

A Project For Change: The Pervasive Need of Support for Children with Developmental Disabilities in China

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Both clinical doctors and public health workers are lack of the knowledge and experience on autism or PDD. (2005) Clinical pediatricians have little information on the prevalence of developmental disorders, such as autism. China has the largest population in the world (Zhang et al., 2005)

PREVIOUS RESEARCH

Prevalence (Zhang and Ji, 2005)

In a study of 7,345 randomly selected children aged 2 to 6 years old in a metropolitan area of China, researchers found:

- The prevalence of ASD was 1.10 cases per 1000
- The prevalence of intellectual disabilities was 10.76 cases per 1000

Coping Strategies (Wang, Michaels, and Day, 2010)

Study of stress and coping strategies being used by 368 families of children with Autism and other developmental disabilities in China. Researchers found:

- Parents exhibit stress around future outlook for their child
- Parents perceived problems for themselves and other family members
- Parents expressed lack of knowledge regarding their child's diagnosis, behaviors and resources
- Nine frequently used coping strategies
Social Support, Active coping, Denial, Behavioral disengagement, Restraint, Substance use, Acceptance, Suppression of completing activities, & Planning

Services Received (Zhang and Ji, 2005)

88.4% of children in the study with developmental/intellectual disability received no treatment at all

Of the 11.59% who did receive some treatment

- Hospital (50%)
- Special Institution (38%)
- Educational Institution - only one child

NO HOME INTERVENTION AT ALL

Of the 8 children identified with Autism

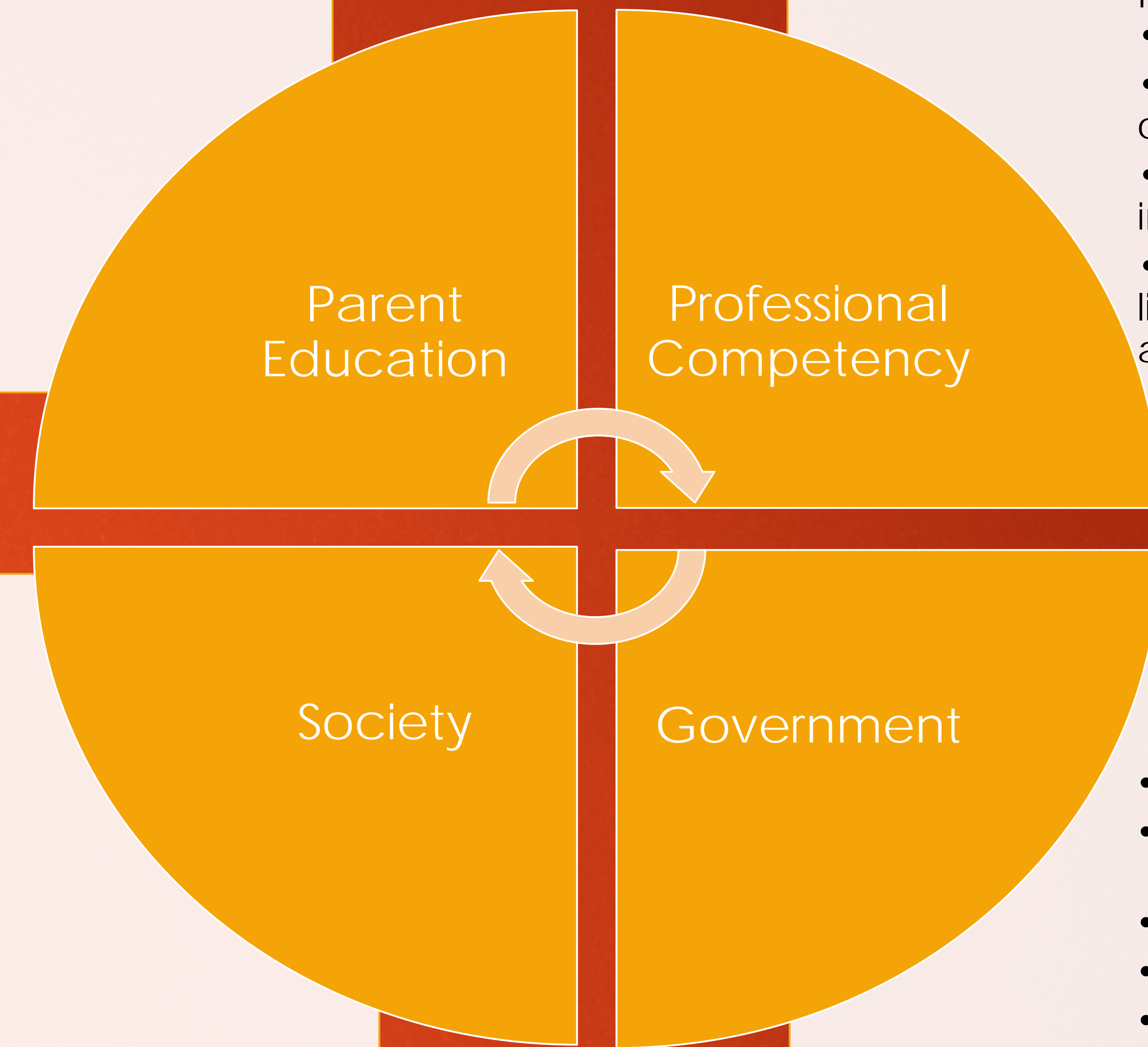
50% received no intervention

The others received interventions at hospitals, educational institutions and at home.

- Understanding Characteristics of various disabilities – especially their own child
- Understand developmental milestones
- Strategies and techniques for teaching specific skills
- Behavioral Management
- Self Advocacy



- Address the stigma of disability
- Cultivate grassroots advocacy efforts
- Community-based programs
- Disability specific parent-led groups and organizations



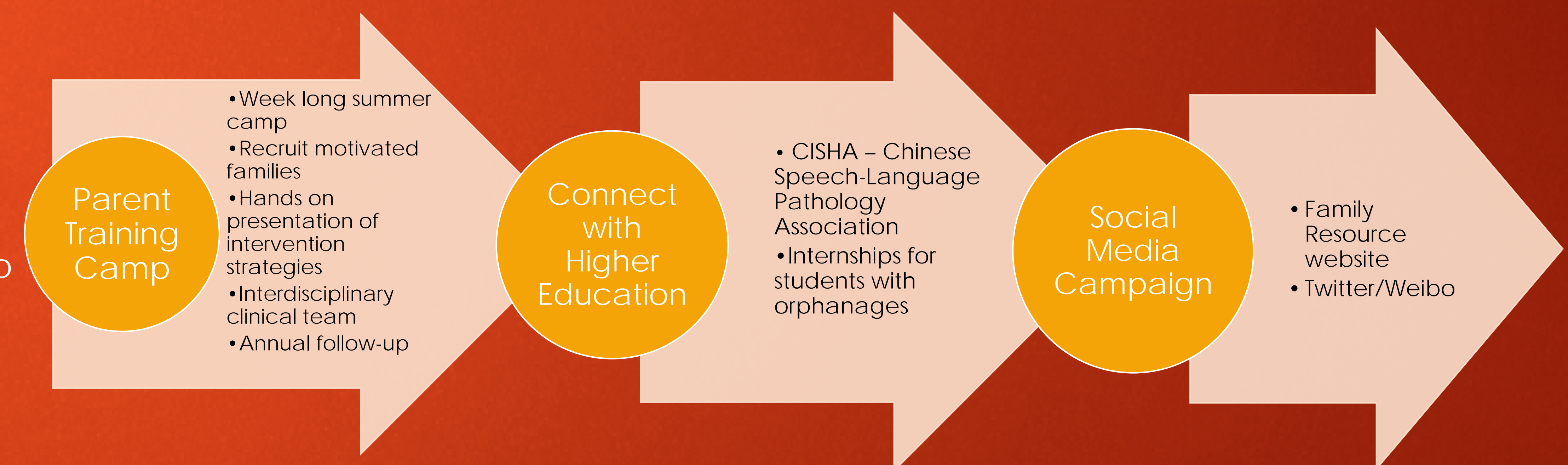
- Identify the possible causes of developmental disorders
- Notify families of the importance of pre-, peri-, post natal checkups
- Provide information to families
- Exchange thoughts with experts outside of China
- Understand and advocate for interdisciplinary teaming
- Developing culturally and linguistically appropriate assessment and intervention tools



- Policies
- Funding for families with developmental disabilities
- Early Intervention services
- Funding for academic programs
- Funding for diagnostic and intervention centers
- Cooperation with NGOs

A PLAN FOR CHANGE

Train caregivers, inspire students, partner with local professionals in non-profit agencies to affect a sustained systematic change.



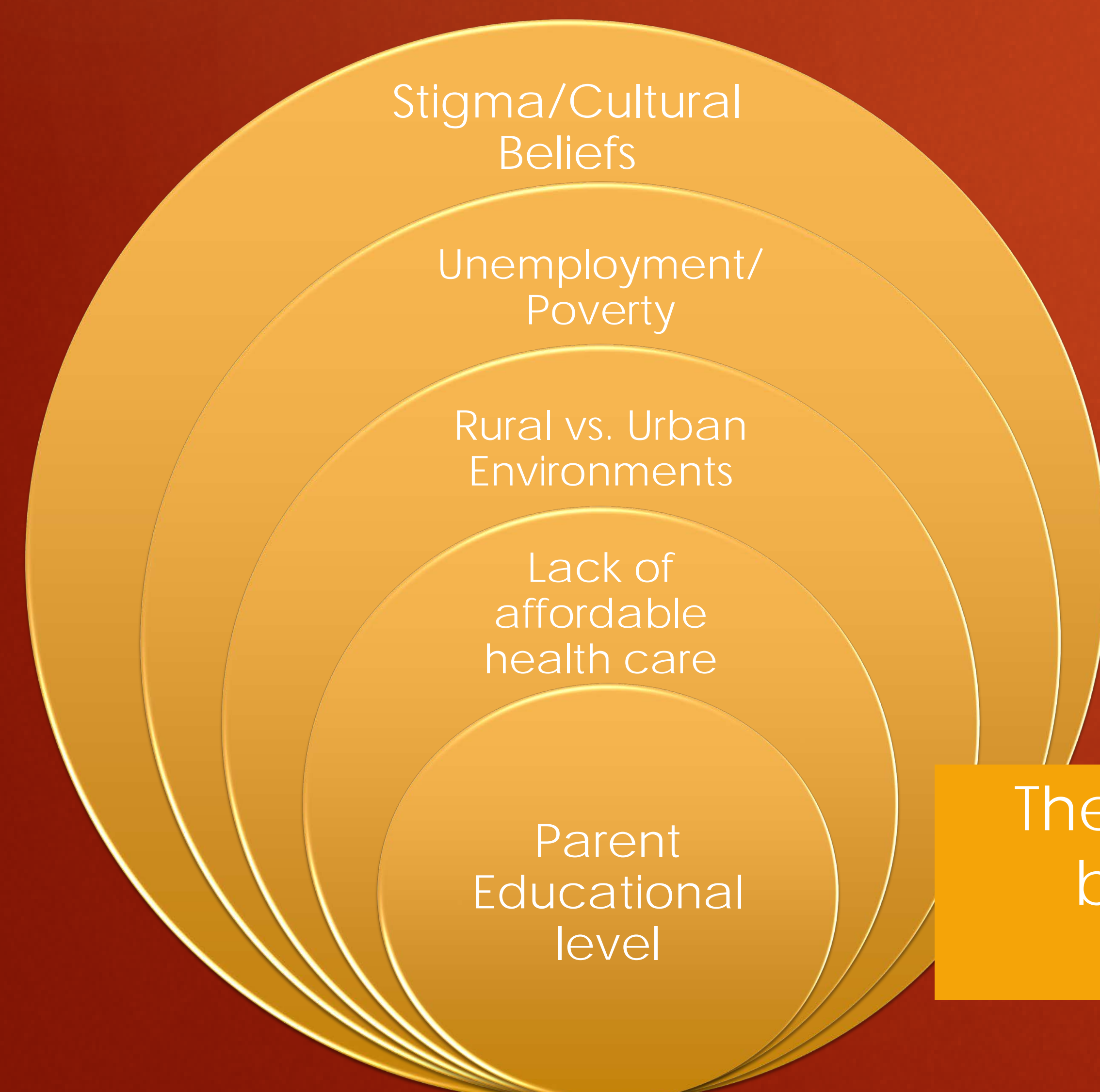
HOW YOU CAN HELP

- Interdisciplinary team to travel to China and conduct the first parent camp
- Locate and acquire funding
- Obtain culturally appropriate diagnostic/intervention materials
- Researchers to continue collecting and analyzing data
- International advocacy skills

REFERENCES

1. Carver, C.S., Scheier, M.F., & Weintraub, J.K., (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56, 267-283.
2. Hao, G., Layton, T.L., Zou, X., & Li, D. (2014). Evaluating autism in a Chinese population: The clinical autism diagnostic scale. *World Journal of Pediatrics*, 10(2), DOI: 10.1007/S12519-014-0466-0.
3. Huang, A. X., Jia, M., & Wheeler, J. J. (2013). Children with autism in the People's Republic of China: diagnosis, legal issues, and educational services. *Journal of autism and developmental disorders*, 43(9), 1991-2001.
4. Qian, M. Y., Smith, C.W., Chen, Z.G., & Xia, G.H. (2002). Psychotherapy in China: A review of its history and contemporary directions. *International Journal of Mental Health*, 30(4), 49-68.
5. Shi, Q.J., Sang, Z. Q., Li, X. Q., Zhou, J., & Wang, H.F. (2005). Current status of counseling and psychotherapy in China. In Q. J. Shi, Q.F. Zeng, X.C. Sheng, & W. Senf (eds.), *Psychotherapy: Theories and practice* (pp.21-34). Beijing, China: Chinese Medicine Pharmacy Science Publishing House. In Chinese.
6. Wang P, Michaels CA, Day MS. (2011). Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of Autism Developmental Disorders*, 41(6), 783-95. doi: 10.1007/s10803-010-1099-3.
7. Zhang X, Ji CY. (2005). Autism and mental retardation of young children in China. *Biomedical Environmental Sciences*, 18(5), 334-40.

BARRIERS



Observations of Private & Government-run orphanages (Gao, 2013)

- The majority of children with special needs are given away to private or government run orphanages
- Government-run agencies provide limited care to children with special needs
- There is no capacity to train families in addition to providing care
- Hospitals and special schools are too expensive or located in urban areas only
- University training for healthcare professionals is limited in the special areas that children with disabilities most commonly need, and there are few professionals practicing in the disability field, fewer yet who engage in family centered care

There are cultural, Social and Economic barriers for families to access family-centered care.