Parent Mediated Intervention for children with ASD in Mainland China

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Autism Spectrum Disorders

• A disorder characterized by difficulties in social interaction and communication, and with repetitive stereotyped behaviors.
• Thought to be rare disorders, but is now well recognized as a common developmental disorder
Rising rate of ASD in China

• Globally, autism rate is rising
• Epidemiological study in China also find the rising trend. but the data may not be so high as we estimated before.
• Prevalence of ASD is related to the awareness of the public and medical professionals. We have to say, we may still underestimate the prevalence of ASD in China.
• 1% of ASD rate in China may be true
Are we ready?

- China government is taking action
- International societies are taking action
- CWDF and CDPF are taking action
- Medical professionals are taking action
- Non-profit organizations are taking action
- Families are taking action. Actually, parents action was earlier than government
• In 1982, Dr. Tao Guotai reported 4 cases of children with autism in mainland China
In 1993, Tian Huiping, the mother of a child with autism found the “Stars rain” in Beijing. This is the first training school for children with autism.
Special Education Institutes

• There are over 1000 special education institutes in Mainland China. Many schools are founded by parents.

• Most schools are day intervention centers. Parents and other family members are encouraged to join the education program.
Intervention approaches

- Applied behavior analysis (ABA)
- Structured training (TEACCH model)
- Language therapy
- DIR model, RDI model
- ESDM model
- SCERTS model

- The intervention approaches above have been introduced into China
But

- China may have more than two millions children with ASD
- China have only three hundred child psychiatrists.
- Primary care pediatricians are lack of the experience of diagnosing and intervening ASD
- The support from Government is not enough
- China belongs to low resource setting country
But （continued）

- Poor public awareness to ASD
- Misunderstanding exists
- Lack of basic data about ASD in China, such as the data about financial burden, comordity, wander away, school bullying, etc.
- Training institute is not enough, the quality of intervention is not as good as we expected
- Home-based training is not well implemented
- No service for adult with ASD
Alternative therapies are popular

- Sensory integration
- Diet and vitamin therapy
- Traditional Chinese medicine and acupuncture
- Stem cell transplantation
- Neuro-nutrition therapy
- .......

No evidences support those therapies
Ecological System (ES) Theory

- Proposed by Urie Brufenbrenner from Cornell University
- A comprehensive theory for child development
- It is very helpful for us to understand the situation of children with ASD
Ecological system of child development

- Individual: temperament, intelligence, disease, etc.
- Micro-system: relationship between child and parents, teachers, peers, etc.
- Meso-system: relationship between parents etc.
- Exo-system: work status of parent, society, etc.
- Macro-system: culture, ethics, view of value, laws, etc.
- Chronosystem: things change with time
这个图展示了一个包含儿童在内的社会系统。系统分为三个层次：外层系统、中间系统和微系统。外层系统包括意识形态、法律、文化、亚文化和社会阶层等。中间系统包括学校、家庭成员的朋友、社区健康和福利中心等。微系统包括儿童、大众传媒、家庭、幼儿园、医院、寺庙、工作场所等。各个系统之间有双向的互动和影响。
Examples of ecological system when a child diagnosed ASD

- Developmental disorder affect the quality of life
- Impaired Parent-child relationship
- Relationship between parents may change because of the diagnosis of ASD.
- The wave of the second child is coming, sibling rival disorder?
- Mother may quit the job because she want to take care the child.
- When a family has a child with ASD, what’s the attitude the parents and other people should have?
- Will the child with ASD be improved or worsen with time?
Allowing yourself the time to grieve after the diagnosis and recognizing the stages of grief.
Foshan city, a child with ASD wandered away and was found back by policemen.
Divorce happened frequently if a child is diagnosed with ASD.
The parents of typical development children refuse the child with ASD go to school.
A teenage in Shenzhen city was refused by the school to go to school.
中华文明五千年
The work we need to do

- To carry out early diagnosis and intervention
- To change the incorrect attitude and view of value toward the people with ASD
- To improve the awareness of public and professionals
- To relieve the family pressure, peer pressure,
- To ensure the rights the people with ASD should have
- The government should pay more attention to people with ASD. To improve the social service system for early diagnosis and intervention, inclusive education, job training, lifetime development etc.
As a low resource setting country, China must implement home-based intervention for children with ASD.
Autism Center in SYSU

• Autism center of the 3rd affiliated hospital, Sun Yat-sen University (SYSU) is the first institute providing comprehensive medical and educational service for children with ASD in Guangdong.

• We have been implementing parents training for children with ASD and other developmental delays for 18 years.
ASD statistics in our center

• Nearly 30,000 cases of ASD were identified from 1999 to 2017.
• Sex ratio is 6:1 (Male: female)
• Age ranges from 10 months to 35 years
• average age is 3.5 years old.
Parent education work we are doing

• Distribute Education and training materials to families
• Two days workshop for parents, 30000 parents participated our workshop.
• Short-term hand on teaching for parents (7 days)
• Child along with parent participate one month intervention program.
• To the mild case, we have the higher level intervention program for one month
• Parent group discussion
• Followed by one to one guidance for years
30,000 parents have participated in our workshop since 2000.
Our intervention model (BSR model)

• **B**: behavioral therapy as the basic approach. By using reinforcement, prompt, planned ignorance, time-out, etc.

• **S**: structured training as the basic framework. The training activities must be well organized.

• **R**: focus on social interaction during child’s daily life. Happy training, natural training.
We are family
One to one training
Walk along with you
We spread our intervention experience and model to a lot of hospitals from different cities of China, by giving lectures, CME and clinical observation and further study on site.
China women development foundation have been promoting the home-based intervention for children with ASD
National Autism Promotion Projects by CWDF

• “10-100-1000-10000 project”
• A project supported by China Women’s Development Foundation
• Since 2012, this project have trained 10000s physicians and therapists and social workers, in 100s hospitals, from 18 provinces, and to help 10000s children with ASD and their families. It will continue to train more physicians and therapists.
National Autism Promotion Projects by CWDF

• To establish a national ASD online registry, assessment, intervention and research platform.

• The goal of this platform is to help thousands of parents to carry out individualized home-based intervention for children with ASD in China, especially for low resource areas.
China Disabled Person Federation have been helping children and families with ASD and will begin home-based intervention program in China.
World Health Organization
PST PROGRAM
in China just initiated

Professionals → non-professionals
facilitator → parents
GENEVA, WHO CONFERENCE FOR AUTISM
Heephong Society and autism education and training in China
The teacher of Heephong society from HK in GD
The teachers from Heephong society in GD
Guangzhou Tower,
April 2 2011
“Light it up blue”
May 17 2015, Miss Peng visited a autism training center in Beijing
Case report

• Xiao ming, 4 years old
• Diagnosis: moderate ASD
• 4 years training, mainly home-based
• He is now 8 years old. He is now in the second grade in primary school. His academic achievement, social adaption and family life is normal.
一定要训练 自然心
一定要有耐 必要快乐
一定要有前途

——邹小兵

“学习节” 2011/11/11
let’s work together to create a better ecological system for our children with ASD and other developmental delays.

THANK YOU