peers



(APA, 2013)

[www.freedigitalphotos.net](http://www.freedigitalphotos.net)



# Restricted, repetitive patterns of behaviour, interests, or activities

- Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour
  - E.g., flapping hands, spinning objects, repetitive speech (echolalia), pacing a perimeter
- Highly restricted, fixated interests that are abnormal in intensity or focus



[www.freedigitalphotos.net](http://www.freedigitalphotos.net)



# CAUSES OF ASD

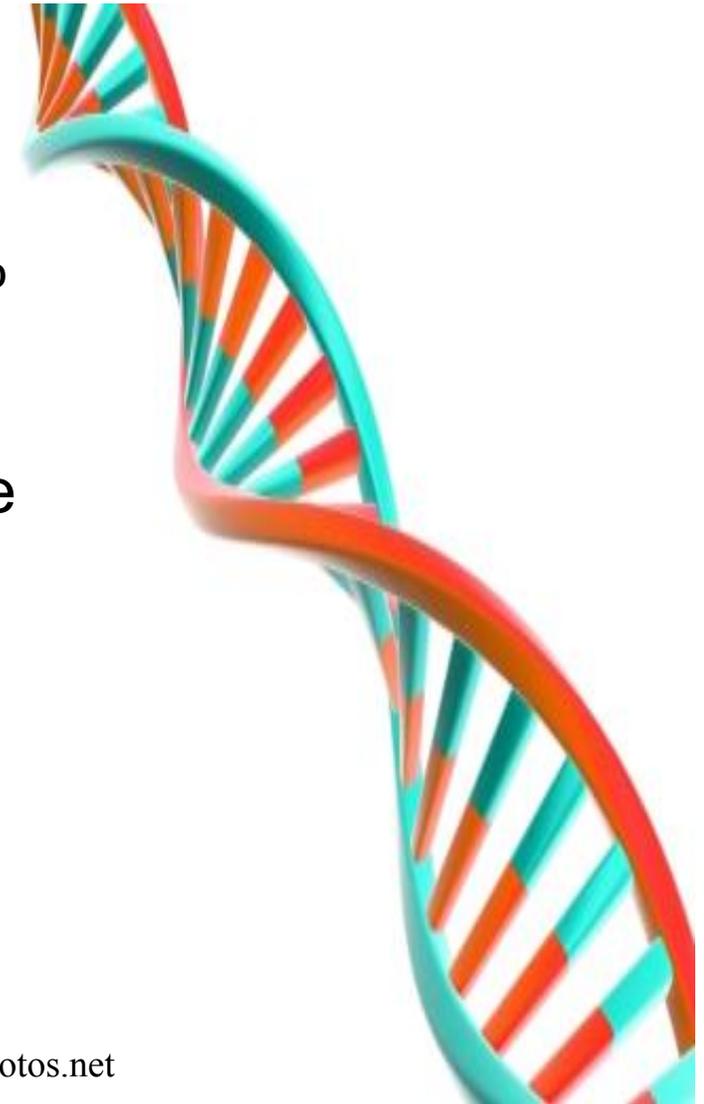


# Some Causes of ASD

- Genetics

- Twin and family studies consistently show that 90% of ASD is attributable to genetic factors
- Parents having 1 child with ASD more likely to have 2<sup>nd</sup> child with ASD
- Is now thought that > 1000 genes may be implicated
- Older parents (fathers in particular) more likely to conceive child with autism

[www.freedigitalphotos.net](http://www.freedigitalphotos.net)



- **Brain differences**

- Increased brain size

- **Cerebellum**

- Explains difficulties in acquiring smooth coordination of mental skills



- **Limbic System**

- In charge of emotions, feelings, moods
- Immature development of structures in autism

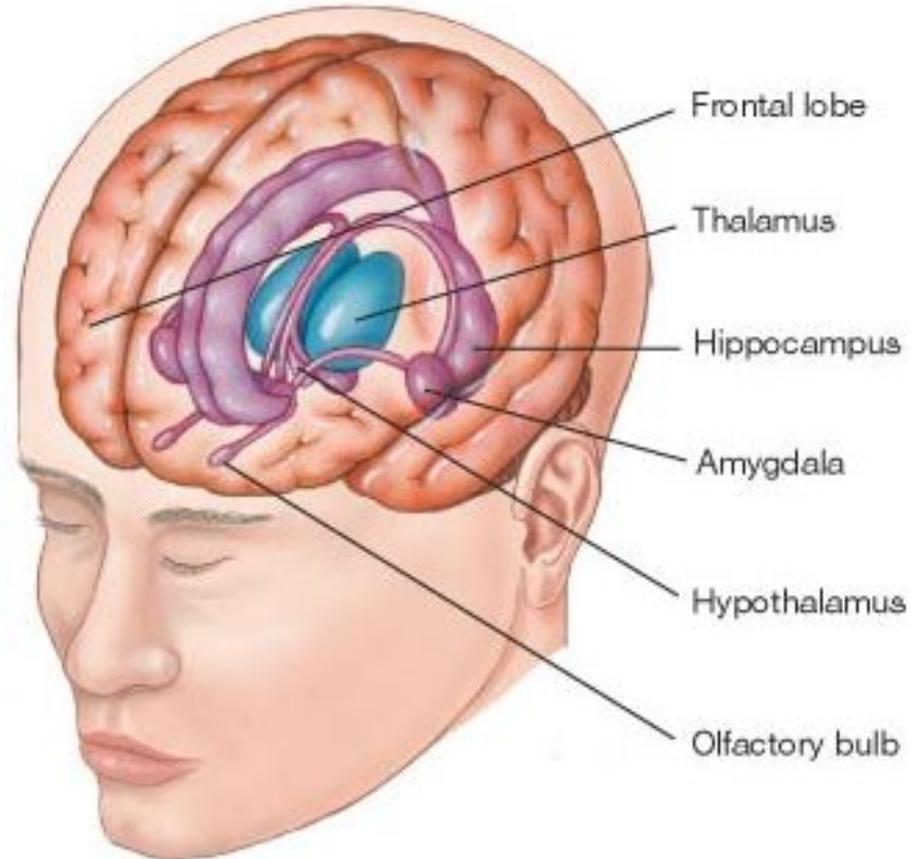


Photo: <http://anxiousnomore.blogspot.com/2009/10/anxiety-and-our-brains-part-4-limbic.html>



# ASD IN CHINA



# Autism Spectrum Disorder in China

- In China ASD literally means “the loneliness disease”
  - “alone syndrome” “self-enclosed syndrome” “Children of the Stars”
- ASD first diagnosed in China in 1982 at Nanjing Brain Hospital and first report published in 1987
  - Not officially recognized as a disability until 2006
- Is thought there is as many as 18 million people (~1/100) with ASD in China but there is no national data
  - 2 million children under age 14
  - 600,000 preschoolers



(Huang et al., 2013; McCabe, 2012; Sun et al., 2019)



# The Challenges of ASD in China

- Lack of knowledge and understanding about autism (even among professionals)
  - Parents not recognizing developmental delay partly due to one-child policy (no comparison with other children)
  - Only take child to doctor when child doesn't speak
    - Delayed language also may be thought of sign of superior intelligence
  - Very few psychiatrists (never mind child psychiatrists) and many have never heard the term “autism”
  - Only about 100 people trained to diagnose autism in the entire country
    - Many, many children remain undiagnosed (Zhu, Z-W et al., 2018)



# The Challenges of ASD in China

- **Misconceptions about autism**
  - Many parents believe their children might be “cured” so they are able to attend public school
  - Autism is a very rare disorder
  - Autism caused by parents spoiling children making them “little emperors”
- **Stigma and shame at having a child with a disability**
  - Many low functioning children are hidden away from family and society
  - Parents blame themselves, or mothers are blamed
  - Difficulty accepting a disability diagnosis given high expectations for child



(McCabe, 2008; Ming, 2012; Tait et al., 2016; Zhang & Spencer, 2015)



# The Challenges of Autism in China

- **Lack of educational options**
  - Public schools not obligated to accept children with autism
  - Although legislation “encourages” public schools to accept children (“Suiban Jiudu” policy), they are not required to and there is no funding provided
  - Very few special education teachers (low prestige)
  - Schools for children with disabilities focus on sensory (blind/deaf) and intellectual disabilities
  - Little to no knowledge about teaching children with autism



(Huang et al., 2013)



# The Challenges of ASD in China

- **Only option are privately run centres**
  - Many of these begun and run by parents who have no training
  - Many use therapies that are not supported by research or are harmful (e.g., “toughening up” children) [3-year-old dies](#)
  - Are expensive for parents (¥800 RMB to ¥3,500 RMB per month--\$148-\$648 CDN)
  - Located in major cities thousands of miles away for many families
  - Are very difficult to get into with long waiting lists
  - Services that do exist are only for children up to about 6 years old (maximum of 10 years old)



(McCabe, 2012; Wang, 2017Wang et al., 2019)



# Change is happening...

- Growth in the number of centres
  - Problem is emphasis is on quantity rather than quality
- Some centres are using “applied behaviour analysis”(ABA) techniques that have been proven effective
  - Problem is that very few have systematic
- Centres are training parents in ABA techniques in 3 month programs so they might be able to teach their children at home
  - E.g., Xingxingyu in Beijing opened in 1993



# Development of Chinese Augmentative and Communication Apps (AAC)



Guest



食物

感覺



社交



食物



水果



飯



麥皮



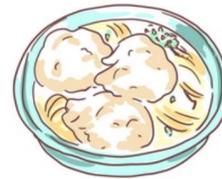
粥



麵



饅頭



雲吞

設置為頂部

添加項目

共享



# Change is happening...

- There are numerous collaborations happening with western researchers
  - E.g., Tianjin and La Trobe University in Melbourne, Australia
    - Autism Research Centre, Cambridge University and the Chinese University of Hong Kong
  - International conferences in China-Regional meeting of the International Society for Autism Research (INSAR)
- More people in China are becoming trained in diagnosis and education
  - Tong Yi Shi Jie Education Institute for Autism in Beijing
- Autism was included in 12<sup>th</sup> 5 year plan (2011-2015)
  - First time autism mentioned in government's blueprint for social and economic development
- June 2018 a new Beijing program that covers the cost of early childhood education up to age 6 (Compton, 2018)
- By the end of 2020 central government aims to financially support 80% of children with autism including those over age 7 (Wang, 2017)



# Going forward...

- Need for more doctors trained in ASD
- Need for more extensive and effective teacher training
  - Special education college in Nanjing has opened and offers a major in autism
- Need for services for adolescents and adults with ASD
- A need to reduce the financial burden of autism for families and stigma surrounding disabilities
- Although there is biomedical research in ASD, there is great need for educational research

(Lu, M-H, et al., 2018; McCabe, 2012; Sun et al., 2013; Wang et al, 2019)

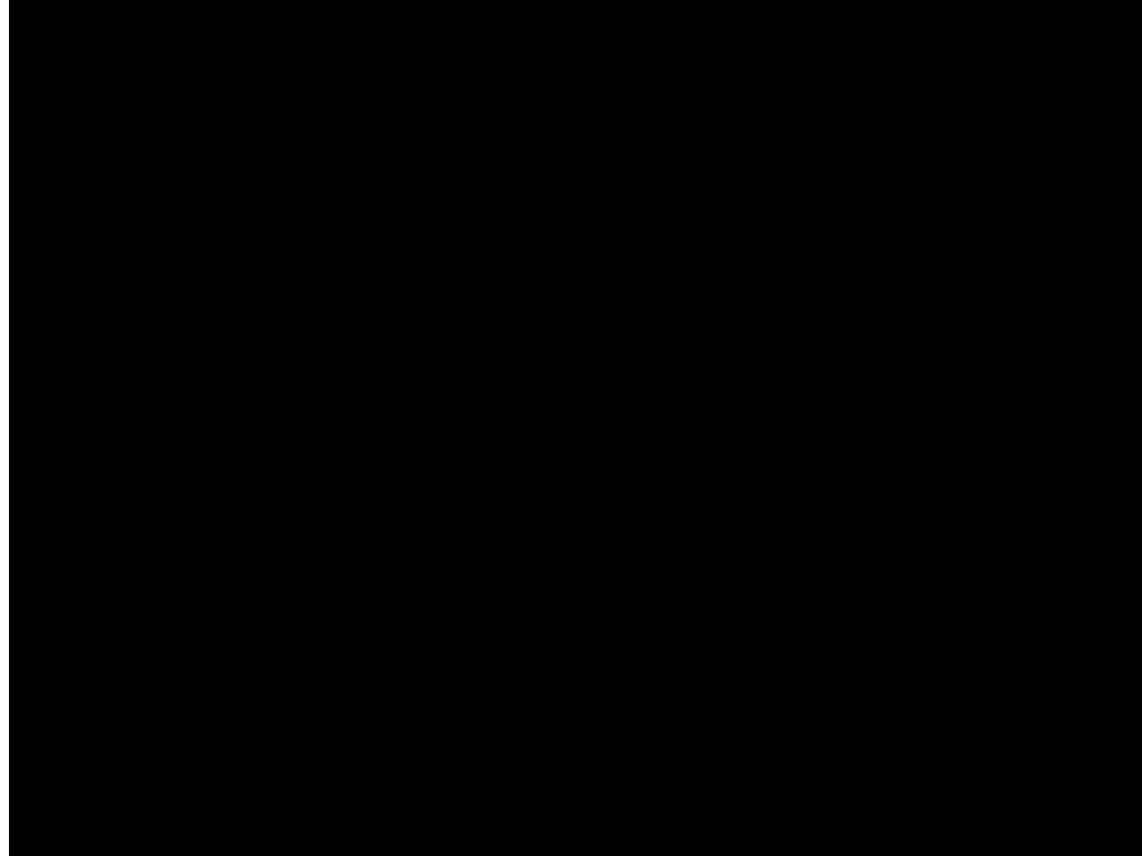


## References

- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5<sup>th</sup> ed.), Arlington, VA: Author.
- Baio J., Wiggins, L., Christensen, L. Maenner, M., Daniels, J., Warren, Z....Dowling, N. (2018). Prevalence of autism spectrum disorder among children aged 8 years. *Surveillance Summaries*, 67(6), 1-23.
- Huang, A., Jia, M., & Wheeler, J. (2013). Children with autism in the People's Republic of China: Diagnosis, legal issues, and educational services., *J. Autism Dev. Disord*, 43 1991-2001.
- McCabe, H. (2008). Autism and family in the People's Republic of China: Learning from parents' perspectives. *Research & Practice for Persons with Severe Disabilities*, 33, 37-47.
- McCabe, H. (2012). Bamboo shoots after the rain: Development and challenges of autism intervention in China. *Autism*, 17, 510-526.
- Ming, J. (2012). Autism in China: A biosocial review. *Journal of Global Health*, [www.ghjournal.org/autism-in-china-a-biosocial-review](http://www.ghjournal.org/autism-in-china-a-biosocial-review)
- Sun, X., Allison, C., Wei, L., Matthews, F., Auyeung, B., Wu, Y...Brayne, C. (2019). Autism prevalence in China is comparable to western prevalence. *Molecular autism*, 10, <https://doi.org/10.1186/s13229-018-0246-0>.
- Tait, K., Fung, F., Hu, A., Sweller, N., & Wang, W. (2016). Understanding Hong Kong Chinese families' experiences of an autism/ASD diagnosis. *Journal of Autism and Developmental Disorders*, 46, 1164-1183.
- Wang, Y. (2017) . "China's autism schools a last resort for youth on the spectrum." *Sixth Tone*. Retrieved September 21, 2019 from <https://www.sixthtone.com/news/1000161/chinas-autism-schools-a-last-resort-for-youth-on-the-spectrum>.
- Wang, B, Cao, F., & Boyland, J. (2019). Addressing autism spectrum disorders in China. In Y. Liu (ED.). *Child and Adolescent Development in China. New Directions for Child and Adolescent Development*, 163, 137-162.
- Zhu, A-W, Jin, Y., Wu, L-L, & Liu, X-L. (2018). Current status and challenge in clinical work of autism spectrum disorders in China. *World Journal of Pediatrics*, 14 209-211.
- Zhang, D., & Spencer, V. (2014). Addressing the needs of students with autism and other disabilities in China: Perspectives from the field. *International Journal of Disability, Development and Education*, 62, 168-181.



# “Children of the Stars” documentary Xingxingyu in Beijing



<https://www.youtube.com/watch?v=VmXnwYuPqfw>



**Thank  
You!  
谢谢  
Xièxiè**

