

David Zheng Song  
LEND fellow  
UCONN MPH Student



# Children with autism spectrum disorders in China: what resources are available to these children and their families?

This is an area with limited research and little attention from society



# Background

# Why this issue matters?

When talking about children with autism, we are NOT talking U.S. children with autism or Chinese children with autism; we are talking children with autism.

Because autism doesn't care that much of nationality, race, or color of skin.



## Why this issue matters? (Cont'd)

For my project, I reviewed 406 papers on children with autism in China. Most of these papers are just literature review of autism-related theories, diagnostic methodologies, or intervention programs that originated from western countries.

**Very few papers are devoted to family resources of these children and their families**



# Why this issue matters? (Cont'd)

For children with autism in China

- Around 5.6 to 28 per 10,000 during 1986 to 2006\*
- Diagnoses are delayed for a long time or never occur
- No such Law as IDEA, no legal protection for early intervention and inclusion
- Very limited family resources
- An area with limited research and little attention from society



\* Based on different Studies



# Study Design

# Study Design



## Study Questions :

- What resources children with autism and their families have in China
- What resources they hope to get in the future

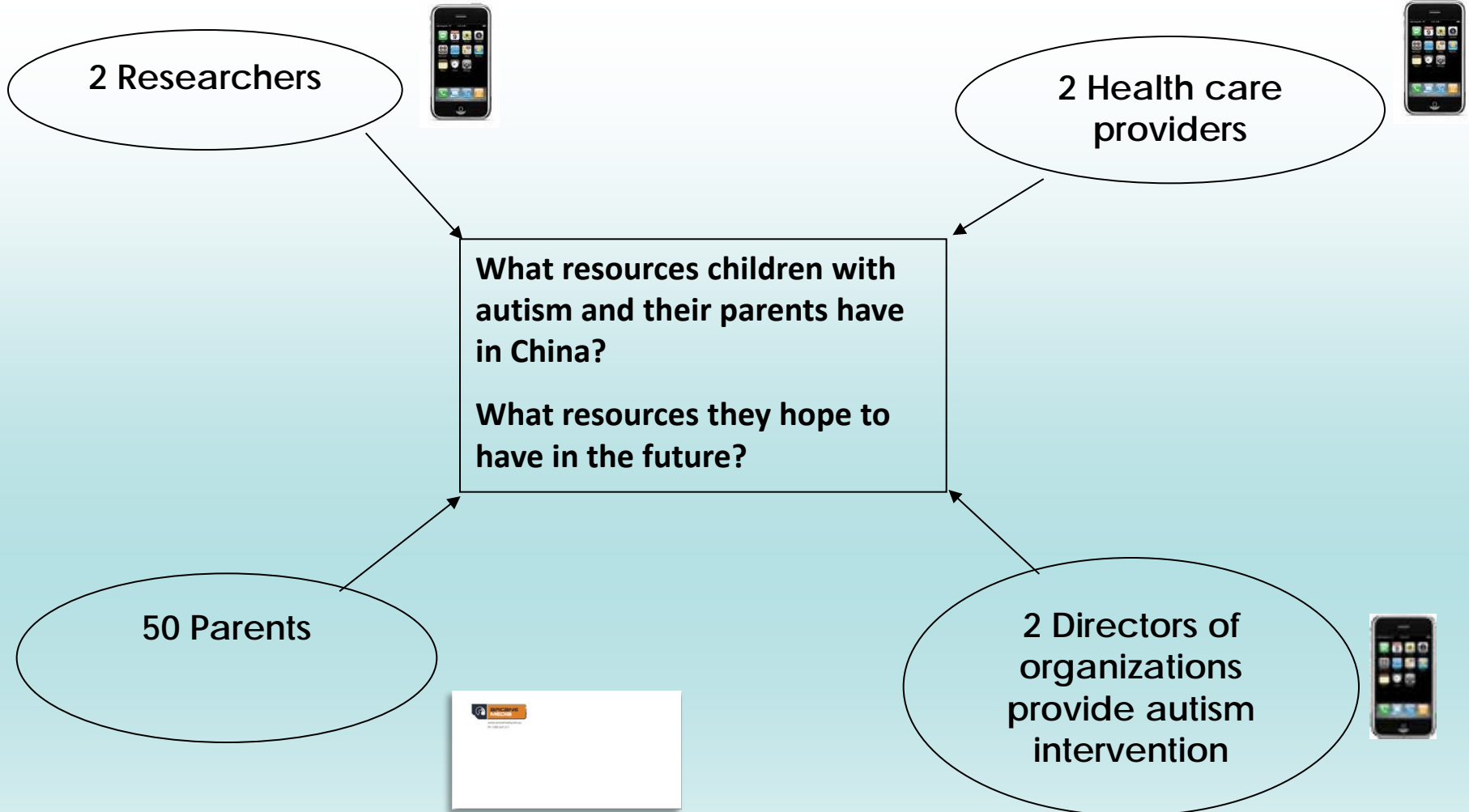
# Study Design (Cont'd)

## My study hypotheses

- **Children with autism and their parents do not have many recourses in China,**  
possible resources could include government subsidies, health insurance,  
legal protection, inclusion, specialized school education, early intervention,  
support from relatives, friends, or the community;
- **Parents would want to have more**  
attention from the government, financial supports, affordable early intervention  
programs and parenting training, understanding, respect and support from the  
society.



# Study Design (Cont'd)



# Study Design (Cont'd)

Institutional Review Boards: Great Wall



# Study Design (Cont'd)

For LEND: Impossible is nothing





# Preliminary Findings

# Preliminary findings

Findings are based my interviews with

2 health care providers

- **Dr. A** works as a child neurologist for the Neurological Diseases Rehabilitation Center at the biggest children's hospital in Beijing. She is seeing some 40-50 children with ASDs every year. Diagnoses are made based on DSM-IV criteria; besides that, she is also counseling parents on early intervention and related issues.
- **Dr. B** has been working for 18 years at the most reputable children's hospital both in Shanghai and in China, and is currently the dean of the Department of Psychology. From 1999 to 2000, she studied as a visiting scholar at the Department of Psychiatry and Behavioral Sciences of Memorial Sloan-Kettering Cancer Center at New York. She is leading a group of health professionals providing screening, evaluating, diagnosing, counseling, and early intervention for autism spectrum disorders in Shanghai.

# Preliminary findings

## 2 NGO directors

- **Mr. D:** a social worker, he has been working for 8 years at an organization dedicated to providing services for children with ASDs; he is currently the executive director of that organization. The organization was founded by a mother of a boy with autism at 1993, when there was no social resource or early intervention could be found. Now it is not only the largest but also the most reputable NGO for children with ASDs in China.
- **Mr. E:** a PhD in computer science, who is also a father of a boy with autism; he has been working for 5 years for a NGO for children with ASDs in China. Since its establishment by parents in 2001, this organization has been regarded by many parents of children with ASDs in China as the best one. Its online forum acts as a very important avenue for parents to find useful information and resources, exchange information, and seek social support.

# Preliminary findings

I am still trying to contact researchers

So far, I've tried to contact 10 researchers (more than 3 attempts for each of them) who have peer-reviewed articles on children with ASDs or reported by mass media as leading scholars in this field in China.

Disappointingly, almost all these researchers acknowledged that they were unfamiliar with resources for children with ASDs and their families in China and were unwilling to take my interview

# Preliminary findings

## Diagnosis

- **Social interactions and language problems at around 1 year old**
- **Noticed by parents or other caretakers (e.g. grandparents) of the children**
- **Most children are diagnosed at 3-5 years old (kindergarten)**  
traditional Chinese belief; parents' denials; no former parenting experience;  
pediatricians are ill-trained for autism; seeing a psychologist or psychiatrist is still  
severely stigmatized in China
- **Diagnosed by psychiatrists or children psychologists in big hospitals**  
Processes of diagnosing are also different, Shanghai;  
three tiers city health care system, M-CHAT;





# Preliminary findings

## Intervention

- **Intervention is delivered at hospitals or organizations**

NGOs rather than public (governmental) entities such as hospitals; hundreds of such organizations providing early intervention & day cares—most founded by parents. 60% preschoolers with autism would receive some early intervention or day care services in these organizations

- **Early intervention professionals**

pediatricians/child education graduates with no training for autism early intervention; they would learn some early intervention methods by themselves from different resources; Personal experience rather than evidence based intervention

- **Cost for intervention**

Parents have to pay out of pocket. Shanghai, since 2006 children under 20 universal health insurance

- **All most all the intervention program are for preschoolers**

# Preliminary findings

## Inclusion

*“When they are at their school age, “over 95%” children with ASDs have to stay at home”*

- **No explicit legal protection**

Compulsory Education Law of the People’s Republic of China;

The Law of the People’s Republic of China on the Protection of Persons with Disabilities

The 1994 Regulations on Education for Persons with Disabilities

- **Schools are ill-prepared**

Schools for typically-developing children; Special schools: children with physical disabilities or intellectual disabilities

- **Some progress**

Shanghai or Shenzhen: special class for children with developmental disabilities; but only serving children living in the districts

# Preliminary findings

## Other family resources

- **Government subsidy**

Government officially added autism under the umbrella of disability  
Government subsidies

- **Health care insurance**

After 2006; big cities; early intervention is not covered in most cases

- **Donation made by individuals or companies**

# Preliminary findings

## Social support

*“Most anxieties of the parents are from concerns for their children’s future: education, working, and who is going to take care of them after parents passed away.”*

*“The society has a lot of misunderstandings and even discriminations for these families; parents often hide these children at home, and they are unwilling to let people know they have children with disabilities. Therefore it is very tough for parents to express themselves, and they have a lot of psychological issues.”*

# Preliminary findings

## Social support

- **Internet**

Peer parents rely a lot on internet to share their information and emotional support; they also have parents clubs as a source for social support

- **Parents clubs**



Next step



Thank you!!!