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The effect of early autism intervention on parental sense of efficacy in a randomized trial depends on the initial level of parent stress

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Early intervention aims to improve outcomes for children with autism spectrum disorder (ASD); however, it may also have secondary effects on parents. Specifically, the impact of child-focused, intensive ASD intervention on parental sense of efficacy is currently unknown. Parental sense of efficacy, the degree to which parents feel competent and confident in parenting their children, may be lower in parents of children with ASD compared to typical development (Rodrigue, Morgan, & Geffken, 1990; Jones & Prinz, 2005). Lower sense of efficacy has been shown to relate to increased anxiety, depression and feelings of guilt in parents of children with ASD (Hasting & Brown, 2002; Kuhn & Carter, 2006). Home-based intervention has the potential to improve parent sense of efficacy through providing increased support. However, it could also decrease parent sense of efficacy by increasing demands on parents depending upon such factors as the number of home visits per week (intensity) and the type of parent involvement required (style).

It is important to understand the impact of intervention on parents because parents are central to addressing the developmental needs of young children with ASD. Parents are often the first to identify emerging signs of ASD, driving the diagnostic process and expediting or even implementing intervention (Vismara, Colombi, Rogers, 2009; Edwards, Brebner, McCormack, MacDougall, 2018). The role parents play in families of children with developmental disabilities can be understood in the larger context of *family adaptive functioning*. Family adaptive functioning refers to the many activities families engage in to support positive outcomes for children with ASD (e.g., family-orchestrated child experiences, parent–child interaction, child health and safety functions; Guralnick, 1997). A parent's level of stress and sense of efficacy is likely related to how effectively they can

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perform adaptive functions, including how well they are able to engage with their children and facilitate effective intervention for their child with ASD (Estes, Swain, MacDuffie, 2019). Parents experience secondary effects of children's interventions due to factors like increased financial burden, time and scheduling demands, effects on other family members, and the need to master new concepts and skills. Thus, parents are both impacted by and have an impact on ASD interventions for their child in this transactional process. Increased understanding of the secondary effects of child-focused ASD intervention on parents has the potential to lead to improved interventions and intervention outcomes through a cascade of positive effects on parents, families, and ultimately, young children with ASD.

Most research to date has focused on the secondary effects of low-intensity *parent-implemented* interventions on parents (also referred to as parent coaching; for review see Estes, Swain, MacDuffie, 2019). For example, in a randomized trial of parent-implemented Early Start Denver Model (ESDM) compared with community intervention as usual for 12-to-24-month-old children with ASD, the community intervention-as-usual parent group experienced a greater increase in stress than the parent-implemented ESDM group over the same 3-month period; however, parental sense of competence did not differ between groups (Estes, Vismara, Mercado, Fitzpatrick et al., 2014). Twelve monthly parent-coaching sessions using Play and Language for Autistic Youngsters (PLAY) were associated with improved parent-child interaction without increasing parental stress or depression compared with usual community services (Solomon et al., 2014). And a 10-week, targeted, parent-mediated Joint Attention, Symbolic Play, Engagement and Regulation (JASPER) intervention increased parent-child joint engagement and reduced parenting stress compared with a psychoeducational intervention for parents (Kasari et al., 2015). A recent review and meta-analysis of the secondary effects on parent stress and efficacy of behavioral parent training to improve challenging behaviors in children with ASD found a small effect on parent stress and no significant effect on parental efficacy; however, when an outlying trial (Whittingham et al., 2009, Stepping Stones Triple P Positive Parenting Program) was removed, a significant effect on parental efficacy was found (Tarver et al., 2019). Thus, low-intensity, short-term parent-implemented interventions may have small secondary, positive effects on parents (Siller & Morgan, 2018; Nevill, Lecavalier, & Stratis, 2018).

Comprehensive, intensive, behavioral intervention delivered by trained clinicians is recommended as an efficacious approach with the greatest empirical support for improving outcomes for young children with ASD (e.g., National Standards Project, 2015; Reichow, 2012); however, the impact of this type of intervention on parents is not yet well understood. Comprehensive early intervention for toddlers and preschoolers with ASD delivered in the home by therapists requires a high level of parental engagement, time, and resources. We are not aware of any randomized trials that have evaluated the secondary effects of high intensity, comprehensive, autism intervention on parents. However, survey data and non-randomized trials provide preliminary evidence of a relationship between the number of hours of comprehensive intervention (intensity) and parent experiences; parents of young children with ASD may experience less stress and less depression when their children receive more hours of intervention (Osborne, McHugh, Saunders, & Reed, 2008; Schwichtenberg & Poehlmann, 2007). A non-randomized study explored parental sense of efficacy in the context of an ABA program for children with ASD and found that

parental stress, child symptom severity, and level of program support was related to parental sense of efficacy (Hastings & Symes, 2002). Given that comprehensive interventions range from approaches that have systematic, curriculum-based roles for parents as part of the intervention to interventions that have no formalized role for parents, there may be significant effects of these style differences on parent efficacy. However, we are aware of no studies to evaluate the effect of intervention style on parent efficacy.

Evaluating the nature of the relationship between child-focused intervention and parent outcomes is complicated by the fact that pre-intervention parent characteristics might influence how a parent responds to different intensities and styles of intervention. Parent stress levels may influence whether daily staff visits or parent coaching sessions are experienced as supportive or as intrusive, for example. These differing experiences may in turn influence a parent's sense of efficacy. A parent who feels taxed or overwhelmed by their child's intervention, by therapy team visits in which "experts" take the lead in intervention, or by coaching sessions in which feedback is given to improve parenting approaches, might end up feeling less confident in their abilities (i.e., a lower sense of efficacy) over time. We know parents of young children with ASD as a group have higher levels of stress (Estes et al., 2009; 2013), but does the initial level of parent stress moderate the effects of intervention intensity and style on parent sense of efficacy?

We examined whether the style of comprehensive, intensive, therapist-delivered intervention (Early Intensive Behavioral Intervention/EIBI vs Early Start Denver Model/ESDM) or treatment intensity (15 vs 25 hours per week) had an effect on parental sense of efficacy and whether these effects varied by baseline level of parenting-related stress. Our exploratory hypothesis was that parents would respond differently to different treatment intensities and treatment styles based on pre-intervention stress levels.

Methods

Participants

We randomized 87 children (21 female, 66 male) age 13 to 30 months (Mean 22.9; SD 4.0) in a multi-site, randomized controlled trial (Intervention Effects of Intensity and Delivery Style for Toddlers With Autism: https://clinicaltrials.gov/; NCT02272192) with an independent data coordinating center (University of California, Los Angeles, Semel Institute). Children, recruited for this study from a wide range of community organizations, pediatricians, and autism clinics, participated in one of four conditions: 15 versus 25 hours of treatment crossed with EIBI versus ESDM (see Figure 1 and further description below). Children were treated at home daily for 12 months by members of highly-trained, supervised, multidisciplinary intervention teams at three sites across the United States (University of California, Davis; University of Washington, Vanderbilt University). The data included in this report were collected between April, 2013 and January, 2018. The larger study was designed to evaluate the effect of treatment styles and treatment intensity levels on child developmental outcomes (Rogers, Yoder, Estes, Warren et al., 2020; Yoder, Rogers, Estes, Warren et al, 2020); the impact of intervention on parent efficacy was not a primary outcome of this trial. The parent stress and efficacy measures were adjuncts to the larger trial to allow investigation of the secondary effects of comprehensive, child-focused interventions

on parents, expanding upon our previous work (e.g., Estes, Munson, Dawson, Koehler et al., 2009; Estes, Olson, Sullivan, Greenson et al., 2013; Estes, Vismara, Mercado, Fitzpatrick et al., 2014).

Participants were included if they: (a) had chronological age of 13 to 30 months at study entry, (b) were ambulatory without primary motor impairments affecting hand use, (c) met ASD diagnostic criteria according to the DSM-5, (d) had an overall developmental quotient of at least 35 on the Mullen Scales of Early Learning (MSEL; Mullen, 1995), (e) had English as a primary language (i.e., English reportedly spoken at least 60% of the time at home), and (f) had hearing and visual acuity within normal limits per screening. Prior to enrollment, all participants were evaluated and met DSM-5 criteria for ASD (American Psychiatric Association, 2013) by direct assessment and data review according to the clinical opinion of two independent study staff (one a licensed psychologist) using all available information including scores from the MSEL, record review, and data from the Autism Diagnostic Observation Schedule for Toddlers (Luyster et al., 2009). Participants were included regardless of the presence of genetic disorders or other health conditions. See Table 1 for additional participant characteristics.

Of the 87 families enrolled in the larger trial, 1 did not complete the Questionnaire on Resources and Stress (QRS; Konstantareas, Homatidis, & Plowright, 1992) at baseline (25-hr/EIBI group) and 1 (25-hr/EIBI group) did not complete either the QRS or the Parent Sense of Competence (PSOC; Johnston & Mash, 1989) questionnaire at baseline and the end of treatment, twelve months later. Thus, a total of 85 families completed questionnaires at both time points. Attrition information from the larger trial in CONSORT format is available in Rogers et al., 2020.

Written parental/guardian informed consent was obtained, as approved by the Institutional Review Board at each site for each participant. Community members were not involved in the study design.

Procedures

Research participants completed phone interviews to obtain initial screening and demographic information. Those who passed screening participated in a structured diagnostic evaluation through the research project. Participants who met inclusion criteria were randomized at the data coordinating center to one of four conditions that varied by intervention intensity and intervention style; 15 vs 25 hours per week crossed with Early Intensive Behavioral Intervention (EIBI) or Early Start Denver Model (ESDM). The parent-child dyads were randomly assigned using an adaptive urn model (Wei, 1978) to one of the four treatment groups using a computer program that equalized groups for age (less than or greater than/equal to 21 months) and developmental quotient (MSEL DQ score less than or greater than/equal to 60). Children were treated at home daily for 12 months by highly trained, supervised, members of multidisciplinary intervention teams at the three University sites across the United States. The 15-hour-per week groups were offered 3 hours of intervention per weekday; the 25-hour-per-week groups were offered 5 hours of intervention per week day. Due to holidays, illnesses, weather events, and other scheduling conflicts, families in the 15-hour groups received, on average, 12.42 hours per week (SD =

1.45), and families in the 25-hour groups received, on average, 20.82 hours per week (SD = 1.40).

The ESDM intervention is based on an evidence-based approach for stimulating developmental growth in young children with ASD in multiple domains (Dawson et al., 2010). The ESDM integrates developmental and behavioral intervention strategies focused on child learning with child-preferred materials and ample child choice in everyday activities, delivered within an affectively warm teaching environment to foster positive relationships between children and their social partners. It emphasizes the social function of language and the development of social attention, dyadic engagement, nonverbal communication, play, and imitation as foundations for verbal language. Relevant to this study, the comprehensive ESDM model was not only therapist-delivered; there was a parent-implemented component in which the lead therapist met with a parent of each child twice monthly to review topics from the parent coaching curriculum, engage in ESDM practice with the parent-child dyad, and coach the parent to integrate new skills into daily routines. The ESDM-group parents were taught the interactive principles associated with ESDM, such as gaining child attention, principles of behavior change, encouraging child vocalization and gesture use, and using strategies within the daily routines, activities, and familiar home interaction patterns (Rogers et al., 2012; Rogers, Dawson, Vismara, 2012; Rogers & Dawson, 2010).

The intensive behavioral intervention (EIBI) approach was based on the model described by Leaf and McEachin (1999) and included discrete trial teaching and other applied behavior analytic teaching methods. The EIBI approach is widely implemented and has demonstrated efficacy (Smith, Groen, & Wynn, 2000; Howard et al., 2014). In this condition, the teaching sessions alternated between adult-led, structured instruction periods that provided multiple opportunities to practice a skill (3-5 min.) and free play periods that served as reinforcement for cooperation and successful completion of the teaching activity (2-4 min.). Reinforcers (e.g., primary, tokens, praise) were presented for correct responses or approximations. EIBI therapists used a child-friendly approach (i.e., natural language, tone of voice) but also directed the selection of targets, antecedents, and pace of teaching. Therapists also joined children during free play. Relevant to this study, the therapist-delivered EIBI model included a twice monthly parent-therapist meeting in which parents could ask questions about their child's progress or any aspect of the intervention.

Measures of therapist fidelity for each model were developed *a priori* to assess therapist adherence to the intervention style and session structure. Treatment fidelity, a combination of treatment adherence and quality, was measured using a 5-point Likert scale that was developed specifically for each treatment style with higher scores indicating greater fidelity [EIBI M = 4.15(SD = 1.3); ESDM M = 4.3(SD = .15)]. Therapists from all sites were required to achieve and maintain 80% or better fidelity scores measured twice a month throughout the project, assessed by senior intervention team leaders via video recordings of treatment sessions. Additional detail describing these two intervention approaches and fidelity procedures have been previously reported (Rogers et al., 2020; Yoder et al., 2020).

Developmental assessments (described in Rogers et al., 2020) were conducted at four time points by expert examiners naïve to intervention group assignment; prior to randomization (baseline phase), 6 months following enrollment (mid-intervention phase), 12 months following enrollment (end-of-intervention phase), and 24 months following enrollment (follow-up phase). This study includes data from the baseline and end-of-intervention phases. Participating families were not paid for assessment or treatment visits. Families in all four intervention groups were provided with the results of the research diagnostic examination, including standardized test scores, diagnostic information, and individualized intervention recommendations at all assessment points.

Measures

Parent Sense of Efficacy.—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). The Efficacy subscale used in this study was collected at the enrollment and end-of-intervention phases and assessed capability, problemsolving ability, and competence. Example items are “Being a parent is manageable, and any problems are easily solved”, “I honestly believe I have all the skills necessary to be a good mother/father to my child”, and “The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired.” Prior research in a non-ASD population has shown strong correlations between PSOC subscales and parent-child wellbeing and 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). The Efficacy subscale is comprised of 8 items rated on a 6-point Likert scale and summed, with high scores representing high degrees of efficacy.

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 has been shown to be internally consistent, reliable and stable; demonstrating acceptable construct and concurrent validity and discriminating between ASD, intellectually disabled, and typically developing children (Konstantareas, Homatidis, & Plowright, 1992). Parenting Stress scores for parents of young children with ASD aged 18-30 months have been previously reported and were comparable with those of Konstantareas et al., 1992, suggesting that the scale can be used with parents of younger children (e.g., Estes et al., 2013). This study used the baseline Parenting Stress score in which all scores were summed and then divided by the number of items for a scale ranging from 1 to 4 to measure parenting-related stress.

Statistical Approach

The dependent variable (DV) was parental sense of efficacy. Analyses were done using a generalized linear mixed model (GLMM) using full information maximum likelihood estimation. The model included a random intercept to account for baseline differences between participants. The change of the DV over time from baseline to the end of intervention (time) was modelled as a fixed slope which varied by treatment style and intensity. The fixed slope-random intercept was chosen due to the limitations on model complexity in relationship with the sample size. Thus, the effects of interest were the effects of treatment intensity, treatment style and their interaction on changes in parental sense of efficacy from the enrollment phase to the end of intervention. Site was included as a covariate to account for possible differences between sites in baseline values and treatment effects.

Following up on these analyses, we evaluated the impact of baseline parent stress as a moderator of the effect of intensity or style on change in parental efficacy. We generated the most parsimonious explanatory model based on these prior analyses by excluding predictors that did not contribute to the explanatory power of the model, and used this model to describe the patterns observed in these data.

Results

Independent of treatment intensity and style, there was a significant increase in parental efficacy over time ($F(1,81) = 17.5$, $p < .001$). The analysis of the effect of treatment style and treatment intensity showed no significant effect on parental efficacy over time (Style, $F(1,81) = 1.23$, $p = .270$; Intensity, $F(1,81) = .00$, $p = .981$). There was no 3-way interaction between time, treatment intensity and style on the trajectory of parental efficacy ($F(1,81) = 0.51$, $p = .476$). Site did not significantly affect participant's overall change over time (F(2,81)=.56, p=.572), or the effects of treatment intensity (F(2,81)=1.66, p=.196), treatment style (F(2,85)=1.05, p=.355, or their interaction (F(2,81)=.52, p=.598) on treatment response.

A second model was run investigating the role of parent stress as a moderator. Baseline parent stress moderated the effect of treatment intensity on the trajectory of parental efficacy ($F(1,80) = 10.75$, $p = .0022$). Baseline stress did not moderate the effect of treatment style on parental efficacy ($F(1,80) = .08$, $p = .771$). The 4-way interaction between baseline stress, treatment intensity, treatment style and time was not significant ($F(1,80) = .01$, $p = .921$).

When controlling for the effects of parent stress, the effect of treatment intensity on the trajectory of parental efficacy became significant ($F(1,80) = 10.61$, $p = .002$), while the effects of treatment style ($F(1,80) = .00$, $p = .979$) and the effects of the interaction between treatment style and treatment ($F(1,80) = .05$, $p = .822$) remained non-significant. Baseline parental stress by itself was not a significant predictor of the change over time (F(1,80)=.04, p=.850). See Table 2. None of the site effects were significant when controlling for baseline stress (data available upon request). This main effect cannot be interpreted independently of the significant moderation effect and higher order interactions, but supports the notion that

baseline parental stress is a meaningful moderator and does not just serve to reduce the error variance within the model.

To allow for easier interpretation of the baseline-stress-moderated effect of intensity on parental efficacy, we pruned the original model by dropping treatment style, given it had no explanatory value, and included only time, treatment intensity, parent stress and interaction terms in the final model. The pruned model performed equally well at explaining the observed data (AIC: 973.4, BIC 1004.5) as the full model (AIC 985.7, BIC 1091.1). In this parsimonious model the 3-way interaction between treatment intensity, baseline parent stress, and time on change in parent sense of efficacy remained significant ($F(1,81) = 9.52$, $p = .003$).

To further explore the structure of this moderation effect we calculated the baseline parent stress scores at which intensity groups differ in predicted parental efficacy at the endpoint. For this moderation effect, the baseline parent stress (QRS) score at which parental efficacy change rate is equal between intensity groups (i.e. the balance point) is 2.23 (95% CI (1.85, 2.58)), with an estimated increase of efficacy from enrollment in the study to the end of intervention of 2.1. For participants with QRS scores lower than 2.23, the *higher* intensity treatment provided proportionally larger increases in efficacy whereas the parents with lower QRS scores who were in the *lower* intensity treatment demonstrated smaller effects or even a decrease in efficacy. This difference becomes statistically significant in this sample at a QRS score of 1.85. Conversely, this model predicts that for participants with higher QRS scores the estimated pattern of change is reversed, with the difference reaching statistical significance at baseline QRS score of 2.58. Figure 2 plots the values from Table 3 to illustrate the change in parental efficacy by intervention intensity from the lower bound of the CI for the balancing point, the balancing point, and the lower bound of the CI for the balancing point of QRS scores. This shows that parents with moderate levels of stress respond to the two intensities similarly, but parents with high vs low stress respond differently to the two different intervention intensity levels.

Discussion

Parents with higher parenting-related stress at the beginning of a one-year, home-based, intervention program had a higher sense of parental efficacy at the end of the intervention program if their child was randomized to *lower* intensity intervention (15 hours/week vs 25 hours/week); whereas, when parenting stress was lower at the start of intervention, *higher* intensity intervention (25 hours/week vs 15 hours/week) resulted in higher parental efficacy at the end of intervention. Style of intervention (EIBI vs ESDM) did not have an effect on parent efficacy nor was there an interaction effect between style and initial level of parenting stress on the rate of change in parental efficacy. This provides new evidence that requires replication, but suggests that the intervention intensity level that optimizes parental sense of efficacy may differ depending upon pre-treatment parent stress. A sense of self-efficacy has long been recognized as critical factor that is associated with well-being and increased human potential (Ryan & Deci, 2000). In the context of raising a young child with ASD, these findings suggest that parent stress and intervention intensity may be

important considerations when creating intervention plans for young children with ASD, with the potential to enhance or undermine parental sense of efficacy.

This is the first randomized study of which we are aware to explore the question of under what conditions does **intensity of intervention** affect the greatest sense of efficacy for parents. Our findings, though in need of replication, suggest that a “one size fits all” approach to recommendations for treatment intensity may not be justified when secondary effects on parents are part of the equation. One conclusion could be that when parental stress is high, the intensity of intervention should be reduced. However, another less obvious but equally plausible, conclusion could be that intervention scientists and providers should develop and investigate strategies that provide a higher level of support to highly stressed parents so that higher-intensity child-focused intervention can result in improved parental sense of efficacy. We previously reported that parents in all four conditions were equally pleased with the intervention they received (Rogers et al., 2020), so the interaction between parenting stress and intervention intensity may be outside of parental awareness. Providing evidence-based autism intervention requires a significant investment of time, effort, and financial resources. Parents and policy makers need evidence to determine how best to maximize the positive effect of early intervention, including improved family adaptive functioning. Publicly-funded early intervention programs (Part C of IDEA) for children with all types of developmental disorders usually provide only a few hours per week of services, but parents of young children with autism are often advised to seek 25 or more hours of week (National Research Council, 2001). Participating in intensive treatments may require difficult choices to forego other activities; decisions that may have broader implications for child and family wellbeing. We took an approach not yet taken in the autism literature by examining treatment intensity in the context of controlling intervention style, generating new hypotheses about the impact of different levels of intensity on parental sense of efficacy.

We did not find evidence that **treatment style** had effects on parent sense of efficacy. This was unexpected given the apparent differences between a naturalistic, developmental behavioral approach and a more directive applied behavior analytic approach. However, these findings are consistent with our previous reports on the effect of intervention style on child-outcomes from this sample. Previously reported data from this trial did not support our hypothesis that initial degree of developmental delay and autism severity would moderate the effects of treatment style on child growth trajectories (Rogers et al., 2020). Treatment intensity, but not style had a positive effect on child frequency and maturity of spontaneous communication for children with relatively mild ASD symptoms (Yoder et al., 2020). Our parent efficacy findings are also consistent with other studies that have concluded there is not clear evidence for one intervention style over another (Goldstein, 2002; Bernard-Opitz et al., 2004). Given the limitations of the existing data on the effect of different intensive early intervention styles on parents (e.g., few studies, small samples, lack of randomized designs) we are cautious about making a definitive comparison between this study and the previous research (e.g., Harris, Wolchik, Milch, 1983; Koegel, Bimbela, Schreibman, 1996; Laski, Charlop, Schreibman, 1988). However, taken together, the emerging evidence suggests that the style of intervention may be less important than other aspects of intervention in supporting positive outcomes for parents of children with ASD. Further research is needed

to help identify the critical components of effective early ASD intervention. Parents, public service systems, educators, and health professionals require this additional information to be able to choose the approaches that best support parents of children with ASD.

These findings should be interpreted as preliminary evidence generating new hypotheses about the role of parent stress and treatment intensity on parent sense of efficacy. Given that the clinical trial was not designed specifically to evaluate parent outcomes, these results need to be replicated in future randomized, controlled studies. The study is also limited by our measurement of parenting stress. Often, higher stress is equated with poorer functioning and lower stress is equated with better functioning. However, a longstanding model of stress actually suggests that when action is required, optimal performance can be described by a U-shaped function in which moderate stress is most adaptive - too much or too little stress is related to poorer performance (Yerkes & Dodson, 1908). Furthermore, our study was limited to evaluating parent stress at one particular point in the lifespan; as parents prepared to begin a year of intensive, in-home, child-focused intervention. The relationship between parent stress and parent sense of efficacy may differ in other phases of engagement with intervention. For example, a recent online survey of parents of children with ASD revealed that parent stress correlated with the phase of engagement with intervention; parent stress was higher when children were actively engaged in intervention or had abandoned intervention than when the child had not yet tried intervention or had completed intervention (Shepherd, Landon, Taylor, & Goedeke, 2018). This suggests that our findings should be extended to measure parent stress at other times, such as when parents are on wait-lists or actively searching for intervention, after intervention is completed and a child is doing well, or when a parent has decided to end treatment because they feel their child did not benefit. The relationship between parent stress and sense of efficacy may differ in these contexts. Although not available in this study, evaluating the causes of parent stress and the mechanisms driving the relationship between parent stress, intervention intensity, and parental efficacy would be a useful future research direction that could identify novel intervention targets and approaches.

Also, critically, this study was an efficacy trial; conducted by university-based intervention teams with a relatively highly educated group of parents who were 56% white and non-Hispanic. It is not yet known whether these results would differ in community effectiveness trials with parents who have fewer resources or are less highly educated. Replication of the findings with more diverse groups is needed, but to do that, researchers will have to plan for and utilize strategies to deliberately engage parents who are not typically involved in research. Future studies are also needed to extend this work to evaluate other outcomes. For instance, baseline parent stress and treatment intensity may differentially affect the extent to which parents participate in treatment and this in turn could affect child intervention delivery and progress. Although it is beyond the scope of this study, examining the relationship of parent stress to child outcomes is a promising future direction.

Another set of limitations have to do with our focus on parental sense of efficacy. First, we note that there are a number of other important parent outcomes one could evaluate (e.g., parent fidelity to treatment, concepts learned by the parent in treatment). Furthermore, measuring a parent’s sense of efficacy is limited to self-report. Since parents are not naïve

to intervention group assignment it is possible that self-reports could be affected by knowing that they received 15 vs 25 hours per week or EIBI vs ESDM. The design of this study may have attenuated this effect to some degree, since all participants did receive active intervention; none were assigned to wait list or community intervention as usual conditions. To date, studies of the impact of child-focused ASD intervention on parents have relied upon parent self-report of stress and related constructs. These self-reports may also be subject to systematic bias due to knowledge of treatment assignment. Future studies could incorporate psychophysiological measures of stress, which have their own strengths and weaknesses. However, with regard to constructs such as sense of efficacy, it may be difficult to avoid the methodological challenge of relying on self-report.

Research on relationships among early autism intervention, parent characteristics such as parenting-related stress, and parent outcomes, such as sense of efficacy, is still in the early stages. More work is needed to understand approaches to intervention that support positive parent outcomes and the factors that result in parents becoming effective advocates for their children (Edwards, Brebner, McCormack, MacDougall, 2018). To our knowledge, this is the first time the secondary effects of intensive, comprehensive autism interventions on sense of efficacy in parents of young children with ASD has been explored in the context of a randomized clinical trial. In therapist-delivered early intervention parent sense of efficacy has particular salience. If a parent can emerge from the process of diagnosis and early intervention with an increased sense that they can make a difference in their child's life, this may set the stage for meeting the long-term demands of advocating, implementing parent-delivered intervention at home, and helping their child meet the myriad developmental challenges to come. And, of course, parent outcomes are worthy targets of intervention in their own right. If replicated, this line of research may lead to individualized treatment recommendations based on parent stress levels at the outset of intervention and to improved strategies for supporting parents of young children with autism. Continued research and clinical innovation is needed to ensure that autism interventions are optimally designed to improve family adaptive functioning and lead to better outcomes for children with ASD and their parents.

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References

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.

Bernard-Opitz V, Ing S, Kong TY (2004). Comparison of behavioural and natural play interventions for young children with autism, Autism, 8(3) 319–333. [PubMed: 15358873]

Dawson G, Rogers S, Munson J, et al. (2010). Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. Pediatrics, 125: 17–23.

Edwards AG, Brebner CM, McCormack PF, MacDougall CJ (2018). From 'Parent' to 'Expert': How Parents of Children with Autism Spectrum Disorder Make Decisions About Which Intervention Approaches to Access. Journal of Autism and Developmental Disorders, 48(6), 2122–2138. doi:10.1007/s10803-018-3473-5 [PubMed: 29396727]

Estes A, Munson J, Dawson G, Koehler E, Zhou X, Abbott R (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Autism: International Journal of Research and Practice, 13(4), 375–387. doi:10.1177/1362361309105658 (PMC2965631)

Estes A, Olson E, Sullivan K, Greenson J, Winter J, Dawson G, Munson J (2013). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. Brain & Development, 35(2), 133–138. doi:10.1016/j.braindev.2012.10.004 (PMC3552060) [PubMed: 23146332]

Estes A, Swain D, MacDuffie K (2019). The effects of early intervention on parents and family adaptive functioning. Pediatric Medicine, 2, 21. doi: 10.21037/pm.2019.05.05 [PubMed: 31583390]

Estes A, Vismara L, Mercado C, Fitzpatrick A, Elder L, Greenson J, Lord C, Munson J, Winter J, Young G, Dawson G, Rogers S (2014). The impact of parent-delivered intervention on parents of young children with autism. Journal of Autism and Developmental Disorders, 44(2), 353–365. doi:10.1007/s10803-013-1874-z (PMC3888483) [PubMed: 23838727]

Goldstein H (2002). Communication intervention for children with autism: A review of treatment efficacy. Journal of Autism and Developmental Disorders, 32(5), 373–396. [PubMed: 12463516]

Guralnick MJ, (1997). Effectiveness of early intervention for vulnerable children: A developmental perspective. American Journal of Mental Retardation, 102, 319.

Harris SL, Wolchik SA, Milch RE (1983). Changing the speech of autistic children and their parents. Child Fam Behav Ther. 4(2-3), 151–173. doi:10.1300/J019v04n02_16

Hastings RP, Brown T (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. American Journal on Mental Retardation, 107 (3), pp. 222–232 [PubMed: 11966335]

Hastings RP, & Symes MD (2002). Early intensive behavioral intervention for children with autism: Parental therapeutic self-efficacy. Research in developmental disabilities, 23(5), 332–341. [PubMed: 12401484]

Howard JS, Stanislaw H, Green G, Sparkman C, Cohen H (2014). Comparison of behavior analytic and eclectic early interventions for young children with autism after three years. Research in Developmental Disabilities 35(12), 3326–3344. doi: 10.1016/j.ridd.2014.08.021. [PubMed: 25190094]

Johnston C, & Mash EJ (1989). A measure of parenting satisfaction and efficacy. Journal of Clinical Child Psychology, 18(2), 167–175.

Jones TL, Prinz RJ, (2005). Potential roles of parental self-efficacy in parent and child adjustment: a review. Clinical psychology review, 25, pp. 341–363 [PubMed: 15792853]

Kasari C, Gulsrud A, Paparella T, Hellemann G, & Berry K (2015). Randomized comparative efficacy study of parent-mediated interventions for toddlers with autism. Journal of consulting and clinical psychology, 83(3), 554–563. 10.1037/a0039080 [PubMed: 25822242]

Koegel RL, Bimbela A, Schreibman L (1996). Collateral effects of parent training on family interactions. Journal of Autism and Developmental Disorders. 126(3), 347–359.

Konstantareas MM, Homatidis S, & Plowright CM (1992). Assessing resources and stress in parents of severely dysfunctional children through the Clarke modification of Holroyd's questionnaire on resources and stress. Journal of Autism and Developmental Disorders, 22(2), 217–234. [PubMed: 1624406]

Kuhn JC, Carter AS (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. American Journal of Orthopsychiatry, 76, pp. 564–575

Laski KE, Charlop MH, Schreibman L (1988). Training parents to use the natural language paradigm to increase their autistic children's speech. Journal of Applied Behavior Analysis. 21(4), 391–400. doi:10.1901/jaba.1988.21-391 [PubMed: 3225256]

Leaf RB, & McEachin J (1999). A work in progress: Behavior management strategies and a curriculum for intensive behavioral treatment of autism. New York: DRL Books.

Luyster R, Gotham K, Guthrie W, Coffing M, Petrak R, Pierce K, Bishop S, Esler A, Hus V, Oti R, Richler J, Risi S, Lord C (2009). The Autism Diagnostic Observation Schedule—Toddler Module: A new module of a standardized diagnostic measure for autism spectrum disorders. Journal of Autism and Developmental Disorders, 39, 1305–1320. doi:10.1007/s10803-009-0746-z [PubMed: 19415479]

Mullen EM (1995). Mullen Scales of Early Learning (AGS ed.). Los Angeles, CA: Western Psychological Services.

National Research Council (2001). Educating children with autism. Washington, DC: National Academy Press.

National Autism Center (2015). Findings and conclusions: National standards project, Phase 2. Retrieved November 29, 2020, from http://www.nationalautismcenter.org/.

Nevill RE, Lecavalier L, Stratis EA (2018). Meta-analysis of parent-mediated interventions for young children with autism spectrum disorder. Autism;22(2):84–98. doi:10.1177/1362361316677838 [PubMed: 29490483]

Osborne LA, McHugh L, Saunders J, Reed P (2008). Parenting Stress Reduces the Effectiveness of Early Teaching Interventions for Autistic Spectrum Disorders. Journal of Autism and Developmental Disorders. 38(6), 1092–1103. doi:10.1007/s10803-007-0497-7 [PubMed: 18027079]

Reichow B (2012). Overview of meta-analyses on early intensive behavioral intervention for young children with autism spectrum disorders. Journal of autism and developmental disorders, 42(4), 512–520. [PubMed: 21404083]

Rodrigue JR, Morgan SB, Geffken G (1990). Families of autistic children: psychological functioning of mothers. Journal of Clinical Child Psychology, 19: 371–379.

Rogers H & Matthews J (2004). The parenting sense of competence scale: Investigation of the factor structure, reliability, and validity for an Australian sample. Australian Psychologist, 39(1), pp 88–96. 10.1080/00050060410001660380

Rogers SJ, Dawson G, Vismara L (2012). An Early Start for Your Child with Autism: Using Everyday Activities to Help Kids Connect, Communicate, and Learn. Guilford Press

Rogers SJ, Dawson G (2010). Early Start Denver Model for Young Children with Autism: Promoting Language, Learning, and Engagement. Guilford Press

Rogers SJ, Estes A, Lord C, Vismara L, Winter J, Fitzpatrick A, Guo M, Dawson G (2012). Effects of a brief ESDM-based parent intervention on toddlers at risk for autism spectrum disorders: a randomized controlled trial. Journal of the American Academy of Child and Adolescent Psychiatry, 51(10), 1052–1065. doi:10.1016/j.jaac.2012.08.003 (PMC3487718) [PubMed: 23021480]

Rogers SJ, Yoder P, Estes A, Warren Z, McEachin J, Munson J, Rocha M, Greenson J, Wallace L, Gardner E, Dawson G, Sugar CA, Hellemann G, Whelan F (2020). A multisite randomized controlled trial comparing the effects of intervention intensity and intervention style on outcomes of young children with autism. Journal of the American Academy of Child and Adolescent Psychiatry

Ryan RM, Deci EL (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. American Psychologist, 55(1), 68–78. doi: 10.1037//0003-066x.55.1.68

Schwichtenberg A, Poehlmann J (2007). Applied behaviour analysis: does intervention intensity relate to family stressors and maternal well-being? Journal of Intellectual Disabilities Research. 51(8), 598–605. doi:10.1111/j.1365-2788.2006.00940.x

Shepherd D, Landon J, Taylor S, Goedeke SCoping and care-related stress in parents of a child with autism spectrum disorder. Anxiety, Stress Coping. 2018;31(3):277–290. doi:10.1080/10615806.2018.1442614 [PubMed: 29463108]

Siller M, Morgan LSystematic Review of Research Evaluating Parent-Mediated Interventions for Young Children with Autism: Years 2013 to 2015. In: Siller M, Morgan L, eds. Handbook of Parent-Implemented Interventions for Very Young Children with Autism. Cham: Springer International Publishing; 2018:1–21. doi:10.1007/978-3-319-90994-3_1

Smith T, Groen AD, Wynn JW (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. American Journal of Mental Retardation, 105: 269. [PubMed: 10934569]

Solomon R, Van Egeren LA, Mahoney G, Quon Huber MS, Zimmerman P (2014). PLAY project home consultation intervention program for young children with autism spectrum disorders: A randomized controlled trial. Journal of Developmental Behavioral Pediatrics, 35(8): 475–485. [PubMed: 25264862]

Tarver J, Palmer M, Webb S, Scott S, Slonims V, Simonoff E, Charman T (2019). Child and parent outcomes following parent interventions for child emotional and behavioral problems in autism spectrum disorders: A systematic review and meta-analysis. Autism. 23(7), 1630–1644. doi:10.1177/1362361319830042 [PubMed: 30818965]

Vismara LA, Colombi C, Rogers SJ, (2009). Can one hour per week of therapy lead to lasting changes in young children with autism?Autism, 13, 93–115. [PubMed: 19176579]

Wei LJ, (1978). An application of an urn model to the design of sequentially controlled clinical trials, Journal of the American Statistical Association, 73, (363)559–563.

Yerkes RM, Dodson JD (1908). The relation of strength of stimulus to rapidity of habit-formation. Journal of Comparative Neurology and Psychology. 18 (5): 459–482. doi:10.1002/cne.920180503

Yoder P, Rogers S, Estes A, Warren Z, Munson J, Hellemann G, McEachin J (2020). Interaction of treatment intensity and autism severity on frequency and maturity of spontaneous communication in toddlers with autism spectrum disorder. Autism Research. 13: 1902–1012. doi: 10.1002/aur.2416 [PubMed: 33098276]

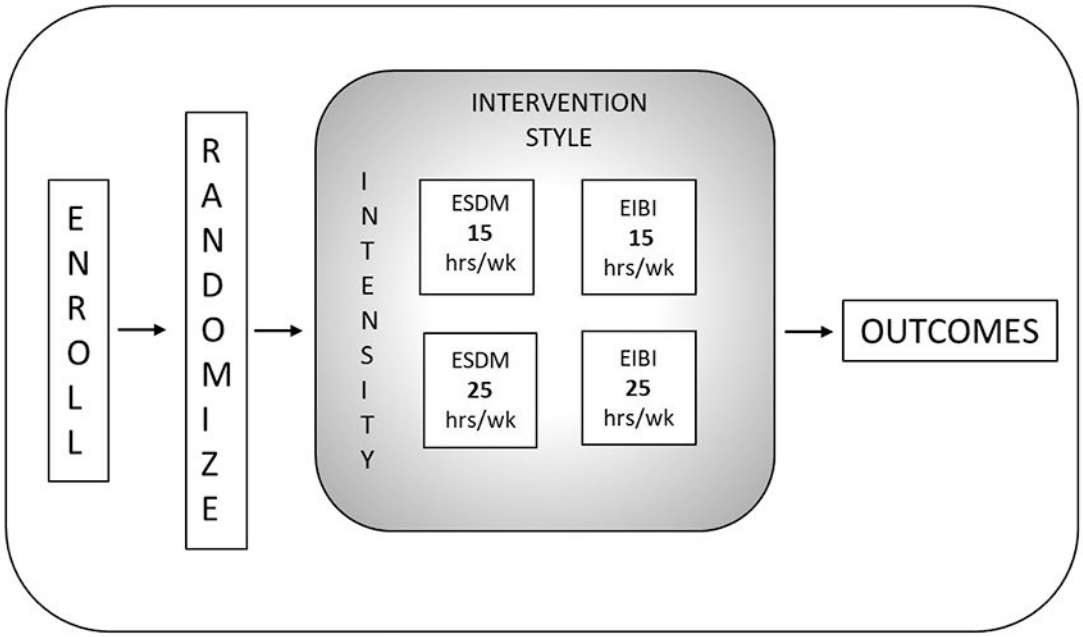

Figure 1:
Study design: lower vs higher intensity crossed with ESDM vs EIBI intervention styles

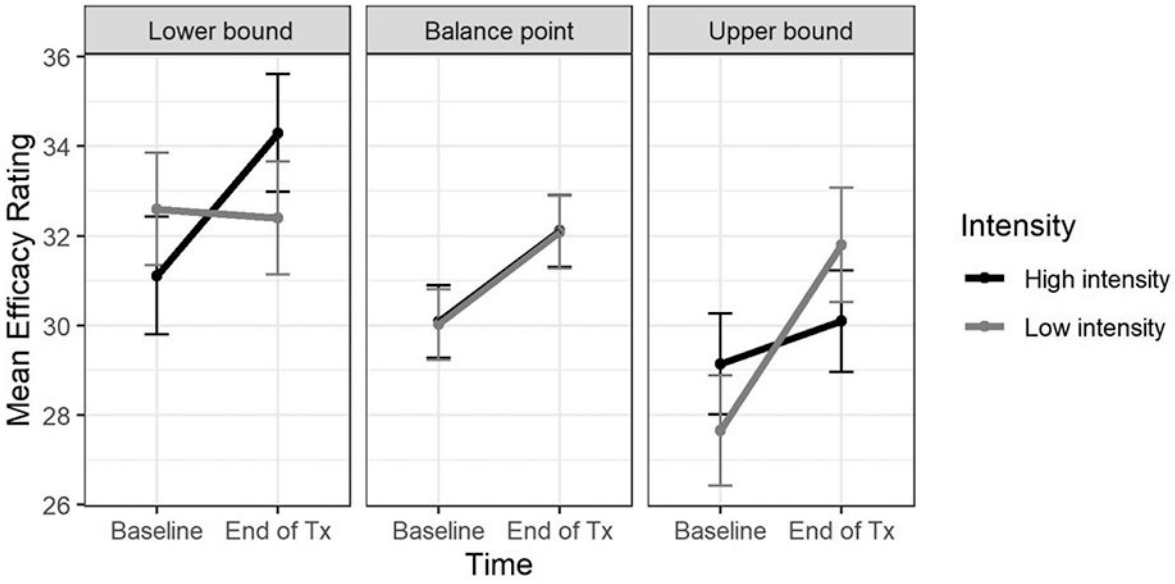

Figure 2:
Illustration of parental stress moderation effect on parental sense of efficacy in lower and higher intensity intervention conditions

Table 1.

Participant demographic characteristics

Variable	EIBI[a] 25hr n=23	EIBI 15hr n=22	ESDM[b] 25hr n=21	ESDM 15hr n=21	Statistics
Race, n (%)					p=0.93
African American	8.7% (2)	13.6% (3)	4.8% (1)	4.8% (1)	
American Indian / Alaska Native	4.3% (1)	0.0% (0)	0.0% (0)	0.0% (0)	
Asian	4.3% (1)	13.6% (3)	9.5% (2)	14.3% (3)	
Caucasian	60.9% (14)	40.9% (9)	57.1% (12)	57.1% (12)	
Multi	17.4% (4)	27.3% (6)	23.8% (5)	23.8% (5)	
Pacific Islander	0.0% (0)	0.0% (0)	4.8% (1)	0.0% (0)	
Unknown	4.3% (1)	4.5% (1)	0.0% (0)	0.0% (0)	
Age (mo), mean (SD)					$F_{3,83}$ = 0.9 p = .46
Baseline	22.6 (3.5)	23.0 (4.7)	24.4 (4.0)	23.8 (3.6)	
End of Tx[c]	35.7 (3.4)	35.2 (4.8)	37.6 (4.2)	36.5 (3.7)	
Ethnicity, n (%)					p = .82
Hispanic/Latino	17.4% (4)	18.2% (4)	19.0% (4)	23.8% (5)	
Non-Hispanic	69.6% (16)	72.7% (16)	76.2% (16)	76.2% (16)	
Unknown	13.0% (3)	9.1% (2)	4.8% (1)	0.0% (0)	
Sex, n (%)					p = .99
F	21.7% (5)	27.3% (6)	23.8% (5)	23.8% (5)	
M	78.3% (18)	72.7% (16)	76.2% (16)	76.2% (16)	
Mullen Composite DQ[d] Baseline	66.96 (19.28)	64.25 (17.88)	61.36 (15.79)	65.05 (22.05)	$F_{3,83}$ = .20 p = .89
ADOS[e] Severity Score Baseline	8.19 (1.86)	8.38 (1.28)	8.29 (1.54)	7.82 (2.22)	$F_{3,82}$ =.76 p = .52
Income ($), Mean (SD)	85000 (29730.9)	91428.6 (36554.9)	96833.3 (32956.5)	84285.7 (36956.7)	$F_{3,54}$ = 0.4 p = .72
Mother's Education (y), Mean (SD)	15.4 (2.8)	16.6 (3.1)	16.3 (2)	16.6 (2.8)	$F_{3,80}$ = 0.9 p = .44

[a] Early Intensive Behavioral Intervention (EIBI)

[b] Early Start Denver Model (ESDM)

[c] Therapy (Tx)

[d] Developmental Quotient (DQ)

[e] Autism Diagnostic Observation Scale (ADOS)

Table 2:

Pruned model investigating effect of initial level of parent stress and treatment intensity, on trajectory of parental efficacy

Variable	Test(df)	Statistic	*p*	Effect size *f*^2
Intercept	*F*(1,85)	112.022	<.001	1.32
Time	*F*(1,80)	0.133	.716	0.00
Intensity	*F*(1,85)	0.017	.896	0.00
Time * Intensity	*F*(1,80)	9.264	.003	0.12
Baseline QRS[a]	*F*(1,85)	5.760	.019	0.07
Time * Baseline QRS	*F*(1,81)	0.995	.322	0.01
Intensity * Baseline QRS	*F*(1,85)	0.016	.898	0.00
Time * Intensity * Baseline QRS	*F*(1,81)	9.528	.003	0.12

[a]Questionnaire on Resources and Stress (QRS)

Table 3.

Parental stress moderation effect on parental sense of efficacy in lower and higher intensity intervention conditions

		LB (QRS score = 1.85)		Balance Point (QRS score = 2.23)		UB (QRS score = 2.58)	
Intensity	**Time**	**Mean**	**Std. Error**	**Mean**	**Std. Error**	**Mean**	**Std. Error**
High	Baseline	31.112	(1.311)	30.085	(.808)	29.1385	(1.129)
	End of Tx	34.296	(1.311)	32.109	(.808)	30.095	(1.129)
Low	Baseline	32.602	(1.250)	30.025	(.789)	27.651	(1.230)
	End of Tx	32.399	(1.268)	32.088	(.811)	31.801	(1.276)