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The impact of parent-delivered intervention on parents of very young children with autism

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Abstract

This study investigated the impact of a parent-coaching intervention based on the Early Start Denver Model (P-ESDM) on parenting-related stress and sense of competence. This was part of a multisite, randomized trial comparing P-ESDM (n=49) with community intervention (n=49) for children aged 12 and 24 months. The P-ESDM group reported no increase in parenting stress, whereas the Community group experienced an increase over the same 3-month period. Parental sense of competence did not differ. Number of negative life events was a significant predictor of parenting stress and sense of competence across both groups. This suggests that a parent-coaching intervention may help maintain parental adjustment directly after a child is diagnosed with ASD.

Keywords

early intervention; parent; stress; autism spectrum disorder; Early Start Denver Model

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Parents of children with autism spectrum disorder (ASD) are consistently found to have elevated levels of parenting-related stress and psychological distress, even when compared with parents of children with non-ASD developmental disabilities (e.g., Gallagher & Bristol, 1989; Abbeduto et al., 2004; Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; Estes et al., 2009; Kasari & Sigman, 1997). However, it is also the case that positive psychological functioning and effective coping strategies are often reported in parents of children with ASDs (e.g., Greenberg, Seltzer, Krauss, Chou, & Hong, 2004; Smith et al., 2008; Kuhn & Carter, 2006). Potential threats and supports to functioning and parent sense of competence in families with autism include such family-related factors as socioeconomic status (Orsmond et al., 2007; Mak et al., 2007), spousal relations (e.g., Higgins, Bailey, & Pearce, 2005; Rodrique, Morgan, & Geffken, 1990), availability of social support (White & Hastings, 2004), and the number of children with disabilities in a family (Orsmond et al., 2007). Negative life events can be associated with increased stress in parents of children with ASD (Barker, Hartley, Selzer, Floyd, Greenberg, Orsmond, 2011; Wong, Seltzer, Greenberg et al., 2012). Specific characteristics of children with ASD, particularly problem behaviors, have also been found to contribute to increased parent stress (e.g., Abbeduto et al., 2004; Blacher & McIntyre, 2006; Dumas, Wolf, Fisman, & Culligan., 1991; Estes et al., 2009; Hastings & Brown, 2002). Effective approaches to supporting parents and families of children with ASD and factors associated with positive parent and family outcomes need to be identified to improve the quality of life for families, parents, and children with ASD.

Research has shown that intensive early intervention can lead to improved outcomes for children with ASD (e.g., Dawson et al., 2010). Emerging findings suggest that parents may also benefit from their child's participation in intensive early intervention (e.g., Osborne, McHugh, Saunders, & Reed, 2008; Schwichtenberg & Poehlmann, 2007; Hastings & Johnson, 2001). Results of a number of multiple baseline studies indicate a positive effect for most parents, including increased parental knowledge, skills, and performance (Harris, Wolchik, & Milch, 1982; Koegel, Bimbela, & Schreibman, 1996; Koegel, Schreibman, Britten, Burke, & O'Neill, 1982; Laski, Charlop-Christy, & Schreibman, 1988; Schreibman, Kaneko, & Koegel, 1991). However, research on the relationship between parent stress and child-focused interventions is still in the early stages. In their review, McConachie and Diggle (2007) discussed how many of the parent-implemented early intervention studies for young children with ASD were either short-term or showed mixed results. For example, a pilot study of a three-month parent support group, behavior management training, and individual early intervention for the child with autism (i.e., the EarlyBird Programme; Shields, 2001) found parent-reported decreased stress three and six-months after the program. A small, nonrandomized controlled study of the Scottish Centre for Autism program found a nonsignificant reduction of parental stress following their parent training program for behavior management (Salt et al., 2002). A randomized controlled trial of a parent intervention on teaching joint attention skills to children with autism compared to children receiving local services found no group differences in parental stress at 12-month follow-up (Drew et al., 2002). Two studies have found that more early intervention hours were associated with greater improvement in parent stress and decreased parent depression (Osborne, McHugh, Saunders, & Reed, 2008; Schwichtenberg & Poehlmann, 2007). Another study reported that parental belief in the efficacy of the intervention received by the child may be associated with lower parent stress (Hastings & Johnson, 2001). However, participation in intensive early intervention can demand a great deal of time, energy and resources from families. It is not always clear that parent stress decreases in families involved in early autism intervention (Baker-Ericzen, Brookman-Fraze, & Stahmer, 2005). For example, mothers have demonstrated a positive, linear relationship between personal strain and number of hours spent delivering early intervention to their children (Schwichtenberg & Poehlmann, 2007). Nonetheless, consistent with early intervention policies and best practices, efforts to involve parents in early intervention have been

increasing (e.g., Carter et al., 2011; Green et al., 2010; Oosterling et al., 2010). Thus, it is important to understand the impact of parent-delivered intervention on parents.

The present study investigated the impact of three months of parent coaching aiming to teach parents to deliver intervention to very young children with ASD on parenting-related stress and sense of competence. The primary outcomes for this randomized, controlled trial testing the efficacy of a 12-week, low-intensity, parent-delivered intervention for toddlers with ASD using the Early Start Denver Model (P-ESDM) have been reported previously (Rogers et al., 2012). No effect of group assignment (Community intervention-as-usual vs P-ESDM) was found on child developmental measures or parent-child interaction patterns. However, younger age at the start of intervention and increased intervention hours were associated with improvement in child outcomes across both groups. The primary hypothesis of the current study is that participation in parent delivery of the Early Start Denver Model (P-ESDM) would lead to improved parenting stress and sense of competence compared with community intervention as usual. Secondly, we investigated a general prediction model to identify a broader range of contributors, both family factors and child factors, to parenting-related stress and sense of competence in parents of young children with ASD, across both the P-ESDM and Community intervention groups.

Methods

Participants

Children ages 12-24 months at risk for autism were recruited from community agencies, pediatricians, local parent advocacy groups, and hospital-based autism clinics for a multisite, randomized trial on the efficacy of parent delivery of the Early Start Denver Model (P-ESDM; Rogers & Dawson, 2010), an evidence-based treatment approach for young children with ASD. All children were diagnosed by the project staff members prior to enrollment. For some children, this was a second diagnosis, but due to their very young ages for many this was the initial diagnosis. A clinician met with each family after research diagnosis of ASD to provide feedback, answer questions, describe the importance of early intervention, and provide referral information to public early intervention services in the community. All families were also given a written diagnostic report. Children enrolled in the P-ESDM group began intervention within a month of diagnosis. Children randomized to the community group received follow-up phone calls 6 and 12 weeks later to determine their interventions. All but one child was receiving early intervention services within the 12 week period following diagnosis.

Ninety-eight children with autism and their primary caregivers qualified, enrolled, and were randomized into two intervention groups (P-ESDM=49 and Community=49). One child was disqualified for not meeting ASD criteria at Time 2 (three months after initially meeting inclusion criteria). This study was conducted at three universities serving as clinical sites, REMOVED FOR BLIND REVIEW. An independent data coordinating center was established at REMOVED FOR BLIND REVIEW. All participants lived within 1 hour of one of these sites.

Families with children who had a history of serious traumatic brain injury, significant sensory or motor impairment, major physical abnormalities, neurological disease of known genetic etiology (e.g., Fragile X), severe parent mental health conditions, or development quotient scores below 30 on the Mullen Scales of Early Learning (Mullen; 1997) were excluded. All children included in the study met criteria for an autism spectrum disorder based on expert clinical judgment by two independent clinicians, algorithm scores on the ADOS-Toddler version (Luyster et al., 2009), and DSM-IV criteria for an autism spectrum disorder at two time points (study entrance and 3 months later). The DSM-IV criteria was

established by integrating information from cognitive test scores, information from family history, clinical observations made during the course of the research assessments, and review of medical records. *A priori* standards for screening new families and for evaluator training and reliability of assessment and diagnosis were established and monitored to ensure comparability of child data and sample characteristics across sites. All assessors met research reliability standards for the ADOS and 20% of ADOSs were reviewed for reliability. Mullen scores were evaluated quarterly using objective fidelity criteria. All cases were reviewed by two independent, expert clinicians to establish diagnosis. Cross-site meetings were held to establish and maintain diagnostic reliability. Additional information regarding reliability is available from the authors. Evaluators were licensed clinical psychologists, postdoctoral fellows, or graduate students under supervision of licensed clinical psychologists; all evaluators were naïve to intervention group assignment.

A total of 98 families were enrolled in the larger study. Of those families enrolled, 83 completed the Parent Sense of Competence (PSOC) questionnaire at both baseline and follow-up three months later, and 77 completed the Questionnaire on Resources and Stress (QRS) at both visits. There were no significant demographic differences between those families who completed questionnaires at both time points and those who did not. Written parental/guardian informed consent was obtained, as approved by REMOVED FOR BLIND REVIEW Institutional Review Board for each participating child.

Study Design

Research participants were interviewed by phone to obtain initial demographic information. Potential participants underwent a research diagnostic evaluation. The children who met inclusion criteria and their primary caregivers were randomized to P-ESDM or community intervention as usual (Community). The randomized groups were stratified according to child age (less than or greater than/equal to 21 months), gender, and Mullen DQ score (less than or greater than/equal to 60; Mullen, 1997). The data coordinating center provided the group assignment to research staff. Families in the P-ESDM group participated in the intervention described below. Families in the Community group were encouraged to obtain intervention in the community. One assessment was conducted prior to randomization and one was conducted twelve weeks later, which coincided with the end of the P-ESDM intervention period. Participating families were paid for the final assessment visit but not for any treatment visits. Families in both the P-ESDM and Community intervention groups were provided with the results of research diagnostic examination, including standardized test scores, diagnostic information, and individualized intervention recommendations at both assessment points. On-site child care was provided during visits to the center to siblings of participants when requested by parents.

Study Procedures

P-ESDM intervention—The parent-delivered intervention condition was based on the ESDM, an evidence-based approach for stimulating developmental growth in young children with ASD (Dawson et al., 2010). The ESDM aims to create an affectively warm and rich teaching environment to foster positive relationships between children and their social partners. It emphasizes the social function of language and the development of nonverbal communication and imitation as foundations for verbal language. In P-ESDM, parents were taught the interactive principles associated with ESDM, such as gaining child attention, principles of behavior change, encouraging child vocalization and gesture use, within the daily routines, activities, and familiar home interaction patterns. They were not taught to elicit specific behavioral learning objectives (e.g., “child will vocalize six different consonants in 10 minutes of play”), though therapists wrote these types of objectives and tracked change using this approach. Daily data on child progress were gathered by the

therapists during weekly session with parents and child. Parents self-identified the primary caretaker that would attend the 12, one-hour-per-week, center-based sessions to learn about the P-ESDM, although additional caretakers were encouraged to attend and participate as well. A detailed parent manual was developed to describe 10 intervention themes essential to the ESDM; (a) social attention and motivation for learning, (b) sensory social routines, (c) dyadic engagement, (d) non-verbal communication, (e) imitation, (f) antecedent-behavior-consequence relationship (ABCs of learning), (g) joint attention, (h) functional play, (i) symbolic play, and (j) speech development. Primary caregivers received step-by-step instruction on how to embed each theme in daily play and caretaking routines at home. We refer readers to the parent manual for more information (Rogers, Dawson, & Vismara, 2012).

An initial 1.5 hour treatment evaluation session in which each child was evaluated by a therapist to determine the child's level on the ESDM Curriculum was conducted. The therapist then generated 12-15 learning objectives for the child from these data in collaboration with the primary caregiver. Objectives were broken down into 4-6 teaching steps. The therapist used these objectives and teaching steps to help the parent identify appropriate toys and activities for their child, and to track weekly child progress. After this initial session, 12, one-hour treatment sessions were carried out, one each week. There was a consistent structure to the 1 hour treatment sessions. The session was broken into 6, 10-minute periods, each with a different activity. At the start of the session, the parents shared their progress practicing the past theme during the week at home with discussion of triumphant moments (e.g., "my child looked up at me and smiled when eating his cheerios in his highchair") and challenges (e.g., "it was difficult to keep my child engaged when singing songs"). In the next 10 minute block parents and their children engaged in a preferred play activity (e.g., toy play, books, bubbles) to demonstrate experiences from the past week. Sessions were videotaped each week and analyzed for parent fidelity to the P-ESDM model. Parent experiences and observations in that play period were discussed and followed up on later in the session. In the next 10 minutes, the therapist explained the next ESDM theme verbally while providing written materials. The therapist then modeled the techniques with the child while parents observed. In the following 10 minutes, parents practiced the new concepts while the therapist coached them as needed. Coaching practices, and the interactive strategies used by the therapist throughout the session were based on the work of Hanft, Rush, and Sheldon (2004). The next 10 minutes involved another parent practice with coaching using a different type of activity to support parent generalization at home. The final 10 minutes addressed any remaining parent interest or question and ended with an action plan of daily times and activities when parents felt they could embed the targeted topics and facilitate child learning within home routines.

A measure of therapist fidelity of administration of the P-ESDM was developed *a priori* to assess adherence to the intervention style (i.e., the adapted Hanft coaching process) and session structure described above. Therapists from all sites were required to achieve fidelity with the second author across three consecutive coaching sessions before working independently with families and were thereafter monitored on a quarterly basis through random selection of one videotaped session by the second author. Therapists were expected to demonstrate 85% or higher fidelity on all domains, as assessed by Likert-based scores (1-4) . If fidelity fell below 85%, supervision was provided through live and videotaped observation of subsequent sessions until all areas of fidelity area(s) were again rated at a level of competent practice (i.e., "3" or higher) over two consecutive sessions.

Measures

Parenting Stress—The Questionnaire on Resources and Stress (QRS; Konstantareas, Homatidis, & Plowright, 1992) is a self-report questionnaire containing 78 items that measure stress and burden of care in families of children with disabilities. Parents rate their agreement or disagreement with questions that relate to parental feelings about their child (e.g., “I worry about what will happen to N when I can no longer take care of him/her.” “I have difficulty leaving the house because of N.”). Parents provide responses on a 4-point Likert scale (strongly agree to strongly disagree) with high scores representing higher parenting-related stress. The QRS was shown to have adequate reliability (internal consistency alpha from .394-.854; split-half reliability $r = .85$ and $.89$; stability $r = .80$) and construct and concurrent validity and the QRS scores correlate significantly with CARS symptom-related stress scores ($r = .62$ and $.67$; Konstantareas et al., 1992). Parenting Stress scores for parents of young children with ASD aged 3-4 years have been previously reported and were comparable with that of the Konstantareas et al., 1992, suggesting that the scale can be used with parents of younger children (e.g., Estes et al., 2009). This study used the Parenting Stress score in which all score are added and then divided by the number of items for a scale ranging from 1 to 4 to measure parenting-related stress.

Caregiver Sense of Competence—The Parent Sense of Competence Scale (PSOC; Johnston & Mash, 1989) is a 16-item parent self-report questionnaire designed to measure the degree to which parents feel competent and confident in parenting their children (i.e., efficacy) and the quality of affect associated with parenting (i.e., satisfaction). Items are rated on a 6-point Likert scale with high scores representing high degrees of satisfaction and efficacy. The Satisfaction subscale reflects parenting frustration, anxiety, and motivation, whereas the Efficacy assesses capability, problem-solving ability, and competence. Prior research has shown strong correlations between these subscales and parent-child well being, as well as parenting style (Rogers & Matthews, 2004) with internal consistency alpha coefficients of 0.75 for the Satisfaction factor and 0.76 for the Efficacy factor (Johnston & Mash, 1989).

Child characteristics—The Mullen Scales of Early Learning (Mullen; Mullen, 1997) is a standardized measure used to assess the developmental level of children from birth to 68 months. The Mullen assesses skills and abilities in five areas: gross motor, visual reception, fine motor, receptive language, and expressive language. This measure also yields a composite score reflecting overall cognitive ability with a mean of 100 and standard deviation of 15. Norms were derived from a sample of 1,849 children ranging in age from 2 days to 69 months (Mullen, 1997). The internal reliability of the Mullen composite score has a median split-half internal consistency coefficient of .91, and the median values range between .75 to .83 for the Mullen subscales (Mullen, 1997). Prior research has also shown that the Mullen has good convergent validity with the Differential Ability Scales (DAS; Elliott, 1990) in both children with and without a diagnosis of ASD (Bishop, Guthrie, Coffing, Lord, 2011).

The Autism Diagnostic Observation Scale- Toddler Version (ADOS-T; Luyster et al., 2009) is a standardized, 45-minute, semi-structured play observation used to diagnose autism spectrum disorders in children under age 30 months. It assesses communication, social interaction, and imaginative play skills and provides opportunities for a range of social initiations and responses. Behavior ratings on a scale of 0-3 are used to rate a series of examiner-initiated presses and observations made throughout the assessment session. The scores are added to provide the diagnostic algorithm score. High scores represent a higher degree of ASD-related symptomatology. Cutoff scores differ depend upon whether children are verbal or nonverbal. A nonverbal cutoff score of 12 and a verbal cutoff score of 10 was

used to qualify children for this study (see Luyster et al, 2009 for details regarding the algorithm score). A modification of the diagnostic algorithms was constructed, called the ADOS Modified Social Affect scale, as a measure of social functioning. It consisted of all the items common to the verbal and nonverbal algorithms to document child progress in social-communication across time. The ADOS-T was normed on 182 children across 360 evaluations. Internal consistency (Chronbach's alpha) for Social Affect algorithms was .88 for nonverbal children and .90 for verbal children.

Family characteristics—The CHARGE family characteristics questionnaire (Hertz-Picciotto et al, 2006) was used to obtain family income, primary caregiver's age and education, number of siblings, and number of siblings with a disability. This is a general demographic questionnaire concerning family composition and size, annual gross incomes, and parents' educational levels and occupations that was obtained through interview at the time of enrollment.

The Life Experiences Survey (LES; Sarason, Johnson, & Siegal, 1978), a 57-item self-report measure that asks respondents to indicate and rate significant positive and negative events they have experienced during the preceding 12 months from a list of 47 common events. The Negative Life Changes scale portion of LES was used to compute negative life events. This score is derived by adding the impact ratings of all negative events. Test-retest reliability of the LES negative events is good (.56 - .88) and the authors reported moderate to strong correlations between the Negative Life Changes score and depression, anxiety and maladaptive responses in research participants (Sarason et al., 1978).

Intervention hours—The Intervention History Form (originally described in Dawson et al., 2010) was used to obtain the hours per week of intervention for each child in both the ESDM and the Community group. This form tracks the type of intervention, hours provided, dates of service, hours per week, and adult to child ratio to measure the intensity of intervention received, for each participant. For this study, individual intervention hours were calculated as described in Rogers et al., 2012. For the P-ESDM group, intervention hours include the intervention received as part of this study as well as other intervention received from the community.

Statistical Analysis

The outcomes investigated in this analysis were based on primary caregiver scores on the PSOC and QRS. Because the sample size differed, two data sets, one for the PSOC and one for the QRS, were created to utilize the full number of cases with data on each measure. The first data set consisted of the primary caregivers who had completed the PSOC at both baseline (visit 1) and outcome (visit 2; $n = 82$, ESDM = 44, Community = 38). The second data set consisted of primary caregivers who had completed the QRS at visit 1 and visit 2 ($n = 76$, ESDM = 39, Community = 37). The same caregiver was required to have completed both visit 1 and visit 2 assessments for inclusion in these analyses. Demographic characteristics for each group were calculated as count and percent for discrete variables and mean and standard deviation for continuous variables in both data sets.

General linear regression was used to compare outcome differences at time 2 between the treatment groups. To assess change in PSOC Total and Parenting Stress scores, the score (PSOC Total or Parenting Stress) measured at visit 2 was considered the outcome or dependent variable with the corresponding baseline score included as an independent variable. Thus, the adjusted models included the outcome measure at baseline and any characteristics that differed significantly between the treatment groups at baseline ($p < .05$). Parent intervention group (P-ESDM, Community) was considered the main effect in these

analyses. Effect size was calculated as a standard difference of the mean for change in PSOC Total and Parenting Stress during the intervention period. We conducted *post hoc* analyses to evaluate the role of intervention hours on PSOC Total and Parenting Stress, adjusted for baseline PSOC Total or Parenting Stress scores.

We next investigated general prediction models of PSOC Total and Parenting Stress. Potential predictors in the models were identified *a priori* and included child factors (child's baseline age (months), baseline Mullen Non-verbal composite, baseline ADOS Modified Social Affect) and family factors (number of siblings, number of siblings with any delay or disability, hours of intervention per week, number of negative life events, primary caregiver's age (<32 years old, 32 – 37 years old, and 38+ years old), primary caregiver's education (High School, College Degree, and Graduate School), family income (Less than \$50,000, \$50,000 - 99,999, and \$100,000 or greater)). A backward, stepwise regression with a p-value cut-point of 0.1 was performed for each outcome beginning with a model including the predictors listed above. In all analyses, primary caregiver's age and education and family income were treated as categorical variables. Analyses were performed using STATA version 11 (StataCorp, College Station, Tex).

Results

Baseline demographic characteristics

Among the parents with PSOC measures at both visits, the children in each treatment group did not significantly differ in terms of gender, age, ethnicity, baseline ADOS Modified Social Affect score, Mullen Nonverbal Composite, or Mullen Early Learning Composite (ELC; Table 1). Parents in the two intervention groups did not significantly differ in term of age or education level, income, number of children in the family or the number of negative life events. There were significant differences by treatment group in the average amount of individual intervention received. Children in the Community group received almost twice as many hours per week of intervention than the P-ESDM group (P-ESDM Mean = 2.6 hrs/wk, Community Mean = 4.8 hrs/wk, p-value=0.02) calculated for those completing both visits of the PSOC (larger of the two sample sizes). Because intervention hours were accumulated over the course of the study and did not differ at baseline, this variable was not adjusted for in our primary ESDM evaluation models.

Baseline demographic characteristics were similar for those with QRS measured at both visit 1 and visit 2 (data not shown) as for those who completed the PSOC at both visits. Within the QRS dataset, there were baseline differences between the intervention groups on ADOS Modified Social Affect scores (P-ESDM Mean = 29.0, Community Mean = 34.0, p-value=0.008). Thus, the ADOS Modified Social Affect scores were included as covariates in QRS models. For those who completed the QRS at both visits, the Community group also had more hours per week of individual intervention treatment than the P-ESDM group (P-ESDM Mean = 1.6 hrs/wk, Community Mean = 4.5 hrs/wk, p-value<0.001).

Intervention group differences in parenting stress and parent sense of competence

Changes in PSOC Total and subscales and Parenting Stress scores from baseline (visit 1) to follow up (visit 2) are shown in Table 2. After adjusting for baseline PSOC Total scores, there were no significant differences in PSOC Total scores between the P-ESDM and Community groups. After accounting for baseline Parenting Stress scores and ADOS Modified Social Affect scores, Parenting Stress scores in the P-ESDM group were significantly lower than in the Community group ($\beta = -0.14$, 95% CI = $-0.27 - -0.02$, $p = 0.04$).

Impact of intervention hours on parent sense of competence and parenting stress

We next evaluated the impact of intervention hours that accrued during the 3-month study period. Although the Community group received more intervention hours than the P-ESDM group over the three month study period, the number of intervention hours did not have an effect on parent sense of competence or parenting stress (see Table 3).

General prediction model of parenting stress and parent sense of competence

To identify variables that predict parent sense of competence and parenting stress in parents of young children with ASD more generally, we combined the two intervention groups and conducted a backward stepwise regression. This statistical method is appropriate for variables that may have high collinearity in that all variables are assessed simultaneously and those accounting for the greatest amount of variability among correlated variables remain in the model. Additionally, this method is robust to a large number of initial predictors (VanBelle et al., 2004). Potential predictors considered for inclusion in the (1) PSOC and (2) Parenting Stress models included family factors (primary caregiver's age, family income, primary caregiver's level of education, number of siblings, number of siblings with any disability, number of hours per week of intervention, number of negative life events) and child characteristics (baseline age, baseline Mullen Nonverbal IQ, baseline ADOS modified social total). Negative life events were associated with significantly reduced parent sense of competence with an average decrease of 0.67 (95% CI: 0.05 - 1.29, $p = 0.035$) in the PSOC Total score for every additional negative life event. An association of borderline significance ($p=0.059$) was found between age and PSOC Total score. Number of negative life events was also significantly associated with increased parenting stress with an increase in Parenting Stress score of 0.05 (95% CI: 0.02 - 0.07, $p < 0.001$) for each additional negative life event. Total R^2 in these regression models ranged from 0.057 for PSOC Total model to 0.165 for the Parenting Stress model. The effect of negative life events had the highest impact in the Parenting Stress model based on both the level of significance ($p < 0.001$) and the strength of the association ($R^2 = 0.165$).

Intervention group differences in parenting stress and parent sense of competence with negative life events

Due to the effect of negative life events on the study outcomes in the stepwise regression, we re-ran models evaluating the P-ESDM group compared with Community group adjusting for this variable. Results were consistent with the model shown in Table 2. Parenting stress was lower in the P-ESDM group compared with the Community group even after accounting for negative life events ($p=0.03$).

Discussion

In this study, caregivers of very young children newly diagnosed with ASD who participated in three months of P-ESDM parent coaching reported lower parenting stress than caregivers receiving community intervention as usual. Caregivers in the P-ESDM group reported no increase in parenting stress, whereas caregivers who obtained community intervention experienced increased levels of parenting stress over the same time period. These results held true even when controlling for baseline child scores on the ADOS Social Affect scale and initial level of parenting stress. Parent sense of competence did not differ between the groups over the same time period. Post-hoc analyses indicated the number of intervention hours had no significant relationship to parenting stress or parent sense of competence. Negative life events were significantly associated with reduced parent sense of competence and increased parenting stress for both intervention groups. However, post-hoc analyses demonstrated that even when accounting for negative life events, the P-ESDM group

continued to demonstrate significantly lower parenting stress than the Community group after 3 months of intervention.

The finding that the P-ESDM group demonstrated lower levels of parenting stress compared to the Community group is consistent with previous studies. One randomized trial of didactic parent discussion and general counseling compared to interactive training in behavior management for parents of 2.5-5 year-old children with ASD found that parents in both groups improved in overall mental health post-intervention and at a six-month follow-up but the parent training group showed a greater reduction in anxiety, insomnia, somatic symptoms and family dysfunction at follow-up (Tonge et al., 2006). We conducted *post hoc* analyses to investigate whether intervention hours contributed to observed group differences. Although the number of intervention hours was greater for the Community group, this did not relate to parenting stress. This suggests the possibility that some other characteristics of the P-ESDM or of community intervention practices may have been related to the observed differences in parenting stress at outcome. One possibility, consistent with previous research, is the collaborative coaching process used in the P-ESDM. Training programs that collaborate with parents to teach strategies easily adopted in naturalistic, daily activities have been shown to result in decreased levels of parent stress (Feldman & Werner, 2002; Koegel, Bimbela, & Schreibman, 1996; Brookman-Frazee, 2004). The P-ESDM model puts parents front and center, working with their child and receiving coaching and support throughout each treatment hour. Therapists spent less than 10 minutes interacting directly with the child, while parents spent 30-40 minutes in direct intervention. Thus, approaches that emphasize collaborative coaching strategies to support and encourage active parental participation may have a positive impact on parents' well-being.

A second possible mechanism is the presence of a generalist primary provider, through whom all interventions are occurring. The generalist model is an important part of ESDM because it allows parents to receive all their input from one other person, rather than having to work with various members of a team, each of whom focuses on their own discipline, and each of whom provides recommendations that are not integrated with the other therapists. This leaves parents having to decide what to do and whose advice to follow. A third possible mechanism is a clear "curriculum" for parents, which is built to provide them with the concepts and skills needed to generate their parenting approaches and problem solving skills. In P-ESDM, parents developed and practiced specific skills with the therapists and then took those routines home to use in daily activities; parents knew what to do and how to do it.

It is important to note that parents receiving weekly ESDM coaching for three months did not differ in their sense of competence compared to the Community group. Thus, we did not find full support for our main hypothesis, that the P-ESDM would also improve parenting sense of competence compared with community intervention as usual. It is possible that P-ESDM does not improve parental sense of competence. However, lack of effects on this variable may also reflect a weakness in the study design - the short time frame over which the intervention was delivered. The short time frame was chosen to examine the effects of a brief intervention occurring directly after diagnosis. However, full benefit of parent implemented interventions may be cumulative and longer term intervention might have made a more significant impact. Whether longer-term P-ESDM parent coaching can facilitate greater change in parents' sense of competence is currently being examined in Phase 2 of our randomized controlled trial. Our approach was also limited to center-based coaching sessions. Providing in-home parent coaching may have helped parents feel more competent and successful, and would be consistent with federal guidelines for early intervention in the United States. It is possible that the comparable sense of competence in the two groups at outcome was due to community intervention providers utilizing strategies

that contributed to parent feelings of competence. However, it was beyond the scope of this study to directly assess specific strategies used in community intervention sessions. An alternative research design would be to directly compare two evidence-based intervention approaches so the type of intervention for all participants would be controlled. Further, comparing the same level of intensity of parent-delivered intervention with therapist-delivered intervention using the same treatment model would allow examination of the effect of parent-delivered intervention. Reliance on parent self-report of perceived levels of parenting-related stress and sense of competence is unavoidable, but has the limitation of the ratings being unblind to intervention group. Thus, future studies may want to incorporate physiological measures, such as cortisol levels, to obtain validation and extension of self-report measures.

The P-ESDM may also have been limited by the focus on child-behavior to the exclusion of broader family factors. We found that the number of negative life events reported by parents was a significant predictor of parenting stress and sense of competence among this group of caregivers, both P-ESDM and Community groups combined. This suggests a potential need to address family context to better support the emotional well-being of parents in addition to addressing children's direct symptoms. Number of intervention hours was not related to parenting stress or parent sense of competence in this study. In contrast, in this same sample, more hours of intervention was associated with greater gains on most behaviors we assessed in the children (Rogers et al., 2012). Parents in the Community group sought out more intervention hours than parents of children randomly assigned to the P-ESDM group. Although the models statistically controlled for number of intervention hours, it is important to consider that the increased parenting stress reported in the Community group may be due to unmeasured factors associated with the quality of intervention hours received by the children. Despite the promise of early autism intervention for improving child outcomes, at times parents may perceive intervention as overly demanding with respect to the therapy schedule, cost, and other factors (Stahmer & Gist, 2001). Thus this study, and most prior studies that use community intervention comparison groups, was not able to describe or identify possible specific components of community intervention that may be important contributors to parenting stress and sense of competence. The challenge of measuring the great variety of interventions provided in the community and characterizing their quality and intensity with a metric that can be easily interpreted and analyzed is critical for future studies. Future innovations are needed to address this gap in the field. Additionally, because this sample excluded young children with developmental quotients under 30, these results may not generalize to parents of the most severely impaired children.

It should also be noted that while a statistically significant difference was found in parenting stress over the 12-weeks of the study, i.e. no change (0.00) for the P-ESDM intervention group and an increase of 0.11 for the community controls, interpreting the clinical significance is less straightforward. The range of the Parenting Stress score across both visits was between 1.30 – 3.05, with small standard deviations (< 0.4) thus accounting for the calculated p-value and suggesting that even small changes may have important implications for parents. Our results are similar to those obtained utilizing the QRS in a different sample of parents (Estes et al., 2012). Estes et al. (2012) reported parents of 18- to 30-month-old toddlers with ASD show significantly increased parenting-related stress as compared with parents of an age-matched group of typically developing toddlers. Furthermore, the level of parenting-related stress reported by parents of children with ASD in this current study are very close to those reported in Estes et al., 2012. However, more work is needed to determine the level of change on this instrument that is meaningful from a clinical perspective and to investigate changes that might occur in parenting-related stress over time.

This study contributes to and clarifies the existing research literature in several ways. First, the use of a randomized design allowed conclusions regarding the impact of P-ESDM parent coaching versus community intervention to be made. The comparison group of caregivers was well matched in terms of key child-variables, developmental age, and chronological age. All children were directly assessed and qualified for the study using standardized measures by highly trained clinicians, naïve to intervention status with high levels of reliability between sites. This study also utilized a longitudinal design which allowed inferences regarding whether family and child factors may be causally related to parenting stress and sense of competence. Because both groups were assessed at the same time points, the impact of developmental changes and very early identification were consistent for both groups. Thus, stronger conclusions are able to be drawn from this study than have been able to be addressed in prior research. This study also investigated a fairly comprehensive model of factors that may impact parenting stress and sense of competence, including family factors (primary caregiver's age, family income, primary caregiver's education, number of siblings, number of siblings with any disability, and number of negative life events) and child characteristics (baseline age, baseline cognitive ability, baseline social ability, and number of hours per week of individual intervention.) This provided important information about salient factors impacting parenting stress and sense of competence for this group of parents of very young children with ASD.

Investigation of parenting stress and sense of competence in the context of early ASD intervention is in the beginning stages. Current research indicates that a large majority of children demonstrate developmental acceleration in high quality, intensive, early intervention for ASD (e.g., Dawson et al., 2010; Smith et al, 2003). Future studies should address the potential relationship between change in child symptoms severity and parental stress and sense of competence. It is also important to study the impact of intensive, therapist-delivered models of early intervention, as compared to short-term parent coaching models, on parenting stress and sense of competence. Intervention delivered by teams of paraprofessionals for 20 hours per week or more is likely to have a different impact on parents than the parent coaching model investigated in this study. And more generally, the first three months after an initial diagnosis is an important time for parents to process, grieve, and decide their course of action. It may be a unique time that is not representative of later parental experience, after the initial adjustment to a new diagnosis is made and intervention has been initiated. Later developmental transitions, such as school entry, may also be associated with positive or negative changes in parenting stress and sense of competence. These questions require longitudinal outcome studies. This sample included a large percentage of highly educated parents. Future studies are needed that include a wider range of socio-economic groups. The current results may not generalize to less educated or lower resource families. Finally, mothers were most often the primary caregivers in both the P-ESDM and Community groups. The effects of parent coaching on secondary caregivers, particularly fathers, were not examined in this study. Fathers of children with ASD have reported that the biggest impact on their lives comes from the indirect effect of their spouse's stress, rather than the impact of the disability itself (Gray, 2003). The benefit of parent coaching for fathers' coping skills and stress management is an important area for future research.

This randomized, controlled trial provides a first step toward understanding whether the content and process of the P-ESDM may enable caregivers to deliver intervention at home to their very young children with ASD while demonstrating lower stress levels than parents receiving community intervention. Caregivers raising children with ASD are at greater risk for experiencing stress, depression, feelings of isolation, and lack of confidence regarding how to help their children learn. They are in need of both informational and emotional support and further efforts are needed to continue to improve the ability of early autism

intervention programs to support parents, reduce parenting-related stress and increase parent sense of competence. Our study suggests that with further development, such as increasing the number of hours per week of coaching, enhancing the coaching approach with innovations from the science of adult intervention, and extending the timeline of the intervention, the P-ESDM holds promise as an approach to support well-being of caregivers and improve outcomes for their children with ASD.

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Table 1

Baseline demographic characteristics for P-ESDM and Community groups in participants who completed all PSOC measures (N=82).

Variable	P-ESDM		Community		Test statistic	p-value/Cohen's d
	N	%	N	%		
CHILD	N	%	N	%	χ^2	
Gender (Male)	32	72.7	30	78.9	0.36	ns
	N	Mean (SD)	N	Mean (SD)	t-test	
Age in months	44	21.1 (3.43)	38	20.9 (3.43)	t=-0.42	ns
Under 21 months	16	36.4	17	44.7	$\chi^2=0.59$	ns
20 months or older	28	63.6	21	55.3		
Race						
White	30	68.2	30	78.9	$\chi^2=0.96$	ns
Black	2	4.5	0	0.0		
Asian	5	11.4	3	7.9		
Mixed	7	15.9	5	13.2		
Hispanic	7	15.9	8	21.1		
ADOS: Modified Social Affect Total	44	29.3 (9.45)	38	33.2 (8.18)	t=1.93	ns
Mullen DQ	44	64.8 (17.50)	38	64.3 (15.9)	t=-0.13	ns
37-60	20	45.5	17	44.7	$\chi^2=.004$	ns
> 60	24	54.5	21	55.3		
Mullen Nonverbal Composite	44	80.9 (16.12)	38	81.6 (13.87)	t=0.37	ns
Mullen Early Learning Composite	44	65.5 (14.95)	38	64.9 (13.01)	t=-0.06	ns
PARENT	N	%	N	%	χ^2	
Primary caregiver						
Mother	42	95.5	35	92.1	0.43	ns
Father	2	4.5	3	7.9		
Clinic						
UCD	16	36.4	16	42.1	0.24	ns
UM	10	22.7	7	18.4		
UW	18	40.9	15	39.5		
Primary caregiver's education						
High School	12	27.3	15	39.5	4.54	ns
College Degree	16	36.4	17	44.7		
Graduate School	14	31.8	5	13.2		
Family Income						
less than \$50,000	7	15.9	12	31.6	4.50	ns
\$50,000-\$99,999	18	40.9	17	44.7		
\$100,000 or more	19	43.2	9	23.7		
	N	Mean (SD)	N	Mean (SD)	t-test	
Primary caregiver's age	32	34.1 (5.15)	25	33.5 (5.43)	t=-0.43	ns
Number of Siblings	44	1.1(1.01)	38	1.0 (1.13)	t=-0.37	ns

Variable	P-ESDM		Community		Test statistic	p-value/Cohen's d
	N=44		N=38			
Siblings with any delay or disability	44	0.4(0.62)	38	0.3 (0.71)	t=-0.55	ns
LES # Negative Events	42	3.1 (2.66)	37	3.5 (3.54)	t=0.53	ns
PSOC total score (Satisfaction + Efficacy)	44	72.9 (11.90)	38	67.3 (13.81)	t=-1.98	ns
QRS Modified Total Parenting Stress	39	2.1 (0.36)	37	2.1 (0.39)	t=0.49	ns

Table 2

Primary caregiver's sense of competence and parenting-related stress by intervention group

Measures	ESDM		Community		Coefficient (B)	95% Confidence Interval	
	N	Mean (SD)	N	Mean (SD)			
PSOC Satisfaction scale[†]							
Visit 1	4	42.5 (6.55)	3	37.7 (9.19)	2.01	-0.44	4.62
Visit 2	4	40.8 (6.37)	8	35.9 (7.88)			
PSOC Efficacy scale[†]							
Visit 1	4	30.4 (7.17)	3	29.6 (6.09)	0.05	-1.47	1.89
Visit 2	4	30.4 (6.73)	8	29.7 (5.28)			
PSOC Total score (satisfaction + efficacy)[†]							
Visit 1	4	72.9 (11.90)	3	67.3 (13.81)	2.02	-1.36	5.92
Visit 2	4	71.2 (10.86)	8	65.6 (11.47)			
QRS Total Parenting Stress^{††}							
Visit 1	3	2.06 (0.36)	3	2.06 (0.39)	-0.14*	-0.27	-0.02
Visit 2	9	2.10 (0.29)	7	2.21 (0.40)			

* p<0.05

[†] PSOC regression models adjusted for baseline PSOC score.^{††} QRS regression model adjusted for baseline QRS score and ADOS modified social score

Table 3

Linear regression testing the association between PSOC and QRS scores with intervention hours accrued during the study period.

Adjusted Visit 2	N	β	Intervention Hours (hrs/wk) ^c			R-squared
			95% Confidence Interval	P-value		
PSOC Satisfaction scale ^a	82	-0.09	-0.36	0.18	0.50	0.518
PSOC Efficacy scale	82	-0.01	-0.20	0.18	0.90	0.635
PSOC total score (satisfaction + efficacy)	82	-0.10	-0.49	0.30	0.62	0.564
QRS Modified Total Parenting Stress ^b	76	0.001	-0.02	0.02	0.97	0.364

^a PSOC regression models adjusted for baseline PSOC score

^b QRS regression model adjusted for baseline QRS and ADOS Modified Social score

^c Intervention hours accrued during the 3-month study period (Visit 1 through Visit 2)

Table 4

General prediction model of parenting stress and parent sense of competence across both intervention groups combined

	Coefficient	95% Confidence Interval		P-value	R-squared
PSOC Total score (Satisfaction + Efficacy)					
Baseline Age (months)	-0.66	-1.355	0.026	0.059	0.057
LES # Negative Events	-0.67	-1.289	-0.048	0.035	
QRS Modified Total Parenting Stress					
LES # Negative Events	0.05	0.023	0.068	<0.001	0.165

Note: Variables entered in the backward stepwise regression: family factors (primary caregiver's age, family income, primary caregiver's education, number of siblings, number of siblings with any disability, number of intervention hours, and number of negative life events) and child characteristics (baseline age, baseline Mullen Nonverbal IQ, baseline ADOS modified social total)