APPENDIX 1. English Survey

INTRODUCTION

Hello, my name is Zheng Song. I am a physician from China, studying as a Master of Public Health student in the University of Connecticut. I am working on a project to understand what resources are available to families of children with autism in China. I believe that listening to your story is essential if we want to make a change for your child in the future. The survey is voluntary and your personal information will NOT be taken; the information you provide will only be used for research purpose. Please skip any question that makes you uncomfortable. Completion and return of the survey implies your consent for participating. This should not take more than 20 minutes. Your participation is very important and highly appreciated. If you have any further question, please contact me or the University of Connecticut Health Center. Thank you very much!

1. How old is your children who has autism? YEAR_________MONTH___________

2. What is the gender of this child?
   □ MALE
   □ FEMALE

3. What was the FIRST sign (or signs) that your child may have autism? (Check all apply)
   □ LIMITED INTERACTION WITH OTHERS
   □ LANGUAGE PROBLEMS
   □ ABNORMAL BEHAVIORS
   □ OTHER _____________
   □ DON’ T KNOW

4. How old was your child when this sign (or signs) firstly noticed?
   YEAR__________MONTH___________

5. Who first noticed this sign (or signs)?
   □ YOU
   □ YOUR SPOUSE
   □ RELATIVES
   □ SCHOOL EDUCATORS
   □ HEALTH CARE PROVIDERS
   □ OTHER _____________

6. Did you send your child to a health care provider right away when the early sign (or signs) was noticed?
   □ YES (SKIP TO QUESTION 8)
   □ THE EARLY SIGN WAS NOTICED BY A HEALTH CARE PROVIDER (SKIP TO QUESTION 8)
   □ NO
7. Why didn’t you send your child to a health care provider when the early sign (or signs) was noticed?
   □ THE COST TO SEE A HEALTH CARE PROVIDER
   □ IT IS TOO FAR FOR US TO SEE A HEALTH CARE PROVIDER
   □ WE WANTED TO WAIT AND OBSERVE MORE
   □ WE THOUGHT IT WAS OK
   □ WE WERE TOLD IT WAS OK
   □ OTHER ______________

8. How old was your child when he/she was diagnosed with autism spectrum disorder?
   YEAR__________MONTH___________

9. What was the diagnosis?
   □ AUTISM
   □ ASPERGER’S SYNDROM
   □ PDD-NOS
   □ OTHER ______________
   □ DON’T KNOW

10. Could you tell me the name of institution that made the diagnosis?
    _______________________________________________________________________

11. How old was your child when he/she started to take early intervention?
    □ MY CHILD DID NOT HAVE ANY INTERVENTION
    YEAR__________MONTH___________

12. What early intervention program you and your child ever got after the diagnosis? How did long it last? Are you satisfied with it?
    □ NONE
    □ NAME________________________________________LASTING TIME______________
    □ VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ Satisfied □ VERY SATISFIED

13. Do you agree that the government provides enough resources to help your family with your autistic child?
    □ STRONGLY AGREE
    □ AGREE
    □ NOT AGREE OR DISAGREE
    □ DISAGREE
    □ STRONGLY DISAGREE
14. What resources did your family get for your child’s autism (Check all that apply)?

How do you satisfied with the resources you got?

- WE DID NOT GET ANY RESOURCE

- SUBSIDY FROM THE GOVERNMENT
  - VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ SATISFIED □ VERY SATISFIED

- HEALTH INSURANCE FOR THE CHILD WITH AUTISM
  - VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ SATISFIED □ VERY SATISFIED

- LEGAL PROTECTION
  - VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ SATISFIED □ VERY SATISFIED

- INCLUSION IN SCHOOLS FOR TYPICALLY DEVELOPING CHILDREN
  - VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ SATISFIED □ VERY SATISFIED

- SPECIAL EDUCATION FOR CHILDREN WITH DISABILITIES
  - VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ SATISFIED □ VERY SATISFIED

- INCLUSION INTO THE SOCIETY
  - VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ SATISFIED □ VERY SATISFIED

- FINANCIAL SUPPORT FROM THE RELATIVES
  - VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ SATISFIED □ VERY SATISFIED

- FINANCIAL SUPPORT FROM THE FRIENDS
  - VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ SATISFIED □ VERY SATISFIED

- FINANCIAL SUPPORT FROM THE COMMUNITY
  - VERY DISSATISFIED □ DISSATISFIED □ NOT SATISFIED OR DISSATISFIED □ SATISFIED □ VERY SATISFIED

- OTHER ______________
15. What are the resources you hope to get in the future for your autistic child? (Check all that apply)
   □ MORE SUBSIDY FROM THE GOVERNMENT
   □ HEALTH INSURANCE FOR THE CHILD
   □ LEGAL PROTECTION
   □ PARENTING TRAINING
   □ INTERVENTION PROGRAMS
   □ INCLUSION IN SCHOOLS FOR TYPICALLY DEVELOPING CHILDREN
   □ SPECIAL EDUCATION FOR CHILDREN WITH DISABILITIES
   □ INCLUSION INTO THE SOCIETY
   □ FINANCIAL SUPPORT FROM THE RELATIVES
   □ FINANCIAL SUPPORT FROM THE FRIENDS
   □ FINANCIAL SUPPORT FROM THE COMMUNITY
   □ OTHER _____________

16. Do you agree that your relatives are emotionally supportive?
   □ STRONGLY AGREE
   □ AGREE
   □ NOT AGREE OR DISAGREE
   □ DISAGREE
   □ STRONGLY DISAGREE

17. Do you agree that your friends are emotionally supportive?
   □ STRONGLY AGREE
   □ AGREE
   □ NOT AGREE OR DISAGREE
   □ DISAGREE
   □ STRONGLY DISAGREE

18. Do you agree that other parents of children with autism are emotionally supportive?
   □ STRONGLY AGREE
   □ AGREE
   □ NOT AGREE OR DISAGREE
   □ DISAGREE
   □ STRONGLY DISAGREE

19. Do you agree that people in the community are emotionally supportive?
   □ STRONGLY AGREE
   □ AGREE
   □ NOT AGREE OR DISAGREE
   □ DISAGREE
   □ STRONGLY DISAGREE
20. Have you ever felt that your child with autism have been discriminated against?
   - YES
   - NO
   - DON’T KNOW

21. Have you ever felt that your family been discriminated against because of this child with autism?
   - YES
   - NO
   - DON’T KNOW

22. What emotional supports do you most want to get in the future?
   - SUPPORT FROM RELATIVES
   - SUPPORT FROM PEER PARENTS
   - SUPPORT FROM THE FRIENDS
   - SUPPORT FROM THE COMMUNITY
   - OTHER ______________

23. What year were you born? _______

24. What is your relationship with the child with autism?
   - MOTHER
   - FATHER
   - OTHER ______________

25. What is your (and your spouse's, if married) combined monthly income? _____ YUAN

26. What is the subsidy that your family gets for the autistic child per month? (Please put “0” for none)? _______ YUAN

27. What is your highest level of education? (Please indicate the highest one)
   - LESS THAN HIGH SCHOOL
   - HIGH SCHOOL OR VOCATIONAL SCHOOL
   - COLLEGE
   - GRADUATE SCHOOL
   - OTHER ______________

28. Where does your family live?
    ________ PROVINCE _________ CITY ________ COUNTY/DISTRICT

29. Any other information or concern you want to share with me?

-END QUESTIONNAIRE; Please put the finished survey in the envelope, seal it, and give it to the staff at Beijing Star and Rain. Thank you very much for participating in this survey and have a nice day!