


The Nurturing Program: An Intervention for Parents of Children with Special Needs

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Abstract Evidence-based psychosocial family interventions enhancing empathy and empowerment are particularly beneficial to families of children who have developmental disabilities. This study assessed the effectiveness of an intervention called the Nurturing Program for Parents and Their Children with Special Needs and Health Challenges (SNHC). Eighty-seven families were enrolled and randomly assigned to a control or treatment group. Forty-six families in the control group received individualized case management (CM) services and forty-one families in the treatment group were assigned to 12 sessions of the SNHC curriculum along with case management services. Before and after the intervention, participants in both conditions completed the Adult and Adolescent Parenting Index-2 assessing parents' attitudes toward child rearing and the Family Empowerment Scale (FES) measuring family empowerment. Caregivers in the intervention condition improved in empathy towards children's needs, $F(1, 54) = 4.52, p = .04$; and all families, both control group and treatment group, improved their attitudes towards the use of corporal punishment by posttest, $F(1, 54) = 6.56, p = .013$. Also, all caregivers increased

in their empowerment over the course of the intervention, $F(1, 50) = 13.28, p = .001$. Attrition, 22–26% among CM and 51–56% among SNHC+CM, limited generalizability as did participants not completing all SNHC sessions. Despite these limitations, findings suggest that early interventions catering to families of children with developmental disabilities have a positive impact on parenting. To varying degrees, both conditions provided caregivers with tools that positively affected the quality of the parent–child relationships and promoted empowerment.

Keywords Parenting intervention · Developmental disability · Empowerment · Case management · Empathy

Introduction

Early evidence-based psychosocial treatments and family interventions aimed at enhancing parental competence and empathy, and reducing stress are appropriate vehicles to address issues ranging from behavioral to emotional problems in children (Carr 2006; Hutchings et al. 2007; Lundahl et al. 2006). Experts (Bigelow 2006; Halperin et al. 2012) assert that early intervention is effective not only in addressing developmental issues, but also in preventing later disorders such as learning disabilities or attention deficit/hyperactivity disorder (ADHD). Parenting interventions also benefit families of children who have a developmental disability (National Academies of Sciences, Engineering, and Medicine 2016).

Parents of children with disabilities experience significantly elevated levels of stress compared to parents of typically developing children (Baker et al. 2002; Baker-

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Ericzén et al. 2005; Cameron et al. 1991; Hayes and Watson 2013). Moreover, studies suggest that caregivers of children with certain types of developmental disorders (e. g., autism spectrum disorders) might experience higher levels of stress than caregivers of children with a chronic physical illness (e.g., cystic fibrosis, HIV, asthma) (Bouma, and Schweitzer 1990; Hayes and Watson 2013). Intervention programs that teach parents coping skills to deal with and modify their children's challenging behaviors have been shown to reduce caregivers' stress as well as produce other positive outcomes. For instance, a meta-analysis evaluating the overall effectiveness of a variety of intervention studies in reducing psychological distress in parents of children with developmental disabilities found that multiple component interventions, namely those that use behavioral parenting strategies and coping skills training and/or another type of support, were significantly more effective than single component interventions addressing only behavioral parent training or coping skills training (Singer et al. 2007). Another meta-analysis of the Stepping Stone Triple P (SSTP) intervention, a program based on the Triple P parenting and family support intervention and designed specifically for families with children with disabilities, reported medium effect sizes on reducing child problems, large effect sizes on parenting styles, satisfaction and efficacy, and small effect sizes on parental adjustment. These effect sizes increased as the level of intervention intensity increased (Tellegen and Sanders 2013).

Because parents of children with disabilities often exhibit higher levels of stress as a result of inadequate coping skills and authoritative parenting styles (Dabrowska and Pisula 2010; Woolfson and Grant 2006), it is not surprising that the risk of physical child abuse is increased among these parents. These parents are also more likely to report favorable attitudes toward the use of corporal punishment (Crouch and Behl 2001). Fortunately, previous research has identified empathy and empowerment as mediating factors contributing to better family functioning by leading to reduced stress and fewer behavioral problems (Bratton and Landreth 1995). Empathy is defined as the understanding and sharing of another's emotional state, and it includes both affective and cognitive dimensions of children's development (Hoffman 2000). The cognitive component, or perspective taking, involves understanding another's point of view; the affective component involves experiencing emotions such as compassion, tenderness, and sympathy (Psychogiou et al. 2008). The expression of empathy is seen in high quality adult-child interactions. When caregiving is characterized by empathy, positive child outcomes such as higher self-esteem and positive socio-emotional maturation are reported (Cassidy and Shaver 1999).

Offered as part of standard services, family empowerment training has become an integral component of many

programs serving children with developmental disabilities. Defined as an intentional process that enables people to access and gain control over valued resources (Nelson 2002), empowerment gives an individual the ability to affect one's environment and situation. Research suggests that empowerment can be taught. In a study evaluating the effectiveness of a training program to empower parents whose children were receiving mental health services, Bickman et al. (1998) found that empowerment training led to greater parent involvement and access to services and providers. More empowered parents seem to promote more effective treatment, better adherence to treatment protocols and ultimately better child outcomes. Similarly, Minjarez et al. 2013 found that participating in a pivotal response training group therapy program enhanced empowerment and reduced stress among parents of children with autism. Family empowerment has demonstrated positive outcomes and improved quality of life among families of children with disabilities and chronic health conditions (Hulme 1999; Resendez et al. 2000). By accessing knowledge, skills, and resources, parents are able to gain influence over their family, service system, and community (Singh et al. 1995).

Although evidence-based parenting interventions such as the SSTP and other multi component interventions addressing both parent well-being and behavioral parent training have a positive impact on families with children of developmental disabilities, they are not widely or typically offered (Shapiro et al. 2014). Further, because children in families of lower socioeconomic status may be disproportionately impacted by developmental disabilities (Bigelow 2006), there is a need for interventions that incorporate principles of empathy and empowerment that are demonstrated to be effective with this population. The current study was based on previous research demonstrating that evidence-based parenting interventions have a positive impact among parents of children with disabilities (Plant and Sanders 2007; Roux et al. 2013; Sofronoff et al. 2011; Tellegen and Sanders 2013).

The goal of the project was to promote the optimal development and actualization of children with developmental disabilities and their families by helping parents gain more positive parenting attitudes and empowering them in their efforts to achieve independence, productivity, integration and inclusion for their children. To implement this goal, the present study was designed as a preliminary evaluation of a curriculum for caregivers of children with developmental disabilities known as the Nurturing Program for Parents and Their Children with Special Needs and Health Challenges (SNHC). The SNHC curriculum is part of a widely disseminated series known as the Nurturing Parenting Programs (Bavolek 1987; Cowen 2001) that are designed to help build nurturing parenting skills as an

alternative to abusive and neglectful parenting and child-rearing practices. These programs are recognized by the National Registry of Effective Programs and Practices (NREPP) of the Substance Abuse and Mental Health Services Administration (SAMHSA) and the Child Welfare League of America (CWLA). Developed in 2012 by Michele McCabe-Tryon and Donna Latour-Elefante in collaboration with Stephen J. Bavolek, SNHC is designed to help parents and their children with chronic medical conditions, developmental delays, disorders, and disabilities (McCabe-Tryon, and Latour-Elefante 2012). Our study compared the standard of care available in our local community for families of children with disabilities (i.e., case management) to the intervention group, which received the 12-session SNHC curriculum plus case management. Specifically, it was hypothesized that families participating in the intervention condition consisting of SNHC plus case management (SNHC+CM) would show a greater improvement in parenting attitudes than families receiving only the standard of care. Similarly, families in the SNHC+CM condition were expected to show a greater perception of family empowerment than families participating in the case management only condition.

Method

Participants

Our target population consisted of families who have historically been underserved, often isolated due to the challenges of caring for a child with developmental disabilities, and who often encountered language, cultural, and/or socioeconomic barriers to learning about and accessing services. Families were recruited from the San Antonio, Texas, area by means of referrals from physicians, clinics, early childhood intervention programs, school district special education and early childhood coordinators, Head Start, agencies of the Texas Health and Human Services Commission, San Antonio Housing Authority, City of San Antonio Department of Community Initiatives, condition-specific organizations, non-profit agencies serving children and families, parent support organizations and United Way. In addition, staff from three partnering agencies, Respite Care of San Antonio, Any Baby Can, and Brighton Center, conducted community outreach, distributed marketing materials including postcards and flyers, and word-of-mouth brought families into the study. Families with children aged 1.5 to 11 years with a diagnosed developmental disability, as defined by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 2000 (P.L. 106–402), were eligible for inclusion if they also had at least one legal caregiver who was expected to remain in the

area for the next two years and had a family income up to 100% of the 2010–2012 federal poverty level (FPL). The family income criterion was subsequently relaxed to 200% of FPL due to difficulties enrolling eligible families. A wide age range of children was incorporated in order to be inclusive of the population served by the participating agencies and to ensure the recruitment of an adequate sample size. The age range was also consistent with the recommended age range of children designed to benefit from the SNHC curriculum. Moreover, although the curriculum was created to be appropriate for children in the 0 to 12 year range, the developers allowed for adaptations to be made based on the developmental age of the child. Families with children who had multiple diagnoses (e.g., both a developmental disability and a chronic health condition) were not excluded from the study. To minimize the influence of external factors, families who received any services from any of the three partnering agencies in the previous three months were excluded from the study.

Eighty-seven families were enrolled. No significant differences were found in child (age, gender, ethnicity, and primary diagnosis), family (income) or caregiver (age, gender, and ethnicity) characteristics between the groups. The average age for child participants was 5.27 years ($SD = 2.78$) and 67.4% of the sample was age five years or younger. Twenty-one children were female (24.1%). Sixty-nine children were Hispanic (79.3%) and 77 (88.5%) were accompanied by their biological mother. The majority of the children, 58.7% in the CM condition and 56.1% in the SNHC+CM condition, had a developmental disability diagnosis on the Autism spectrum. It should be noted that although the most common diagnostic category was Autism spectrum disorders, no effort was made to over-sample one diagnostic category over another. With regard to preferred language, differences were noted despite random assignment to the control and experimental groups. Among caregivers self-reporting they read and spoke only Spanish ($n = 14$), 21% ($n = 3$) were randomly assigned to the control group while 79% ($n = 11$) were randomly assigned to the experimental group. See Table 1 for a summary of diagnoses and Table 2 for a summary of the sample characteristics.

Procedure

The University of Texas Health Science Center-San Antonio Institutional Review Board- Human Subjects reviewed and approved the study.

This study, funded as a demonstration project by U.S. DHHS Administration for Children and Families, was conducted in a real-world setting by staff from three community agencies experienced in providing services to families raising children with developmental disabilities.

Table 1 Primary diagnoses by group

Primary diagnosis	CM (control) <i>n</i> = 46	SNHC + CM (intervention) <i>n</i> = 41
Anoxic brain injury	–	1 (2.4%)
Attention deficit/ hyperactivity disorder	1 (2.2%)	–
Asthma	–	2 (4.9%)
Autism spectrum	26 (56.5%)	22 (53.7%)
Brain injury	1 (2.2%)	–
Cerebral palsy	–	1 (2.4%)
Developmental delays	6 (13.0%)	3 (7.3%)
Down's syndrome	1 (2.2%)	4 (9.8%)
Drug addicted infant	–	1 (2.4%)
Encephalopathy	1 (2.2%)	–
Fetal alcohol syndrome	1 (2.2%)	–
Fragile X syndrome	–	1 (2.4%)
Gastroschisis (Prune- Belly syndrome)	1 (2.2%)	–
Genetic and chromosome disorder	1 (2.2%)	–
Heart abnormality	–	1 (2.4%)
Hearing impaired	1 (2.2%)	–
Mental retardation	1 (2.2%)	1 (2.4%)
Oral dyspraxia	–	1 (2.4%)
Plagiocephaly	1 (2.2%)	–
Prader Willi syndrome	–	2 (4.9%)
Seizure disorder	4 (8.7%)	–
Missing diagnosis	–	1 (2.4%)

Table 2 Participant characteristics

Characteristic	CM (control) <i>n</i> = 46	SNHC + CM (intervention) <i>n</i> = 41
Child gender		
Female	11 (23.9%)	10 (24.4%)
Male	35 (76.1%)	31 (75.6%)
Caregiver gender		
Female	46 (100%)	40 (97.6%)
Male	0 (0%)	1 (2.4%)
Child ethnicity		
Hispanic	38 (82.6%)	31 (75.6%)
Non-Hispanic	8 (17.4%)	10 (24.4%)
Caregiver ethnicity		
Hispanic	36 (78.3%)	34 (82.9%)
Non-Hispanic	10 (21.7%)	7 (17.1%)
Caregiver relationship		
Biological mother	40 (87.0%)	37 (90.2%)
Other	6 (13.0%)	4 (9.8%)
Caregiver languages (read and speak)		
English	22 (47.8%)	16 (39%)
Spanish	3 (6.5%)	11 (26.8%)
Both, no preference	15 (32.6%)	7 (17.1%)
Both, English preferred	6 (13%)	4 (9.8%)
Both, Spanish preferred	0 (0%)	3 (7.3%)
Primary diagnosis		
Autism spectrum	26 (56.5%)	22 (53.7%)
Other	20 (43.5%)	19 (46.3%)

Founded in 1987 as a pilot program from the Texas Council on Developmental Disabilities, Respite Care of San Antonio is one of the few agencies medically equipped to offer inclusive care for families in a community where children (with and without disabilities) receive an opportunity to socialize, integrate, and grow. A long-standing collaborator, Any Baby Can, identified the need to help families navigate the complex health and human services systems in 1982 and now provides an array of wrap around services to families in Bexar County and 10 surrounding counties. The eldest of the three agencies, Brighton Center, Inc. began its legacy in 1969 as a school for children with Down Syndrome and has since evolved and expanded to provide services for all children with developmental disabilities and their families. The collective mission of the agencies is to annually serve over 5500 families of children with disabilities and special healthcare needs by providing respite, case management, parenting education, and advocacy.

Case management was offered to all participants so that the entire sample could receive a service commonly assumed to benefit its recipients. In the SNHC+CM condition, at least two facilitators trained in the delivery of the

curriculum worked with groups of four to 10 adult caregivers; a ratio of one trained facilitator to four children was employed for the children's groups. One cohort was conducted using bilingual facilitators and Spanish workbooks.. Due to the abbreviated period of funding, coupled with the fact that that enrollment of monolingual Spanish speakers was slower than expected, no other groups were conducted in Spanish. Instead, a professional bilingual interpreter was assigned to provide individualized translation services during sessions for individuals who enrolled after the Spanish-speaking cohort had commenced. All SNHC+CM facilitators completed a five-day training conducted by the curriculum developers, reviewed training tapes available on the Nurturing website <http://www.nurturingparenting.com> and conducted mock curriculum sessions with guidance from trained supervisors. The qualifications of these paraprofessionals varied widely. Despite the diverse educational backgrounds, at a minimum, all had a high school diploma and at least one year experience working with children with developmental disabilities.

In the SNHC+CM condition, one of the facilitators also served as the primary case manager for the group, whereas

the CM condition employed case managers not exposed to the curriculum. Each case manager received training in procedures specific to their intervention condition. The minimum qualification for the case managers in both conditions was a Bachelor's degree in Social Work or a related field. All case managers, regardless of assignment to the control or the treatment condition, received orientation and ongoing training pertaining to children with developmental disabilities by the parent agency.

Design

Using a randomized repeated measures design, participants were assigned according to a two-to-one ratio to the CM (control) or the SNHC+CM (treatment) condition. This schedule was originally chosen because the SNHC+CM condition was the more resource-intensive arm. When notified that federal funding was to be reduced from five to three years, families were henceforth equally randomized to each condition. The funding change also altered the original data collection time line. Outcome measures, which were available in English and Spanish, and assessed parenting attitudes and family empowerment were initially to be collected at baseline and at three time points after baseline (i.e., 4-, 6- and 12-month follow-up). A posttest/follow-up data collection window beginning 30 days before the due date and lasting 30 days following the due date was considered to be acceptable. Upon notification of a reduction in the length of the grant, posttest data collection was modified to only one time point rather than three. Prior to notification of the shortened study timeline, data for some participants had been collected at four-month follow-up, others at four and six month follow-up and still others only at six-month follow-up, the latter situation occurring because we had been unsuccessful in gathering four-month data. Based on the revised data collection plan, only the data collected at four month follow-up was analyzed for those participants for whom both four and six month data had been collected. Also, there were two intervention participants and one control participant who received a follow-up at two months post-baseline because the end of the study was approaching and attempts were being made to maximize the number of participants from whom data were available. Hence, the posttest data collection window ranged from two to seven months following enrollment. A \$25 gift card incentive was provided at posttest. See Fig. 1 for a consort diagram of participation.

Interventions

Case management (CM) is a rather broad term that has generally come to mean a range of activities designed to link families to clinical, social, community, and other

services that affect overall health and well-being. It has long been considered a key need of children with disabilities and their families (Elder and Magrab 1980; Jackson et al. 1992). Forty-six families were assigned to receive individualized CM services similar to those available in the local community for families with a child with a developmental disability. These services included the development of a care plan, referral coordination and linkage, advocacy and crisis intervention. Home or office-based services were delivered during the first four months of enrollment with frequency based on the needs of each family. The duration of services could be extended if requested.

Forty-one families were assigned to receive the SNHC curriculum and case management (SNHC+CM). The SNHC program consisted of 12, weekly, two-hour group-based sessions, with parents and children meeting separately for the first 90 min and together for a healthy snack and a family activity during the last 30 min of the session. In order to reduce barriers to attendance, SNHC sessions were held on weekdays in the early evening hours and transportation assistance was offered (e.g., bus tokens, taxi fares) to the meeting site.

Theories and models that inform the SNHC program content include: 1) Family Centered Care (Shelton et al. 1994) which posits that the family is a central part of the child's development and success, and in order for children to thrive families must have the necessary resources and a say in the child's health and academic services; 2) Adlerian theory (Croake 1983; Hinkle et al. 1980) which maintains that every child (despite abilities) desires to belong and feel significant; 3) Interpersonal neurobiology (Badenoch 2008; Siegel 2001) which values understanding of human experience and how it shapes the brain and supports insight/empathy or not, and the ability to self-regulate; and 4) Attachment theory (Bowlby 1969, p. 194) which promulgates the importance of supportive primary caretakers who are responsive to a child's needs and cues and the impact that their responses have on the child's ability to form relationships and cope with adversity.

The SNHC program is based on the same five constructs (practices) assumed to contribute to the maltreatment of children and teens as for all Nurturing Parenting Programs. The constructs are: inappropriate expectations of children; lack of parental empathy towards children's needs; value of corporal punishment; parent-child role reversal; and suppression of children's power and independence. Each activity in the Adult Facilitator Manual and the Children's Facilitator Manual identifies which construct is being addressed. The curriculum developers added four sessions to the original 8-week program for parents with children with health challenges (i.e., medical health challenges and life-threatening physical health challenges), in order to include information on parenting children with

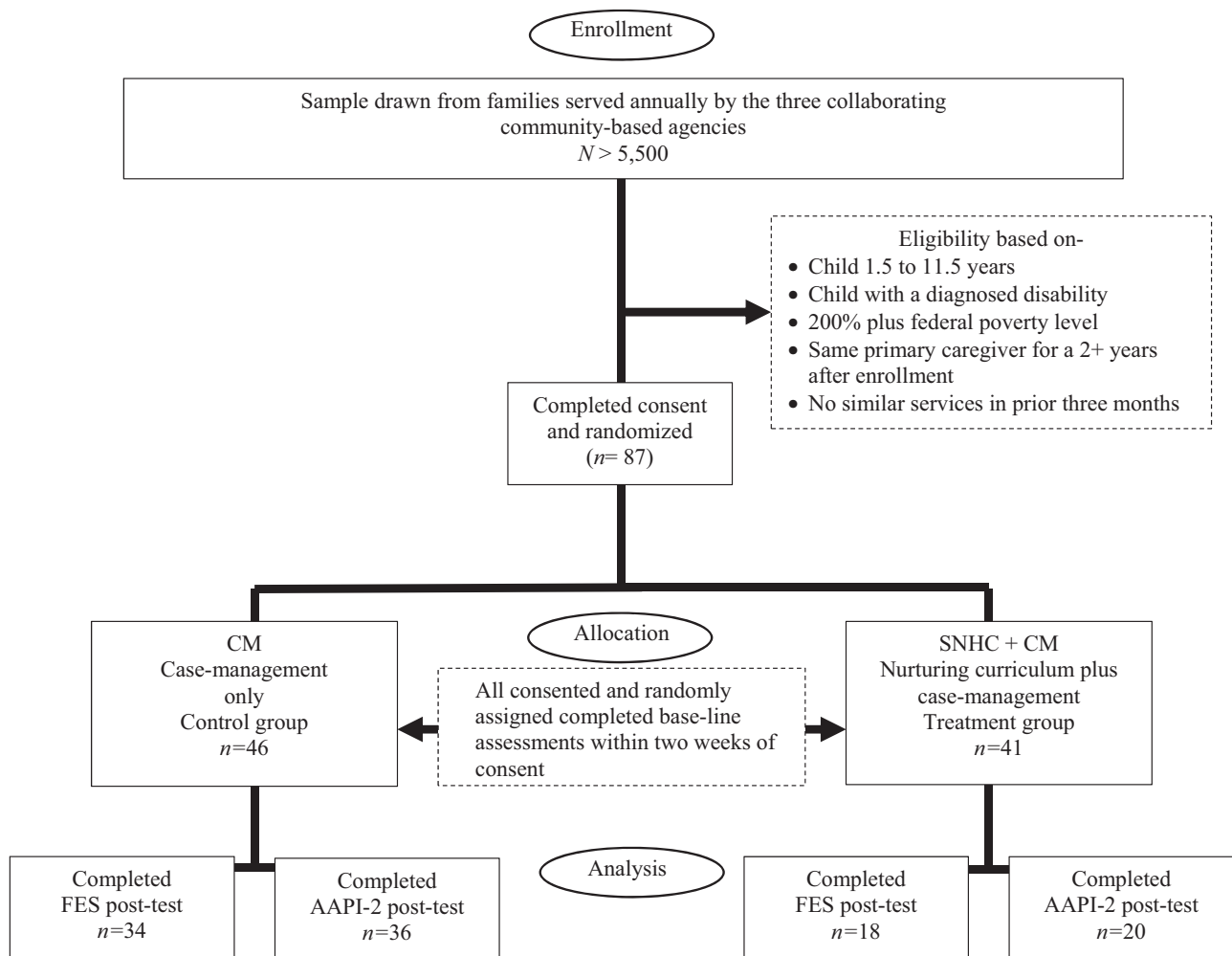


Fig. 1 Diagram showing number of potential participants approached for enrollment to final participants included in analyses. The reasons underlying those lost to follow-up are not available as the

administering agencies declined to identify reasons participants failed to continue in the program

developmental delays, neurological disorders, and behavior challenges. The expanded content focused on children with “special needs.” In addition, the developers added a competency component at the end of each session to ensure that the parent understood the information.

Parent group facilitators used manuals to guide the format and content of the sessions. Parent sessions included experiential activities, worksheets, role-plays by facilitators, and guided discussions on key topics (e.g., discipline). Parents were provided a workbook that was intended to facilitate participation and engagement in the sessions. The workbook contained the session outline, a summary of key information presented in the session, worksheets and the Home Practice Assignment associated with each session.

Children’s groups were comprised of children with disabilities and their siblings without disabilities in order to increase the external validity of the intervention. Facilitators used a child manual to guide delivery of each session. Child

sessions were experientially based and each session included activities such as “brain gym”, “circle time”, “large motor activity”, “art time”, and “story time.” Each session was designed to complement the material and themes covered in the respective parent session. Given the wide span in age and developmental stage, the activities often had to be adapted and modified to meet the needs of each child. For instance, the Brain Gym activity, which was part of every session, and designed to facilitate optimal achievement of mental potential, could be modified so that the facilitator or a sibling could help the child with a disability if he or she needed it but also allowed independence when the child was able to do it alone. Parents and children re-united for the final 30 min of the session to engage in family strengthening activities including but not limited to the creation of a family mural that commemorates the family’s journey and accomplishments over the course of the program, creating a list of current and potential family traditions, and sharing

Table 3 Adult and children session topics

Week	Adult sessions activity	Children sessions activity
One	Introduction overview and getting to know you	Orientation-me and my family
Two	Brain development; ages and stages; comfort and calming	Accepting differences: comfort and calming
Three	Ages and stages, personality: family structure, grief and loss	Feelings: understanding change
Four	Personal power and independence	Praise and self-esteem
Five	Discipline	Personal power
Six	Discipline	Body ownership
Seven	Health and healing	Hope and healing
Eight	Feelings and needs	Feelings: understanding and expressing anger
Nine	Helping children cope, socialization and sibling support	Brothers, sisters, and friends
Ten	Stress and humor/play; specific health/special needs	Expressing worry and stress
Eleven	Communication and advocacy	Communication
Twelve	Closure and celebration	Saying good-bye; celebration

funny family stories as a way to build rapport and reduce stress through humor. Adult and child session topics addressed each week are shown in Table 3.

Families were also offered weekly, home-based case management and parenting sessions in tandem with the curriculum. Home visits were designed to address typical case management issues relevant to a population with developmental disabilities. After each of the 12 SNHC group sessions, individual, home-based meetings with parents were offered by either the case manager or the parent facilitator as a make-up session or to reinforce information conveyed in the SNHC curriculum. During the in-home parenting meetings the parent facilitator would review the topics outlined in the SNHC session one-on-one with the parent, using the facilitator's manual and the parent handbook to ensure the parent understood the core competencies of the SNHC parent session. In accordance with the SNHC curriculum, families were permitted to miss/make-up a maximum of four group sessions and receive a certificate of completion. Families who participated in less than eight group sessions received a certificate of participation. The family could request additional home visits, as needed, for up to three months.

Measures

Adult and Adolescent Parenting Index-2 (AAPI-2)

The AAPI-2 (Bavolek and Keene 2001), administered to participants at baseline and posttest, is a revised and re-normed version of the original AAPI (Bavolek and Keene 1999), and is designed to assess parents' attitudes toward child rearing. Although there are no published studies of the use of the AAPI-2 with children with developmental

disabilities, it is widely used as a measure for assessing the potential for child maltreatment and recommended for use with all Nurturing Programs by the program developers. The AAPI-2 has two versions (Form A and Form B) both with 40 items rated on a five-point scale and five subscales. Both versions have high internal consistency and were used interchangeably in this study to reduce practice effects. This assessment uses a 5-point Likert-type scale ranging from Strongly Agree to Strongly Disagree for each of 40 items. The AAPI-2 includes five subscales: Inappropriate Expectations of Children; Parental Lack of Empathy Toward Children's Needs; Strong Parental Belief in the Use of Corporal Punishment; Reversing Parent-Child Family Roles; and Oppressing Children's Power and Independence. Higher scores on the constructs indicate the presence of attitudes consistent with a nurturing, non-abusive parenting philosophy. Bavolek and Keene (1999) report internal reliability scores ranging from 0.80 to 0.92 across both forms and good discriminative ability (abusive versus non-abusive parenting).

Family Empowerment Scale (FES)

The 34-item FES (Koren et al. 1992) completed by caregivers at baseline and posttest, has been used in at least 30 studies world-wide to measure empowerment of families taking care of children with emotional, behavioral as well as developmental disabilities (Herbert et al. 2009). It consists of three subscales: Family (12 items), Community (10 items) and Service System Empowerment (12 items). Higher scores on each subscale indicate higher levels of empowerment. Koren et al. (1992), whose original sample included children with emotional disabilities but also a subset of children with developmental disabilities, report

internal coefficients ranged from .87 to .88 and test–retest coefficients ranging from .77 to .85. Some evidence exists for the validity of FES in discriminating groups of parents who differ on community-focused activities (Koren et al. 1992).

Data Analyses

The Adult and Adolescent Parenting Index-2 (AAPI-2) and Family Empowerment Scale (FES) were scored. For each measure, the appropriate subscales were also scored resulting in ten measures- AAPI-2 overall, AAPI-2 Inappropriate Expectations of Children, AAPI-2 Parental Lack of Empathy Toward Children's Needs; AAPI-2 Strong Parental Belief in the Use of Corporal Punishment, AAPI-2 Reversing Parent-Child Family Roles, AAPI-2 Oppressing Children's Power and Independence, FES overall, FES Family, FES Community, and FES Service System Empowerment. Repeated-measures analysis of variance (ANOVA) were utilized to investigate changes pre and post for participants in the control (CM) and treatment groups (SNHC+CM).

Results

The average number of sessions for the forty-six families in the CM group was 5.32 ($SD = 3.37$; Range 0–19). These case management visits occurred in the home and covered such activities as linkage to needed community resources, relationship building etc., but did not address topics or issues related to the delivery of the SNHC curriculum.

The average total SNHC curriculum, home based parenting, and case management sessions received by the forty-one families in the treatment group (SNHC+CM) was 18.10 ($SD = 11.50$; Range 0–48). On average, families received 6.20 ($SD = 4.54$; Range 0–17) case management sessions and 6.33 ($SD = 6.01$; Range 0–25) home-based parenting sessions with content specifically related to the nurturing curriculum. In addition, families received 5.58 ($SD = 4.57$; Range 0–17) SNHC curriculum sessions, 36.6% completed the SNHC curriculum, and 10 families (24.4%) attended no sessions. The most frequently attended session was Session 2-Brain Development, while Session 7-Health and Healing was the least attended. Although we expected families to complete all 12 group sessions, this finding is tempered by the additional home-based parenting meetings. To ensure families received the core SNHC content, the facilitator completed the Competency Assessment form in partnership with the caregiver at the end of each session. Although competency assessment data was not collected for data analysis, the caregiver completed the competency statements and answered the questions in the parent handbook at the end of the current session. Areas of

strength were noted, and a plan for reinforcement of concepts was discussed and implemented for the areas that need attention or additional review.

Hypothesis one, that families receiving SNHC+CM would evidence more positive scores on the AAPI-2 than families receiving CM was investigated with a mixed-model, repeated measures analysis of variance. Thirty-six families in the CM group and 20 families in the SNHC + CM group completed the AAPI-2 at baseline and post-test. For the Empathy towards Children's Needs scale, a significant time X intervention groups interaction was found, $F(1, 54) = 4.52$, $p = .04$, $\eta^2 = .08$, power = .55 (see Fig. 2). Subsequent investigation of the mean values revealed that score improvements were greater for families receiving SNHC+CM than families receiving CM, $t(54) = 2.13$, $p < .05$. See Fig. 2. For the Use of Corporal Punishment scale, a significant main effect for time was found, $F(1, 54) = 6.56$, $p = .013$, $\eta^2 = .11$, power = .71. Average scores on the Use of Corporal Punishment scale increased for participants regardless of group. Families in both conditions had higher scores at post-test than at baseline measurement indicating negative attitudes concerning corporal punishment, thus an increase in nurturing attitudes. For the Parent-Child Role Responsibilities, Expectations of Children and Children's Power and Independence scales, no significant effects were found, $F(1, 54) < 1$, n.s. Table 4 provides a summary of group comparisons.

Hypothesis two, that families receiving SNHC+CM would evidence greater empowerment than families

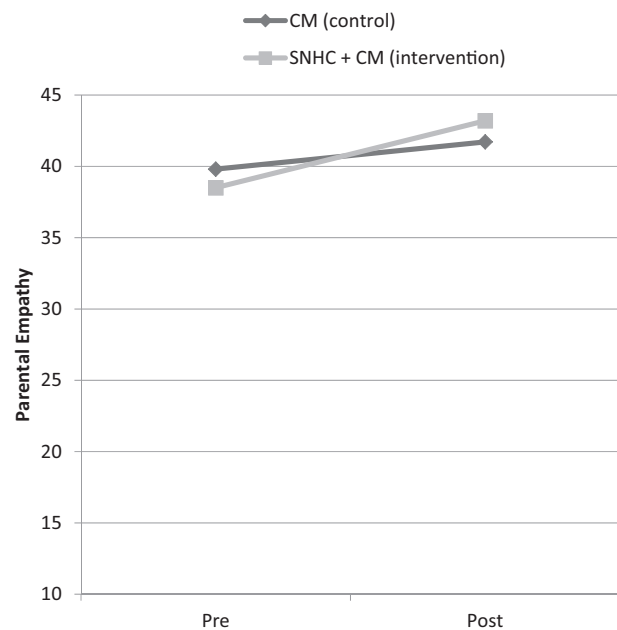


Fig. 2 Mean scores for the AAPI-2 Empathy towards Children's Needs Scales representing the significant ($p = .04$) interaction of time (pre/post) X intervention group (CM/SNHC+CM)

Table 4 AAPI-2 baseline and post-test participant scores

Subscales	CM (control) <i>n</i> =36			
	Baseline		Post-test	
	M (SD)	95% CI	M (SD)	95% CI
Child expectations	21.69 (4.99)	[20.00, 23.38]	21.58 (4.74)	[20.00, 23.21]
Empathy toward children	39.81 (5.00)	[38.01, 41.60]	41.72 (4.83)	[40.08, 43.36]
Corporal punishment	41.83 (6.96) ^a	[39.52, 44.15]	42.97 (6.71) ^a	[40.77, 45.18]
Parent-child role	27.06 (5.47)	[25.24, 28.87]	26.28 (5.15)	[24.65, 27.91]
Children's power	19.72 (3.01)	[18.81, 20.63]	18.94 (4.41)	[17.61, 20.28]
SNHC + CM (intervention) <i>n</i> = 20				
Child expectations	21.15 (5.17)	[18.88, 23.42]	23.20 (5.11)	[21.02, 25.38]
Empathy toward children	38.50 (6.01)	[36.09, 40.91]	43.20 (5.06)	[41.00, 45.40]
Corporal punishment	40.55 (6.91) ^b	[37.44, 43.66]	43.40 (6.37) ^b	[40.45, 46.36]
Parent-child role	27.70 (5.35)	[25.27, 30.13]	26.80 (4.34)	[24.61, 29.00]
Children's power	20.70 (2.08)	[19.48, 21.92]	19.85 (3.12)	[18.06, 21.64]

Note: AAPI-2 Subscale values with the same superscript are significantly different at *p* < .001

Table 5 FES baseline and post-test participant scores

	CM (control) <i>n</i> = 34			
	Baseline		Post-Test	
	<i>M</i> (<i>SD</i>)	95% CI	<i>M</i> (<i>SD</i>)	95% CI
Composite scale	131.47 (17.21)	[125.67, 137.27]	136.91 (17.06)	[131.06, 142.76]
Family	3.96 (.57)	[3.77, 4.16]	4.21 (.45)	[4.05, 4.37]
Community	3.13 (.96)	[2.821, 3.44]	3.24 (.90)	[2.94, 3.54]
Service system	4.41 (.45)	[4.24, 4.58]	4.51 (.43)	[4.36, 4.66]
SNHC + CM (intervention) <i>n</i> = 18				
Composite scale	126.22 (16.02)	[118.25, 134.20]	134.56 (16.85)	[126.51, 142.60]
Family	3.91 (.59)	[3.64, 4.19]	4.08 (.46)	[3.87, 4.30]
Community	2.87 (.75)	[2.44, 3.29]	3.29 (.83)	[2.88, 3.71]
Service system	4.21 (.58)	[3.98, 4.45]	4.42 (.45)	[4.21, 4.63]

Note: All baseline to post-test comparisons for the Family Empowerment Scale are significantly different at *p* < .001 for comparisons within control and intervention groups

receiving CM was investigated with a mixed-model, repeated measures analysis of variance. Thirty-four families in the CM group and 18 families in the SNHC+CM group completed the FES at baseline and posttest. With regard to total scores on the FES, there was a significant main effect for time, $F(1, 50) = 13.28, p = .001, \eta^2 = .21, \text{power} = .95$. Families in both groups had higher FES scores at post-test as compared to baseline. Thus, all caregivers increased in their empowerment over the course of the intervention. The results for the FES subscales were also investigated and a similar pattern of results emerged. For the FES family, community and service system empowerment subscales, there was a significant main effect for time, $F(1, 50) = 10.98, p = .002, \eta^2 = .18, \text{power} = .90, F(1, 50) = 9.50, p = .003, \eta^2 = .16, \text{power} = .86$, and $F(1, 50) = 5.37, p$

$= .025, \eta^2 = .10, \text{power} = .62$, respectively. FES scores increased on average for participants regardless of group. No main effects for group and no interactions were found. Table 5 provides a summary of group comparisons.

Discussion

This study was designed to assess the effectiveness of the Nurturing Program for Parents and Their Children with Special Needs and Health Challenges (SNHC). It was aimed at teaching parenting strategies with the purpose of building family strength and alleviating the challenges associated with raising children with medical and developmental disorders or disabilities. Due to concerns about exposing

families to an untested intervention whilst withholding standard of care services, both groups received case management and no true control group was included.

The first aim of the study was to explore whether families participating in a treatment condition consisting of the SNHC+CM would gain more positive parenting attitudes compared to families participating in CM only. Based on previous studies demonstrating that evidence-based parenting interventions have a positive impact among parents of children with disabilities (Plant and Sanders 2007; Roux et al. 2013; Sofronoff et al. 2011; Tellegen and Sanders 2013), parents in the treatment condition were expected to differ over time in all areas assessed by the AAPI-2. Compared to caregivers in the CM only condition, those in the SNHC+CM condition improved in empathy towards children's needs by posttest, and all families, regardless of their placement, improved their attitudes towards the use of corporal punishment by posttest. Assuming that learning empathy leads to an expansion of points of view (Kohlberg and Hersh 1977) and that lack of empathy is negatively related to the use of positive parenting strategies (Brems and Sohl 1995), the authors believe that becoming more empathic allowed parents to take their children's point of view and to be more aware of the challenges their child endures. It is important to note that our curriculum was infused with activities designed to promote empathy, thus we believe that the parents were well exposed to and consequently reported more empathic attitudes. Additionally, it is also possible that empathy increased because caregivers perceived that the researchers and the project desired them to exhibit more empathic responsiveness towards their children. Thus, it is important then, to be able to replicate the study or conduct additional follow up with these families to determine whether or not these empathy levels are maintained over time.

The reason why both groups improved with regard to scores on the corporal punishment scale is not clear. Although the case managers in the CM condition had no training or exposure to the SNHC curriculum, all case managers, including the SNHC+CM case manager had prior experience working with persons/families with disabilities. This may have influenced caregivers as case managers may have informally shared information or attitudes against the use of harsh discipline. Moreover, although families who had received similar services in the previous three months were excluded from the study, it is unknown if families, particularly in the CM condition, participated in other parenting programs available in the community during their concurrent participation this study.

The second aim of the study was to explore whether the families in the SNHC+CM condition would gain a greater perception of family empowerment than those participating in the CM condition. Contrary to our initial expectation,

families in both groups reported increased empowerment over time. For the FES family, community, and service system subscales, caregivers in both groups had higher scores at post-test as compared to pre-test. These findings are likely the result of the case management services offered in both conditions although the lack of a waitlist control requires this conclusion be stated with reservation. Although case management is widely considered to be an effective modality (Rosenbaum et al. 2009; Johnson and Rosenthal 2009) and is provided by most agencies serving children with disabilities, our review of the literature revealed a dearth of controlled studies addressing the value of case management, particularly with regard to children with special needs. Hence, although not originally hypothesized, the current study suggests evidence for the benefit of case management in helping parents feel more empowered as well as more disapproving of harsh disciplinary practices that are all too often associated with parenting a child with special needs (Hendricks et al. 2013). Notwithstanding the value of case management alone, the SNHC+CM intervention yielded the additional benefit of increased parental empathy. As noted by Petrenko (2013), although the majority of existing interventions for families of children with developmental disabilities consist of a single-component intervention, multi-component interventions may yield greater benefits for families of young children with disabilities than single ones.

Our study also targeted low-income families that, due to the lack of monetary resources, clearly encounter more challenges typically associated with raising children with disabilities. Additionally, it focused on the necessity to assist individuals and families with limited English proficiency. Due to the combination of low socioeconomic status and limited English, some of these families may not be aware of the availability of support services and may experience logistical and language barriers and, because in some cases they may be recent immigrants or possibly undocumented, may be reluctant to access help. Finally, in supporting previous research that early intervention approaches have a positive impact on a range of outcomes for children with developmental disabilities (Shapiro et al. 2014), another strength of this study is that it is an early intervention offered to families with children as young as 1.5 years old.

The study also encountered some challenges that present limitations. A major limitation is the relatively high rate of attrition that made it difficult to evaluate the efficacy of the intervention. Among the SNHC + CM group approximately 49% (20 of 41 participants) of those recruited failed to complete follow-up. This completion rate stands in contrast to the control group where 78% (36 of 46 participants) of those recruited persisted to follow-up. Complicating this issue are the differences in language barriers between the

two groups. Approximately 27% ($n = 11$) of the participants recruited to the SNHC + CM group were Spanish speakers compared to approximately 7% ($n = 3$) of the CM group. This disparity was the failure of randomization to equally distribute Spanish only speakers in the two groups; of the fourteen caregivers reporting to read and speak only Spanish, three Spanish speakers (21%) were randomly assigned to the CM only group while eleven Spanish speakers (79%) were randomly assigned to the SNHC+CM group. Despite the availability of Spanish posttest measures and the utilization of bilingual staff, a majority (64%; $n = 9$) of Spanish-speaking families whose caregivers reported reading and speaking only Spanish ($n = 14$) did not complete follow-up. Further investigation revealed that 73% (8 of 11 participants) of caregivers reporting to read and speak only Spanish were lost to follow-up from the SNHC+CM group while only 33% (1 of 3 participants) were lost from the CM only group. The disparity in attrition despite access to Spanish language services suggests that additional issues common among Spanish-speaking participants may have impacted participation and completion. Future studies should investigate a constellation of demographic factors that create barriers to services.

In conjunction with attrition, the resulting small sample size restricted the statistical power and hence impacted the likelihood of finding expected significance. Although results suggest that score improvements on the AAPI-2's Empathy towards Children's Needs scale were greater for families receiving SNHC+CM than families receiving CM alone, the implications of the finding are limited by the test's low power. The same concerns regarding power of significant findings also encourage conservative interpretation of results regarding increasingly negative views towards corporal punishment at post-test. Without implementation of the curriculum in a greater sample of participants, confidence in the generalizability remains limited. Our study is not unique in this respect. According to Petrenko (2013), recruitment and retention issues are major challenges confronted by researchers conducting controlled trials with children with developmental disabilities and their families. Samples sizes in the treatment studies reviewed by Petrenko (2013) typically ranged between 20 and 30 children per group and reported pre/post attrition rates were as great as 54%.

Because the research team was sensitive to the attrition issue, sessions were held on weekdays in the early evening hours and transportation assistance was offered. Despite these efforts, families in the SNHC intervention only received an average of five group curriculum sessions and 10 families (24.4%) did not participate in any sessions. Given that 12 sessions were judged to be appropriate for the delivery of an intervention (Cuijpers 1999), our families were offered both group sessions and supplemental home

visits to reinforce material presented in groups. Hence, families had to set aside an average of three hours of their time (two hours for the group and one hour for transportation) each week to attend the community-based sessions as well as additional time at home for the supplemental sessions. Thus, this underlines the need for effective programs that do not place excessive participation time demands on caregivers whose lives are already strained by caring for a child with a disability. Future studies designed to attenuate attrition might focus on alleviating time demands whilst retaining core program elements by reducing the length of sessions and/or eliminating the supplemental home visiting component. Alternatively, a viable option may be to adapt the curriculum so that it can be delivered entirely in a home-based format as studies have found home visitation an effective modality to enhance child development and parenting skills (Martin et al. 2008; Olds et al. 1998). In fact, it has been argued that home visitation may facilitate retention because it has the advantage of offering services in a comfortable and familiar environment that spares already overburdened families the additional stress of travelling to another location (Azzillessing 2011).

A final limitation is the disparity in attention/contact with professionals for those assigned to the SNHC+CM group and the CM group alone. Coupled with the lack of a true, no-treatment control group, the statistical differences in the SNHC+CM group and the CM only group on the AAPI measures may be related to the amount of contact in addition to the intervention itself even though differences are related to specific content covered in the nurturing curriculum.

In sum, evidence-based parenting interventions have demonstrated a positive impact on parenting among parents of children with disabilities. This study tested the effectiveness of the SNHC curriculum in teaching parents appropriate and practical strategies to enhance family strength. Although not all the hypotheses were confirmed, and despite limitations including high attrition rates, SNHC +CM appears to be a promising and feasible intervention for community based agencies to offer families of children with disabilities, especially in regards to deployment on a broader scale with paraprofessionals as a vehicle to reach a larger population. This study suggests that providing families of children with disabilities appropriate tools can positively affect the quality of parent-child relationships as well as enhance family empowerment. Future more adequately powered studies that employ a waitlist control are needed to replicate our findings and confirm that SNHC +CM offers benefits distinct from case-management alone.

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Author Contributions R.S.B participated in the design of the study and assumed the primary role in writing the paper. J.Z.C conducted the data analysis and contributed to writing the paper. C.M and H.H. designed and participated in the execution of the study and contributed to writing the paper; L.G.F. and N.A participated in the execution of the study and contributed to writing the paper.

Compliance with Ethical Standards

Conflict of Interest The authors of the study have no conflict of interest to disclose and the study adheres to all federal regulations and guidelines for the protection of human subjects.

Ethical Approval The study was approved as exempt by the University of Texas Health Science Center at San Antonio Institutional Review Board-Human Subjects Committee. Exempt determination was made under DHHS Regulation 45 CFR 46.101(b)(5).

Informed Consent All participants provided written informed consent prior to participation.

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