

# **Need for Cross-Cultural Comparison on QOL: Cerebral Palsy and Rehabilitation in China Guangxi Autonomous Region**

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# Background

- Proposal
  - “Quality of Life of People with Cerebral Palsy: A Cross Cultural Comparison”
- Quality of Life (QOL) measures
  - In Western and European Countries
  - In Mainland China
- Plans
  - To build a collaborative research team between U.S. and China
  - To cross train the research team for the purposes of developing cross cultural QOL measurements



# Objectives

- To develop QOL measures suitable for assessing the quality of life of both CP children and CP adults in Chinese cultural settings
- To develop comparative measurements that could be used to assess the effectiveness of Western and Eastern medicine approaches on treatments and interventions of people with CP.



# Specific Aims

- Develop a conceptual framework for evaluating and creating QOL instruments for people with CP that are cross cultural and of varying ages
- Evaluate QOL instruments for CP-specific children and adolescents; and, translate a culturally sensitive pediatric QOL instrument into the Chinese language
- Develop parallel QOL instruments for CP-specific aging adults in the United States and China



# Research Network

- Building a research team in the U.S.
  - Working with the UCP of Greater Cleveland
  - Developing future work with the Cerebral Palsy Program and the Pediatric Rehabilitation Clinics at the University of Michigan
- Chinese collaborators
  - GuangXi University, School of Social Policy and Social Work
  - Women's Research Center
  - Disabled Persons' Federation of Guangxi Autonomous Region



# Basic Data

- Prevalence rate of cerebral palsy in China is about 1-2 cases per 1,000 people
  - A survey of 388,192 children under age 7, in the Jiangsu Province, were found to have a prevalence rate of CP to be 1.6 per 1000 live births during 1993-1996
  - In May 1997 to December 1998, a cross sectional survey reported a prevalence rating of 1.92 per 1000 live births among 1,047,327 children aged 1 to 6 years, in six provinces of China



# GuangXi Data

- In the Guangxi Zhuang Autonomous Region:
  - 50,806 children surveyed from June to December 1998 between ages 1 to 6, were reported to have a prevalence rating of 1.28 per 1000 live births diagnosed with CP



# Research Sites in China

- Potential research sites in China
  - Angel House in NanNing, GuangXi
  - Recovery Center for Children, at GuangXi Healthcare Hospital for Women and Children, NanNing, GuangXi
  - Children Neurological Rehabilitation Training Room, at YuLin First People's Hospital, YuLin, GuangXi
  - Special education school in YuLin
- Possible recruitment of adults with CP





# Site One

- The Angel House was established in June 1, 2002
- In 2008, the founder, Ms. Wang Fang, was one of the five honorary certificate recipients awarded by the United Nations for their contributions in promoting rights of people with disabilities
- Has residential quarters (currently serves 29 children) and day care centers (total is about 80 children)
- Reaches families that have children with CP in both urban and rural areas



# Site Two

- Recovery Center for Children
  - Established in 2000
  - Strong medical team
  - The largest rehabilitation center in GuangXi region
  - Good facilities and equipment
  - Some international exchange activities
  - Serves children with disabilities including CP



# Site Three

- Children Neurological Rehabilitation Training Room
  - Specialized to treatment children with CP
  - Does extensive measurements and evaluations on each patient



# Site Four

- Special Education School
  - Limited space
  - Partial financial support from the department of education
  - Serves children with disabilities, including CP



# Another Site

- American sponsored new families for children with disabilities
  - Parents are hired to parenting jobs
  - They are married couples and are paid with employment salaries
  - Children were orphans
  - Wife stays with the kids and husband can work outside the village (home)



# Issues

- Limited space for admissions
- Not enough information for families of people with CP
- The state-run health insurance does not cover the cost for rehabilitation
- Chinese regular educational system does not incorporate the special education programs
- Cultural sensitive measure issues



# Our Goals

- To develop QOL instruments
  - a translated pediatric instrument for CP children, and
  - a new adult QOL instrument for aging persons with CP
- The newly created measures
  - would be conceptually grounded
  - could be used to assess the effectiveness of Western and Eastern medicine approaches on treatments and interventions
  - will aid to explore the similarities and differences across nations and various cultural groups regarding QOL of persons with CP



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