



Skill Training for Parents with ASD Children in China

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Background: Parental involvement is key to both short-term and long-term prognosis of autistic children. However, currently in China, parents have limited access to professional knowledge and training of early intervention.

Methods: We designed an eight-session parental training course (Skill Training for Parents with ASD Children, STPAC) with the aim to help parents with young ASD children to master the basic intervention skills. The theory and strategies are derived from Early Start Denver Model (ESDM) and WHO Caregiver Skills Training (CST) program. The course was composed of eight sessions. There was one session each week which lasted three hours. Furthermore, there were three sections for each session: (I) delivery of theoretical intervention knowledge by one trainer; (II) video-based analysis and rating of parent-child interaction interventions by one trainer; (III) trainer demonstration of the key skill and parent practice of the skill. To assess parents' knowledge about the autism intervention, we designed a questionnaire called Knowledge of Autism Intervention Questionnaire (KAIQ). Besides the questionnaire, we designed a Parent Skill Rating Form (PSRF) as well, which was based on the ESDM and CST Fidelity Rating System, to evaluate the parent mastery of intervention skills and the quality of parent-child interaction interventions. At the beginning of the study, parents were asked to fill in the KAIQ and were evaluated for the fidelity score on PSRF by the trainer with the onset of enrollment, and at the end of the training, the KAIQ and PSRF scores were assessed again. Paired t tests were applied to compare the outcomes with baseline scores.

Results: A total of 55 families (seven groups) with ASD children were recruited. After eight weeks of training, the average correct answer rate of parent's KAIQ was increased from 54.5% to 81.8% (P value <0.0001). The average fidelity score of parent-child interaction intervention from PSRF was increased from 2.4 to 3.5 (P value <0.0001).

Conclusions: This skill training course is helpful for parents with young ASD children. Next steps involve setting up a pilot randomized controlled trial to test the effects on parent skills in a more rigorous manner and to examine effects on children whose parents are receiving the training.

Keywords: Autism spectrum disorder; parental training; Early Start Denver Model (ESDM); Caregiver Skills Training (CST); Skill Training for Parents with ASD Children (STPAC)

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Introduction

Autism spectrum disorder (ASD) is a group of heterogeneous neurodevelopmental disorders, which are characterized by deficits in social communication and interaction, and restricted and repetitive patterns of behaviors, interests, or activities (1). The disorder brings huge economic and emotional burdens to autistic families with its ever-increasing prevalence (2,3). The key to treatment is early detection, early diagnosis and early intervention. Due to the potential plasticity of neurological development in the early stage of childhood, early standardized behavioral intervention is proved to improve the prognosis of ASD children, integrate them into society more effectively and reduce the burden of the disorder (4,5).

Currently in China, early intervention for ASD children are mainly offered by therapists from medical and rehabilitation institutions. Optimism has been further tempered by the serious shortage of qualified therapists, lack of standardized training programs, as well as unequally distributed and inefficiently used resources. Young children with ASD spend most of their time at home, where their parents would have sufficient opportunities to interact with their children. However, these families have limited access to professional knowledge and training programs of early intervention (6). Longitudinal and cross-sectional studies have showed that parental involvement is key to both short-term and long-term outcomes. Parent-implemented intervention can not only improve autistic children's social communication and adaptive behavior but also reduce challenging behavior. It also contributes to the generalization and maintenance of skills (7-19). If parents could master the intervention strategies and use these strategies with their children in daily activities, it could produce a positive effect on the prognosis of children with ASD, thus reduce parenting pressure and relieve their economic burden as well (13,15).

In recent years, the study of parent-implemented early interventions for children with ASD has become a hotspot. World Health Organization has developed a Caregiver Skills Training (CST) program for children with ASD and developmental disorders. The program aims to help low-resourced caregivers grasp the basic intervention skills (20-22). CST does not only improve the efficiency of training and benefit more families, but also improves the efficiency and enthusiasm of learning by supporting each other within the group. However, CST is generally for children with developmental disabilities, not specifically

for ASD families. Early Start Denver Model (ESDM) is a representative approach of Naturalistic Developmental Behavioral Interventions (NDBIs) (23), which underlines implementing intervention in the context of naturally-occurring social activities. It is used widely for parent-implemented intervention and multiple studies of its efficacy have been published (4,5,8,14,19). We introduced ESDM since 2013, and we introduced the parent-implemented version, P-ESDM, and tested its effects on developmental and social-communicational outcomes of Chinese toddlers with ASD using the same curriculum and techniques as those in the original P-ESDM studies, and at a higher intensity and a longer duration than in the previous P-ESDM studies (8). However, we had initial problems involving a long waiting list for parents to get the P-ESDM training. We learned a great deal from the CST training approach and designed a new eight-session parental training course, which was called Skill Training for Parents with ASD Children (STPAC), based on a merger of the CST program with ESDM.

The objective of this pilot study was to determine if the skill training course would be helpful for parents to master both the basic knowledge and skills in ASD intervention.

Methods

Participants

The children were recruited from the Children's Hospital of Fudan University from October 2017 to June 2018. Inclusion criteria: (I) the ASD diagnosis was made based on the criteria of ASD in Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) informed by ADOS-2 administration; (II) aged 18–54 months old; (III) parents were at least middle school educated, and agreed to practice planned activities with the child at least 20 hours per week.

Exclusion criteria: (I) children with syndromic ASD caused by known genetic defects or inherited metabolic diseases, such as Fragile X Syndrome, Angelman Syndrome, Prader-Willi Syndrome, tuberous sclerosis; (II) visual, auditory and physical disabilities; (III) complication with other serious chronic diseases, such as liver and kidney failure, connective tissue diseases, tumors, etc.

Procedures

We recruited eight families at each round as a group and

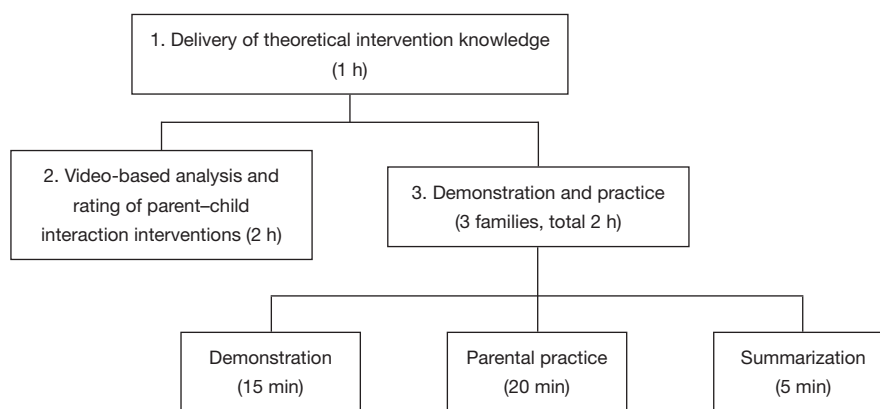


Figure 1 Flow chart of parental training model.

there were two trainers in the training session. The parents attended the training course once a week. There was a total of eight sessions each lasting three hours. All the STPAC trainers had attended the introductory and advanced ESDM workshop held by Rogers' team (one of the founders of ESDM), and learned the WHO CST training program developed by consultants to the World Health Organization and Autism Speaks. All trainers have been engaged in ASD intervention for more than 10 years.

Each session consisted of three sections (*Figure 1*):

- (I) Section 1: Delivery of theoretical intervention knowledge. One trainer delivered theoretical intervention knowledge and showed therapist-child interaction intervention videos to parents (duration: one hour).

In the eight sessions, each was implemented with independent theme: (I) building trust and routine; (II) management of child attention; (III) dealing with challenge behavior; (IV) using sensory social routines; (V) nonverbal communication; (VI) building imitation skills; (VII) using antecedent behavior-consequence technique; (VIII) verbal communication. We selected these eight themes as the basic skills for parents with ASD children, as the core deficits for ASD children are in social and communication ability. A set of therapist-child interaction intervention videos were also displayed to parents, showing how to set up an environment and intervention strategies (natural reinforcement, prompting, fading, etc.), how to address the children's specific learning needs, how to deal with challenging behavior, as well as to notice the child's communication and responses.

- (II) Section 2: Video-based analysis and rating of parent-child interaction interventions. One trainer rated, commented and made suggestions on parent-child interaction videos (duration: two hours).

Parents were asked to prepare two 5–10 minutes of parent-child interaction videos. The interaction should represent typical interaction routines at home, such as toy play, social play, daily routines and activities, etc. The trainer would rate and comment one by one, correct the mistakes of parent-implemented intervention strategies, help the parents come up with solutions.

- (III) Section 3: Demonstration and practice. Meanwhile, the other trainer demonstrated intervention skills and help parents practice in the other room (duration: two hours).

In this section, three families were invited to practice intervention skills with their own children, one family 40 minutes respectively. In this section, firstly, the trainer demonstrated how to interact with the children for about 15 minutes; secondly, the parent practiced the technique in activities while the trainer provided coaching beside them, usually for 20 minutes. Lastly, the trainer summarized the interactions, usually for 5 minutes.

Section 2 and Section 3 were carried out simultaneously. While one trainer was giving comments on the intervention videos, the other trainer was demonstrating and coaching parents to practice.

To evaluate the effectiveness of this parental training course, we designed two indexes, one was a questionnaire called Knowledge of Autism Intervention Questionnaire (KAIQ, Appendix 1) to assess parents' knowledge about

Table 1 Demographic characteristics of study participants

Characteristics	N	%
Age (month)		
18–24	6	10.9
24–36	33	60.0
36–48	12	21.8
48–54	4	7.2
Paternal education		
Primary/middle school	0	0
High school/vocational	9	16.4
College or higher	46	83.6
Maternal education		
Primary/middle school	0	0
High school/vocational	15	27.3
College or higher	40	72.7

the autism intervention. The questionnaire includes 11 questions and we took the correct rate as a result. If all the 11 questions were answered correctly, the correct rate would be 100%. KAIQ is only focused on the knowledge of interventions about autism, which is different from most widely acknowledged measures (24).

The other was a Parent Skill Rating Form (PSRF) which was based on the ESDM and CST Fidelity Rating System, to evaluate the parent mastery of intervention skills and the quality of interaction. The Parent Skill Rating Form includes 11 items with the score ranging from 1 to 5 for each item. The 11 items were: (I) setting up the environment with the child face to face; (II) matching the language level with the child's language goals; (III) adult use of positive effects; (IV) the child attention management; (V) challenging behavior management; (VI) sparing enough time to develop two-way communication; (VII) multiple varied communicative functions; (VIII) creating enough learning opportunities; (IX) sensitive and prompt response to initiative communication from the child; (X) appropriate reinforcement; (XI) using a variety of teaching techniques. Average rating score of the 11 items was taken as a result. The higher the score was, the better intervention skills the parents had. Taking item 1 as an example. Score 1= the environment is chaotic with cluttered items thus holding back the ability of the child to build up the routines or to initiate the activities; disruptive or dangerous items are

not removed or the positions of the adult and child are not at the same level (adult not in front and down to the child's level with the activity/object in between them); 2= the environment is relatively well set-up (no cluttered or disruptive items, good range of materials within child's reach) and the positions of the adult and child are fine but the adult is only able to maintain the engagement for a short period of time (30%); 3= the environment is well set-up (no cluttered or disruptive items, good range of materials within child's reach) and the positions of the adult and child are good (adult and child is face to face with the shared materials and activities in between them thus they can both reach and see the objects) for half of the time (50%); 4= the environment is well set-up and adult is well positioned to sustain engagement (adult and child is face to face at the same level with objects/activities in between them) for the majority of the time (80%); the adult could apply strategies to improve pacing or the quality of environmental to better support the child's engagement ; 5= the environment is well set-up and adult is well positioned to sustain engagement (adult and child is face to face at the same level with objects/activities in between them) throughout the session (80–100% time); appropriate adjustments of the environment are made to support the engagement and initiations of the child throughout the session.

For the pilot study, there was only one doctor as a coder who participated in training with both ESDM and CST.

Statistical methods

Parents were asked to fill in the KAIQ at the enrollment with the correct rate calculated by the trainer. At the same time, we collected one 5–10 minutes of parent-child interaction video that was recorded at home. Then the fidelity scores of parents' intervention skills on PSRF were also given by the trainer. At the end of the training course, the same procedures were applied. Paired t tests were applied to compare the baseline and outcome results. Significant level was set at P value <0.05.

Results

A total of 55 families with ASD children were recruited. These families came from Shanghai, and three other provinces, including Jiangsu, Anhui and Zhejiang. The parents all had an education above middle school. The average age of the fathers was 34.8±3.73 years old, of whom 83.6% graduated from college. For mothers, the average

Table 2 Correct rate and fidelity score pre- and post- training

	Pre-training, mean	Post-training, mean	t	df	P value
Correct rate of KAIQ	54.5%	81.8%	25.177	47	<0.0001
Fidelity score of STPAC	2.4	3.5	19.86	47	<0.0001

KAIQ, Knowledge of Autism Intervention Questionnaire; STPAC, Skill Training for Parents with ASD Children.

age was 33.4 ± 3.68 years, of whom 72.7% graduated from college (*Table 1*).

Parental mastery of intervention skills: (I) for the theoretical intervention knowledge, all of the parents made progress after finishing the training course. On average, the correct rate of KAIQ completion significantly increased from 54.5% to 81.8% (paired t-test P value <0.0001). (II) For the practical intervention skills, the average fidelity scores of STPAC, increased from 2.4 ± 0.37 to 3.5 ± 0.31 (paired t-test P value <0.0001) (*Table 2*). The extent of the improvement of parents' skills varied in different items. There were 3 items, the average score were increased more than 1.1 from baseline: Item 1 setting up the environment with the child face to face; Item 2 matching the language level with the child's language goals; and Item 3 adult use of positive effect. And the average score in the following items had less than a 0.8 improvement from baseline: Item 6 sparing enough time to develop two-way communication; Item 7 multiple varied communicative functions; Item 8 creating enough learning opportunities; and Item 11, using a variety of teaching techniques.

Discussion

ASD is a neurodevelopmental disorder with its ever increasing prevalence in the world. A critical period of intervention for the child with ASD is when they are between 1 and 5 years old, given the rapid brain development and learning patterns occurring in these years (2-5). The growing recognition of ASD exerts major demands on early intervention services and results in calls for innovative intervention models (25-27).

However, qualified therapist resources are still insufficient in China, especially in remote, rural and suburban areas. Improving the outcomes of ASD children is tough for the parents due to the difficulty of seeking qualified clinicians, the long waiting list, the high cost of intensive therapist-delivered interventions, plus the accommodation and transportation fees for long-term rehabilitation. These challenges highlight the urgent needs for effective and

efficient parental training models. Furthermore, parental involvement is critical element in both short-term and long-term prognosis of the autistic children (7-19). So, we sought to develop a practical parent training course which would help parents master the basic intervention skills, in order to both relieve the parents' distress and to improve the outcomes of their children. By doing so, the pressure of on medical and rehabilitation institutions might also be somewhat alleviated.

The underpinnings of the STPAC course are based on ESDM and WHO CST program with some innovations and adjustments. One reason for integrating two approaches was the difficulty for parents to master all the ESDM strategies in a short time. The ESDM model is a comprehensive early intervention approach for toddlers with autism ages 12-48 months (28,29). It addresses all the developmental skills of early childhood: language, play, social interaction, joint attention, imitation, motor skills, self-care, and behavior. The teaching contents and procedures are thoroughly described. It takes time for the parents to master the ESDM strategies and maintain them without ongoing support (28,29). Second, the WHO CST program was designed for children with developmental disorders including ASD and focuses on lack of social initiation, using eight group sessions and three individual home visits to teach caregivers skills and strategies to increase their children's engagement and spontaneous communication (21) through play and home routines (22). We integrated these two approaches into the STPAC, which adds two ESDM techniques: Sensory Social Routine (SSR) and imitating specifically for children with ASD. We also added comments on parents' videos of their home sessions, and added a Demonstration section to help parents master the basic intervention skills. We used the parent group format to contribute to parent learning and encouragement from each other during the course.

In this earliest step of intervention development research, we found that all parents made a significant progress in mastering both the basic knowledge and the basic intervention skills that were taught. There initial pilot result

suggest that STPAC may be a promising parent training model. Next steps involve setting up a pilot randomized controlled trial to test the effects on parent skills in a more rigorous manner and to examine effects on children whose parents are receiving the training.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Ethics Committee of Children's Hospital of Fudan University and written informed consent was obtained from all patients.

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Appendix 1 Knowledge of Autism Intervention Questionnaire

1. Child can interact with people and stuffs at three different levels: First, an occasional glance; Second, pays attention to and carefully observe what you are playing with; Third, Interactive participation - want to join in and interact with you. The first level is “unengaged”, the second level is “object engaged”, and the third level is _____
2. The best position when you play with a child is _____
3. What are the appropriate communication behaviors: _____
A. takes a look at you B. points to the object in your hand C. reaches for the object in your hands
D. pronounces unconsciously E. says "yes" unclearly F. cries or screams
G. goes away H. goes to you I. pulls your hand J. hands the object to you.
4. Nonverbal communication includes: _____
A. gestures B. body postures C. eye contact D. facial expressions E. changes of voice and intonation.
5. There are four levels of play skills, arranged from low to high-level: _____
A. simple play B. advanced pretend play C. puts together (combination play) D. early pretend play
6. Prompts include: _____
A. full physical prompts B. partial physical prompts C. demonstrations D. language hints
7. When you interact with child, you need to: _____
A. follow his/her interests B. set up opportunities for him to request and share C. ask the child to follow you
8. When you play toys with children, you should first: _____
A. make the child imitating you B. explain how to play with the toy
C. follow the child D. imitate the child E. be the child's assistant
9. If the child asks for biscuits hysterically, what will you do: _____
A. comforts him/her and gives him/her the biscuit B. ignores him/her
C. hugs interaction intervention videos s to him/her why he/she shouldn't eat
D. if explanation doesn't work, shouts and beats him/her
10. What does imitation mean and how to imitate?
11. If the child does not generate meaningful words at present and vocalize unconsciously, what language goals do you set for him/her?