

# Short-term family-centered workshop for children with developmental delays enhances family functioning and satisfaction

## A prospective clinical trial

Ru-Lan Hsieh, MD<sup>a,b,\*</sup>, Wen-Huei Hsieh, PhD<sup>c</sup>, Wen-Chung Lee, MD, PhD<sup>d</sup>

### Abstract

We investigated the clinical efficacy on family functioning and parental satisfaction of a short-term family-centered workshop for children with developmental delays.

A total of 32 children with developmental delays and their parents participated in 2-hour weekly group therapy sessions over 6 weeks. The workshop was conducted by rehabilitation professionals and teachers using a family-centered multidisciplinary approach. Both before and after the 6-week workshop, the parents were administered the Pediatric Quality of Life Inventory (PedsQL) Family Impact Module, the PedsQL Healthcare Satisfaction Module, the Hospital Anxiety and Depression Scale, and the World Health Organization Quality of Life brief assessment instrument. Overall satisfaction with the workshop was also evaluated.

Significant improvements were noted in physical aspect ( $P=0.03$ ), communication ( $P=0.002$ ), and daily activities ( $P=0.04$ ) in the PedsQL Family Impact Module, and in communication ( $P=0.03$ ) and technical skills ( $P=0.05$ ) in the PedsQL Healthcare Satisfaction Module. Overall satisfaction with the workshop was rated as very high. There was no significant effect on psychological distress or quality of life.

Short-term family-centered workshops for children with developmental delays improved family functioning and the parental perception of satisfaction, including health care satisfaction.

**Abbreviations:** HADS = Hospital Anxiety and Depression Scale, HRQOL = health-related quality of life, PedsQL = Pediatric Quality of Life Inventory, WHOQOL-BREF = World Health Organization Quality of Life brief version.

**Keywords:** children, developmental delays, family functioning, family-centered, workshop

Editor: Girish Bhatt.

Trial registration number: ClinicalTrials.gov (NCT02181036).

This study was partially supported by research grants (H10320, DOH-SKH-103-07; SKH-8302-102-DR-32, SKH-8302-103-DR-36, SKH-8302-104-DR-29; SKH-8302-105-DR-24; MOST 105-2314-B-341-002; MOST 105-2314-B-002-049-MY3) from Department of Health, Taipei City Government, Shin Kong Wu Ho-Su Memorial Hospital, and Ministry of Science and Technology, Taiwan.

The authors have no conflicts of interest to disclose.

<sup>a</sup> Department of Physical Medicine and Rehabilitation, Shin Kong Wu Ho-Su Memorial Hospital, <sup>b</sup> Department of Physical Medicine and Rehabilitation, School of Medicine, College of Medicine, Taipei Medical University, <sup>c</sup> Department of Child Care and Education and Research Center for Industry of Human Ecology, College of Human Ecology, Chang Gung University of Science and Technology, <sup>d</sup> Institute of Epidemiology and Preventive Medicine, College of Public Health, National Taiwan University, Taipei, Taiwan.

\* Correspondence: Ru-Lan Hsieh, Department of Physical Medicine and Rehabilitation, Shin-Kong Wu Ho-Su Memorial Hospital, No. 95, Wen Chang Rd, Shih Lin District, Taipei 11101, Taiwan (e-mail: M001052@ms.skh.org.tw).

Copyright © 2016 the Author(s). Published by Wolters Kluwer Health, Inc. All rights reserved.

This is an open access article distributed under the terms of the Creative Commons Attribution-Non Commercial License 4.0 (CCBY-NC), where it is permissible to download, share, remix, transform, and buildup the work provided it is properly cited. The work cannot be used commercially.

Medicine (2016) 95:31(e4200)

Received: 25 November 2015 / Received in final form: 3 June 2016 / Accepted: 12 June 2016

<http://dx.doi.org/10.1097/MD.0000000000004200>

## 1. Introduction

It is estimated that 10% to 15% of children have motor, speech-language, social, cognitive, or adaptive development delays<sup>[1]</sup> and require specialized health care.<sup>[2,3]</sup> Children with developmental delays have lower health-related quality of life (HRQOL) than do typically developing children, and their condition has a substantial negative impact on family functioning.<sup>[4]</sup> Compared with parents of typically developing children, parents of children with developmental delays experience greater psychological distress, such as anxiety and depression, lower satisfaction with their child's health care, and a lower HRQOL.<sup>[4-6]</sup>

In Taiwan, the National Health Insurance system funds free early developmental interventions for children, including evaluation and rehabilitation programs. The Protection of Children and Youths Welfare and Rights Act promulgated in 2012 and Early Childhood Developmental Delay Habilitation Services established in 2013 by the Ministry of the Interior provide children with developmental delays aged 0 to 6 years and their family with necessary treatment, education, counseling, referral, placement, and other services.

Group therapy conducted in a hospital was shown to improve parent-child interactions and maternal mental health in children with autism.<sup>[5]</sup> In addition, group therapy that engages both parents and teachers at school was found to promote early childhood learning and self-regulation.<sup>[7]</sup> Family-centered interventions have led to positive outcomes, especially regarding parents' perception of satisfaction and efficacy.<sup>[8,9]</sup> However,

there is still a lack of group therapy provided by both medical professionals and teachers to children with developmental delays and their parents.

The aforementioned findings warrant investigating the effects on family functioning of a family-centered workshop conducted by medical and education professionals and parents for children with developmental delays. In this study, we investigated the effectiveness of a short-term family-centered workshop arranged in a group format that combines rehabilitation professionals, teachers, and parents. We hypothesized that this workshop for children with developmental delays would improve several aspects of family functioning for the parents; specifically, it would reduce psychological distress and the family impact and enhance the HRQOL and parental perception of satisfaction, including health care satisfaction and workshop satisfaction.

## 2. Methods

This study was prospectively conducted from June 2014 to November 2014 at Shin Kong Wu Ho-Su Memorial Hospital, a teaching hospital with 872 beds in Northern Taiwan. Children with suspected developmental delays were evaluated by the early developmental evaluation team.<sup>[3,4]</sup> The team members included a physiatrist, pediatrician, psychiatrist, ophthalmologist, otolaryngologist, psychologist, occupational therapists, speech therapists, physical therapists, and a social worker. Assessment tools commonly used are the Child Expression Evaluation Tool, Preschool Language Evaluation Tool, Bayley III Scale of Infant and Toddler Development, Chinese Wechsler Intelligence Scale for Children (3<sup>rd</sup> edition), Peabody Developmental Motor Scales, and Gross Motor Function Measure. Hearing, visual acuity, family structure, and social support were routinely evaluated. Additional examinations such as brain echo, magnetic resonance image, electroencephalography, and a genetic chromosomal checkup were arranged by the pediatrician according to the child's condition. Developmental delay was defined by performance scores falling below at least 2 standard deviations of the mean for the general population (control children) on age-appropriate norm-referenced standardized developmental tests. The detailed procedure has been presented in our previous studies.<sup>[3,4]</sup>

The eligibility criteria for the study were as follows: an age of 18 to 36 months; a confirmed speech delay with or without 1 or more delays in gross motor, fine motor, cognitive, social, or emotional functioning by the early developmental evaluation team; and the availability of children to attend with their parents one 2-hour workshop session per week for 6 weeks. Treating physicians informed eligible families about the study in a clinic for children with developmental delays. If parents were interested in the study, they could participate in the workshop. All parents provided informed written consent for themselves and their child to participate in the study.

This study was approved by the Institutional Review Board for the Protection of Human Subjects at Shin Kong Wu Ho-Su Memorial Hospital, and the study was performed in accordance with the World Medical Association Declaration of Helsinki. The trial has been registered on ClinicalTrials.gov (NCT02181036).

### 2.1. Intervention

The program for the workshop was designed by a physiatrist, 2 speech therapists, 2 occupational therapists, a psychologist, and 2 child care and education teachers. Among them, the physiatrist

was the major coordinator and prime consultant for the parents. The workshop comprised one 2-hour session per week for 6 weeks and was structured in a group format containing 6 to 7 pairs of parents and their children (Fig. 1).

The program was conducted by 1 child care and education teacher, 1 speech therapist, and 1 occupational therapist, totaling 3 professionals involved with each child in each session. They informed the parents about techniques for improving their child's ability to understand and use language or other communication methods, such as gestures and facial expressions; for helping the child exercise muscles, use her or his hands, perform whole-body movements, and pretend to perform daily living activities by using puppets and role play;<sup>[10,11]</sup> for nurturing parent-child interactions, such as the stimulation of learning, sharing of books and information, collaboration, and the reinforcement of competencies; and for developing parent-therapist-educator interaction through free communication during the workshop.<sup>[10,12]</sup>

### 2.2. Family functioning

The Pediatric Quality of Life Inventory (PedsQL) Family Impact Module<sup>[13]</sup> was used to assess the impact of pediatric health conditions on family functioning with satisfactory reliability.<sup>[3,4,14-16]</sup> It contains a parental QOL summary score, a family functioning summary score, and a total score. The scores range from 0 to 100, with a higher score indicating greater family functioning.

The Hospital Anxiety and Depression Scale (HADS) was used to evaluate parental psychological distress with high reliability in

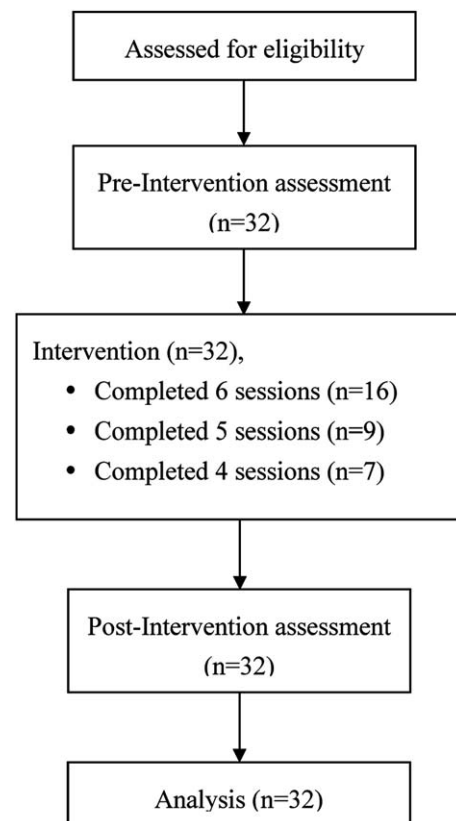


Figure 1. Trial profile.

Chinese.<sup>[4,14,17]</sup> It was designed to measure anxiety and depression.

The Chinese version of the World Health Organization Quality of Life brief assessment instrument (WHOQOL-BREF)<sup>[3,4,18,19]</sup> questionnaire was used for HRQOL evaluation with high reliability.<sup>[14]</sup> The scores range from 0 to 100, with a higher score indicating a higher HRQOL.

### 2.3. Parental perception of satisfaction

The PedsQL Health Satisfaction Module was used to evaluate parents' satisfaction with their child's health care with satisfactory reliability.<sup>[3,4,14,15]</sup> The scores range from 0 to 100, with a higher score denoting greater satisfaction with health care.

The parental perception of satisfaction survey related to the family-centered workshop comprised 6 questions. Answers were provided on a 5-point scale. A total mean score was obtained and transformed to a scale of 0 to 100, with a higher score indicating greater satisfaction with the workshop.

The parents were evaluated using the PedsQL Family Impact Module, HADS, WHOQOL-BREF, and PedsQL Healthcare Satisfaction Module, both before and after the 6-week period. Parental satisfaction with the workshop was evaluated after the completion of the workshop. All evaluations were performed by the same examiner. Additional data were collected from the parents on their age, employment status, and the structure of their family unit (nuclear family: a child living with parents and siblings; extended family: a child living with parents, siblings, and other relatives such as the grandparents, aunt, and/or uncle).

### 2.4. Statistical analysis

Statistical analyses were performed using SAS Version 9.2. The results were expressed as mean  $\pm$  standard deviation. Between-group differences in the change from the baseline in outcome measures were conducted using paired *t* tests. Estimates of the effect size and 95% confidence intervals were reported. The following interpretation for the magnitude of the effect size is suggested: 0–0.1, no effect; 0.2–0.4, a small effect; 0.5–0.7, an intermediate effect; and 0.8 and higher, a large effect.<sup>[20]</sup> The level of significance was set at 0.05.

## 3. Results

A total of 32 parents of children with developmental delays were included in this study. Only 1 questionnaire was administered to a father; the remainders were administered to mothers. Four of the children were preterm births, 1 of whom was small for the gestational age (25 weeks of gestational age and birth body weight of 800g). Nineteen of the children had unspecified developmental delays, 9 had autism spectrum disorder, 2 had attention deficit hyperactivity disorder, 1 had congenital brain anomaly, and 1 had seizure. The mean age of the children was 29.9 months (range: 18–35 months); 24 were boys and 8 were girls. The basic demographics of the children and their parents are shown in Table 1. All participants underwent pre- and postintervention evaluations. Among the 32 participants, 18 of them completed all 6 sessions of the intervention (full participation rate = 56.2%, 95% confidence interval: 39.1% to 73.4%). The main reasons for being absent from intervention sessions (absent 1 session: 11 participants; absent 2 sessions: 3 participants) were sickness of the child and parental personal time. No adverse event was reported during the intervention.

**Table 1**

### Basic demographics of participants.

Variable	Value
Children	
Child's age, mean $\pm$ SD, mo	29.9 $\pm$ 5.5
Child's gender	
Male	24 (75)
Female	8 (25)
Delayed development	
Gross motor	18 (56)
Fine motor	14 (44)
Speech-language	32 (100)
Cognition	7 (22)
Social emotional	17 (53)
Multiple domains	3 (9)
Diagnosis	
Unspecified developmental delays	19 (59.4)
Autism spectrum disorder	9 (28.1)
Attention deficit hyperactivity disorder	2 (6.3)
Congenital brain anomaly	1 (3.1)
Seizure	1 (3.1)
Parents	
Parent age, mean (y) (range)	
Father	40.1 (34–52)
Mother	37.3 (30–54)
Parents' employment	
Father: yes	32 (100)
Mother: yes	18 (56)
Family structure	
Nuclear	22 (68)
Extended	10 (32)

Note: data are given as number (%) except where otherwise indicated. SD = standard deviation.

The results regarding family functioning evaluated using the PedsQL Family Impact Module, HADS, and WHOQOL-BREF are shown in Table 2. Regarding family impact, the parents reported improvement in physical aspects (53.3 vs 82.9, effect size: 1.75,  $P=0.03$ ), communication (53.2 vs 72.6, effect size: 1.34,  $P=0.002$ ), and daily activities (51.6 vs 85.1, effect size: 3.01,  $P=0.04$ ). Anxiety and depression scores on the HADS improved after 6 weeks; however, the improvement did not reach statistical significance. Regarding HRQOL, scores in all 4 domains tended to improve after 6 weeks, but these improvements did not reach statistical significance.

The results regarding parental perception of satisfaction with the child's health care by the workshop are shown in Table 3. Statistically significant improvements were evident in communication (71.3 vs 80.2, effect size: 0.38,  $P=0.03$ ) and technical skills (75.6 vs 79.7, effect size: 0.21,  $P=0.05$ ). The overall rating for parental satisfaction with the workshop was 94.2, indicating a very high level.

## 4. Discussion

This is the first study to investigate the effects of a short-term family-centered workshop conducted by rehabilitation professionals, teachers, and parents for children with developmental delays on family functioning and parental perception of satisfaction. The present study showed that the 6-week small-group-based family-centered workshop led by professional rehabilitation therapists and school teachers improved the family functioning of children with developmental delays. In particular,

**Table 2**  
**Family functioning.**

Variables	Before workshop mean (SD)	After workshop mean (SD)	Mean difference, after vs before (95% CI)	Effect size (d)	P value
PedsQL family impact module					
Physical aspects	53.3 (15.6)	82.9 (18.1)	29.6 (1.17, 2.32)	1.75	0.028*
Emotional aspects	63.8 (10.9)	74.3 (15.9)	10.5 (0.26, 1.27)	0.77	0.112
Social functioning	60.3 (19.2)	82.4 (12.5)	22.1 (0.82, 1.91)	1.36	0.075
Cognitive functioning	74.1 (20.1)	87.7 (13.7)	13.6 (0.28, 1.29)	0.79	0.067
Communication	53.5 (14.2)	72.6 (14.3)	19.1 (0.79, 1.88)	1.34	0.002†
Worry	56.2 (17.1)	68.2 (15.2)	12.0 (0.23, 1.24)	0.74	0.098
Daily activities	51.6 (9.9)	85.1 (12.2)	33.5 (2.29, 3.73)	3.01	0.035*
Family relationships	77.5 (15.9)	80.6 (8.8)	3.1 (−0.25, 0.73)	0.24	0.221
Parental QOL summary	71.2 (19.6)	80.1 (17.2)	8.9 (−0.01, 0.97)	0.48	0.054
Family functional summary	68.8 (19.7)	82.3 (18.1)	13.5 (0.2, 1.21)	0.71	0.211
Total impact score	62.4 (11.8)	79.0 (10.3)	16.6 (0.94, 2.05)	1.49	0.223
HADS					
Anxiety	6.4 (2.1)	5.2 (2.7)	−1.2 (−0.99, 0.001)	−0.49	0.091
Depression	7.1 (3.2)	4.4 (1.5)	−2.7 (−1.6, −0.55)	−1.08	0.067
WHOQOL-BREF					
Physical	53.3 (20.5)	60.5 (20.2)	7.2 (−0.14, 0.84)	0.35	0.098
Psychological	47.0 (18.1)	59.8 (17.8)	12.8 (0.2, 1.21)	0.71	0.561
Social relationships	55.8 (15.4)	62.1 (15.2)	6.3 (−0.08, 0.9)	0.41	0.326
Environment	63.3 (21.2)	67.9 (16.9)	4.6 (−0.25, 0.73)	0.23	0.157

Data are expressed as SD = standard deviation.

HADS = Hospital Anxiety and Depression Scale, Pediatric Quality of Life Inventory Family Impact Module, PedsQL-Family Impact Module, WHOQOL-BREF = World Health Organization Quality of Life brief version.

\*  $P < 0.05$ .

†  $P < 0.01$ .

**Table 3**  
**Parental perception of satisfaction.**

Variables	Before workshop mean (SD)	After workshop mean (SD)	Mean difference, after-before (95% CI)	Effect size (d)	P value
Health care satisfaction generic module					
Information	70.1 (16.3)	70.3 (18.1)	0.2 (−0.47, 0.50)	0.01	0.287
Inclusion of family	68.7 (29.1)	67.9 (28.3)	−0.8 (−0.51, 0.46)	−0.02	0.102
Communication	71.3 (22.6)	80.2 (24.1)	8.9 (−0.11, 0.87)	0.38	0.025*
Technical skills	75.6 (19.2)	79.7 (18.9)	4.1 (−0.27, 0.7)	0.21	0.049*
Emotional needs	62.7 (22.5)	63.5 (21.6)	0.8 (−0.45, 0.52)	0.03	0.067
Overall satisfaction	75.4 (20.7)	77.2 (23.8)	1.8 (−0.4, 0.57)	0.08	0.334
Total score	66.7 (20.3)	67.3 (19.2)	0.6 (−0.45, 0.52)	0.03	0.097
Workshop satisfaction (0–100)	—	94.2	—	—	—

Data are expressed as CI = confidence interval, SD = standard deviation.

PedsQL-Health Satisfaction = Pediatric Quality of Life Inventory Health Satisfaction.

\*  $P < 0.05$ .

improvements were reported in physical functioning, communication, and daily activities, as well as in parental perception of child's health care satisfaction regarding communication and technical skills. The overall parental satisfaction with the workshop was very high.

Parents of children with developmental delays provide care during home-based daily living activities, manage responsibilities related to the child's health and functioning, and coordinate visits with health care providers. These responsibilities may change the parents' lifestyles and their household, social, and professional roles, resulting in a substantial parental burden and a decrease in family functioning.<sup>[19,21–24]</sup> Compared with parents of typically developing children, parents of children with developmental delays are associated with an increased level of depression,

anxiety, and physical, mental, financial, and social stress.<sup>[24]</sup> They also face more difficulties in parenting skills, child care, and family functioning, while experiencing more psychiatric problems, stress, and relationship conflicts, as well as lower health care satisfaction, HRQOL, and health status.<sup>[3–6,25–30]</sup> Therefore, it is crucial to improve family functioning, including the family impact, psychological distress, and HRQOL.

In contrast to conventional rehabilitation programs, the therapists and teachers in our workshop provided education and training on strategies for increasing positive outcomes in the children's linguistic, cognitive, and physical behavior through play rather than by providing services to the children.<sup>[5,31]</sup> The workshop emphasized sharing experiences and information with other parents.<sup>[12]</sup> It also reduced parental stress and focused on

educating the parents.<sup>[5]</sup> Finally, the workshop mandated parental participation, improvement of the family role, and placement of the child and family at the core of the service.<sup>[8]</sup> This study showed that the short-term family-centered workshop improved family functioning in physical functions, communication, and daily activities. Additional studies are recommended for identifying the long-term effects of family-centered workshops on the family functioning of children with developmental delays.

Group-based interventions lead to improvements in parental anxiety, depression, and sleep and life satisfaction.<sup>[5]</sup> Recently, a study showed that 6 weeks of group therapy in 1.5-hour weekly sessions provided by supervised peer mentors significantly reduced anxiety and depression and improved life satisfaction in mothers of children with autism.<sup>[5]</sup> The present study also showed that psychological distress, including depression and anxiety, and parental QOL tended to improve after the 6-week family-centered workshop; however, this improvement was not statistically significant. The varying severity and types of conditions affecting the children with developmental delays might have affected the results.

Family-centered interventions involve providing anticipatory guidance to parents regarding a child's disability, parental advocacy, and respite care in full-time caregiving.<sup>[5,32,33]</sup> The small-group-based family-centered workshop focused on anticipatory guidance and sharing information and experiences to shape the learning, physical, and overall environment of the child.<sup>[12]</sup> It enhanced the parents' perception of satisfaction and efficacy.<sup>[7,33,34]</sup> Parents' perception of satisfaction is crucial, because it typically determines the health care utilization of children.<sup>[35]</sup> The purpose of the workshop was not only to increase family functioning but also to improve parental satisfaction.<sup>[36]</sup> This study showed that the workshop improved parental health care satisfaction with communication and technical skills and that the parents had high overall satisfaction with the workshop. By emphasizing parental engagement rather than traditional treatments for children with developmental delays, the small-group format of the workshop enabled the parents to share their experiences with others,<sup>[5]</sup> receive needed care assistance,<sup>[37,38]</sup> develop positive partnerships with health care providers and educators,<sup>[37]</sup> and increase communication among health care providers, teachers, and other parents. All of these factors contributed to positive outcomes in parental health care satisfaction and high overall satisfaction with the workshop.

Kube et al.<sup>[39]</sup> published an evaluation of a parent-led curriculum on developmental disabilities for pediatric and medical/pediatric residents. The program was designed to introduce residents to the concept of a family-centered approach to supporting families of children with chronic special health care needs by conducting a parent interview and home visit. The residents were highly satisfied with the parent-led curriculum programs, and the experience was relevant to their future resident training and practice programs. The present study demonstrated that short-term family-centered workshops for children with developmental delays enhance family functioning and satisfaction. Therefore, we may supplement the potential of our workshops by giving feedback to the caregivers in a manner that is more institutionalized, similar to pediatric and physical medicine and rehabilitation resident training, to educate residents on providing effective and efficient care to children with disabilities by developing a close relationship with their families.

This study had several limitations. First, we did not include an untreated control group; therefore, we could not rule out the possibility of the improved parental outcomes being associated

with the workshop rather than the time effect. Thus, a randomized controlled designed trial should be included in future studies. Second, the developmental disorders and diagnoses of the children varied; therefore, we could not generalize these results to parents of children with specifically diagnosed developmental delays. However, because the parents in this study were recruited from a clinic for children with developmental delays, they represent parents of children with commonly treated developmental delays in clinical settings. Third, although the course helped the parents to communicate about special needs and understand the professionals, the effects of social interaction between the parents were not examined in the present study. Therefore, the social interaction effects between parents should be investigated in the future. Finally, we did not follow up with the parents in the long term; whether the observed benefits of the small-group-based family-centered workshop continued after the workshop is unclear.

In conclusion, the short-term family-centered workshop conducted by medical and education professionals and parents for children with developmental delays improved family functioning in physical functioning, communication, and daily activities, as well as in parental perception of the child's health care satisfaction regarding communication and technical skills and workshop satisfaction.

## References

- [1] Committee on Children With Disabilities. Role of the pediatrician in family-centered early intervention services. *Pediatrics* 2001;107:1155–7.
- [2] Data Resource Center for Child & Adolescent Health. National Survey of Children with Special Health Care Needs 2011. 2005–6.
- [3] Hsieh RL, Huang HY, Lin MI, et al. Quality of life, health satisfaction and family impact on caregivers of children with developmental delays. *Child Care Health Dev* 2009;35:243–9.
- [4] Hsieh RL, Hsueh YM, Huang HY, et al. Quality of life and impact of children with unclassified developmental delays. *J Paediatr Child Health* 2013;49:E116–121.
- [5] Dykens EM, Fisher MH, Taylor JL, et al. Reducing distress in mothers of children with autism and other disabilities: a randomized trial. *Pediatrics* 2014;134:e454–63.
- [6] Miodrag N, Hodapp RM. Chronic stress and health among parents of children with intellectual and developmental disabilities. *Curr Opin Psychiatry* 2010;23:407–11.
- [7] Brotman LM, Dawson-McClure S, Calzada EJ, et al. Cluster (school) RCT of ParentCorps: impact on kindergarten academic achievement. *Pediatrics* 2013;131:e1521–9.
- [8] Beatson JE. Preparing speech-language pathologists as family-centered practitioners in assessment and program planning for children with autism spectrum disorder. *Semin Speech Lang* 2006;27:1–9.
- [9] Kingsley K, Mailloux Z. Evidence for the effectiveness of different service delivery models in early intervention services. *Am J Occup Ther* 2013;67:431–6.
- [10] Hintz SR, Kendrick DE, Vohr BR, et al. National Institute of Child Health and Human Development (NICHD) Neonatal Research Network. Community supports after surviving extremely low-birth-weight, extremely preterm birth: special outpatient services in early childhood. *Arch Pediatr Adolesc Med* 2008;162:748–55.
- [11] Guerrero AD, Chen J, Inkelas M, et al. Racial and ethnic disparities in pediatric experiences of family-centered care. *Med Care* 2010;48:388–93.
- [12] Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. *Med Care* 1999;37:126–39.
- [13] Hsieh RL, Huang HY, Lee WC. The Correlation of Pediatric Outcome Data Collection Instrument With Health Related Quality of Life, Emotion in Children and Their Parents With Developmental Delays. Taipei: Taiwan Academy of Physical Medicine and Rehabilitation; 2009.
- [14] Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care* 2001;39:800–12.
- [15] Chan LF, Chow SM, Lo SK. Preliminary validation of the Chinese version of the Pediatric Quality of Life Inventory. *Int J Rehabil Res* 2005;28:219–27.

- [16] Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67:361–70.
- [17] Hwang HF, Liang WM, Chiu YN, et al. Suitability of the WHOQOL-BREF for community dwelling older people in Taiwan. *Age Ageing* 2003;32:593–600.
- [18] WHOQOL. Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychol Med* 1998;28:551–8.
- [19] Chi DL, McManus BM, Carle AC. Caregiver burden and preventive dental care use for US children with special health care needs: a stratified analysis based on functional limitation. *Matern Child Health J* 2014;18:882–90.
- [20] Cohen J. *Statistical Power Analysis for the Behavioral Sciences*. 2nd ed. Hillsdale, NJ: L. Erlbaum Associates; 1988.
- [21] Canning RD, Harris ES, Kelleher KJ. Factors predicting distress among caregivers to children with chronic medical conditions. *J Pediatr Psychol* 1996;21:735–49.
- [22] Murphy NA, Christian B, Caplin DA, et al. The health of caregivers for children with disabilities: Caregiver perspectives. *Child Care Health Dev* 2006;33:180–7.
- [23] Kuo DZ, Cohen E, Agrawal R, et al. A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med* 2011;165:1020–6.
- [24] Platt C, Roper SO, Mandleco B, et al. Sibling cooperative and externalizing behaviors in families raising children with disabilities. *Nurs Res* 2014;63:235–42.
- [25] Hastings RP, Daley D, Burns C, et al. Maternal distress and expressed emotion: cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *Am J Ment Retard* 2006;111:48–61.
- [26] Coker TR, Rodriguez MA, Flores G. Family-centered care for US children with special health care needs: who gets it and why? *Pediatrics* 2010;125:1159–67.
- [27] Blanchard LT, Gurka MJ, Blackman JA. Emotional, developmental, and behavioral health of American children and their families: a report from the 2003 National Survey of Children's Health. *Pediatrics* 2006;117:e1202–12.
- [28] Kersh J, Hedvat TT, Hauser-Cram P, et al. The contribution of marital quality to the well-being of parents of children with developmental disabilities. *J Intellect Disabil Res* 2006;50(pt 12):883–93.
- [29] Carter B, Coad J, Bray L, et al. Home-based care for special healthcare needs: community children's nursing services. *Nurs Res* 2012;61:260–8.
- [30] Hsieh RL, Lin MI, Huang HY, et al. Correlations between functional performance, health-related quality of life, and parental impact on children with developmental delays. *Dev Neurorehabil* 2014;17:176–83.
- [31] Matson JL, Mahan S, LoVullo SV. Parent training: a review of methods for children with developmental disabilities. *Res Dev Disabil* 2009;30:961–8.
- [32] Robertson J, Hatton C, Wells E, et al. The impacts of short break provision on families with a disabled child: an international literature review. *Health Soc Care Community* 2011;19:337–71.
- [33] Bruder MB. *An Examination of an Alternative Early Intervention Service Delivery Model for Latino Families Whose Children Are English Language Learners*. Washington, DC: U.S. Department of Education Office of Educational Research and Improvement; 2003.
- [34] McCart A, Wolf N, Sweeney HM, et al. The application of a family-based multi-tiered system of support. *NHSA Dialog A Research-to-Practice J Early Childhood Field* 2009;12:122–32.
- [35] Raat H, Mohangoo AD, Grootenhuis MA. Pediatric health-related quality of life questionnaires in clinical trials. *Curr Opin Allergy Clin Immunol* 2006;6:180–5.
- [36] Petitgout JM, Pelzer DE, McConkey SA, et al. Development of a hospital-based care coordination program for children with special health care needs. *J Pediatr Health Care* 2013;27:419–25.
- [37] Miller K. Care coordination impacts on access to care for children with special health care needs enrolled in Medicaid and CHIP. *Matern Child Health J* 2014;18:864–72.
- [38] Turchi RM, Berhane Z, Bethell C, et al. Care coordination for CSHCN: associations with family-provider relations and family/child outcomes. *Pediatrics* 2009;124:S428–34.
- [39] Kube DA, Bishop EA, Roth JM, et al. Evaluation of a parent led curriculum in developmental disabilities for pediatric and medicine/pediatric residents. *Matern Child Health J* 2013;17:1304–8.