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# Research in Autism Spectrum Disorders

journal homepage: www.elsevier.com/locate/rasd



# Feasibility of *The Incredible Years Parent Program for Preschool Children on The Autism Spectrum* in two U.S. sites



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# ARTICLE INFO

Number of reviews completed is 2 Keywords: Autism Caregivers Parent stress Incredible Years Parenting interventions Child behavior Coping

## ABSTRACT

Background: Parent strain and burden are high in families raising children with Autism Spectrum Disorder (ASD). Caregivers of young children with ASD are particularly vulnerable to stress. Yet, few interventions address the direct needs of this growing population of parents. This pilot trial describes the feasibility, acceptability, and short-term outcomes of *The Incredible Years Parent Program for Preschool Children on the Autism Spectrum or with Language Delays (IY-ASD)* in two U.S. locations.

*Method:* We recruited caregivers of children ages to 2–6 years old with ASD to participate in a non-randomized pilot trial of *IY-ASD*. We aimed to describe our program delivery process and assess 1) participant retention rates and reasons for program/research discontinuation; 2) caregiver acceptability of *IY-ASD*; and 3) pre- and post-intervention measures of parenting stress, caregiver coping, and child behavior.

*Results*: Of the 50 parents who enrolled, 42 completed *IY-ASD* (84%). We analyzed data for 36 participants after accounting for partners and a participant lost to follow-up. Program acceptability was high. Total and child-related parenting stress significantly decreased at posttest. We found no statistically significant changes in caregiver coping, parent-related stress, or challenging child behaviors.

*Conclusions: IY-ASD* is a feasible and acceptable program for parents raising young children with ASD. A randomized controlled trial is needed to rigorously test the effectiveness of the intervention. Future research should consider a longer program period (i.e., 15–16 weeks); ASD-specific outcome measures; and, longer-term follow-up to examine program effects beyond post-intervention, as well as potential *IY-ASD* modifications to meet the diverse needs of participants.

# 1. Introduction

An estimated 1 in 59 children in the United States (U.S.) have an autism spectrum disorder (ASD) (Baio, Wiggins, & Christensen, 2018). Parents of children with ASD report greater stress than those raising children without ASD (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Padden & James, 2017)). Increased parenting stress is related to challenging child behaviors (Kim, Ekas, & Hock, 2016; Lecavalier, Leone, & Wiltz, 2006), as well as maladaptive parent coping strategies, anxiety, and depression (Bromley, Hare, Davison, & Emerson, 2004; Davis & Carter, 2008; Estes et al., 2013; Padden & James, 2017; Schieve, Blumberg, Rice, Visser, & Boyle, 2007).

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https://doi.org/10.1016/j.rasd.2018.10.010

Received 28 February 2018; Received in revised form 7 October 2018; Accepted 28 October 2018 1750-9467/ @ 2018 Elsevier Ltd. All rights reserved.

Early intervention can reduce maternal stress related to caring for a child with ASD (Baker-Ericzen et al., 2005; Bradshaw, Steiner, Gengoux, & Koegel, 2015). Increased child ASD symptom severity and overall challenging behaviors are strong predictors of parenting stress and psychological distress (Estes et al., 2013; Ingersoll & Hambrick, 2011; Lyons, Leon, Roecker Phelps, & Dunleavy, 2010), further reinforcing the importance of early intervention to reduce parental burden. Research suggests that toddlers diagnosed with ASD need different early intervention programs than older children (Schertz, Odom, Baggett, & Sideris, 2013), and evidence supports the use of parent-implemented interventions for young children with ASD (Schertz et al., 2013; Wetherby & Woods, 2006). Two recent reviews highlighted the lack of attention paid to parent outcomes in ASD early intervention research (Dababnah & Parish, 2016b; Wainer, Hepburn, & McMahon Griffith, 2017), despite the importance of parent engagement to improved child outcomes in early interventions (Epley, Summers, & Turnbull, 2011).

Group-based parent early interventions have had significant positive effects on child behavior and parent mental health in families of children with ASD (McConachie, Randle, Hammal, & Le Couteur, 2005; Stadnick, Stahmer, & Brookman-Frazee, 2015; Tonge et al., 2006). Stahmer and Pellecchia (2015) suggested adapting existing evidence-based practices from the broader childhood development field, in order to replicate the successes these practices have had in improving both child and parent outcomes. Yet, to our knowledge, only one evidence-based parenting program, *Stepping Stones Triple P*, has been rigorously tested for parents of children with ASD (Tellegen & Sanders, 2014; Whittingham, Sofronoff, Sheffield, & Sanders, 2009).

Another widely available evidence-based program, *The Incredible Years (IY)* training series, offers a number of developmentally appropriate, group-based interventions targeting parents, young children, and teachers (Webster-Stratton, 2011). Originally developed for children with conduct disorders, the program currently has been evaluated in multiple languages and with diverse groups of children and families (Webster-Stratton & Reid, 2003). The National Registry of Evidence-Based Programs and Practices rated the quality of evidence supporting *IY* to improve parenting skills, child externalizing problems, emotional literacy, self-regulation, and social competence as 3.5 and higher on a 4.0 scale (SAMHSA, 2012). A review of independent studies of *IY* concluded the evidence for the preschool parenting program (*Basic IY*) is strong (Pidano & Allen, 2015). Research adapting *Basic IY* with parents raising children with ASD found the program was both feasible and acceptable, and reduced parenting stress (Dababah & Parish, 2016a). In order to better address the needs of parents raising children with ASD, modifications to *Basic IY*, including videos depicting children with ASD, methods to engage children with social communication challenges, and less focus on time-out strategies, were manualized into a new program, *The Incredible Years Parent Program for Preschool Children on the Autism Spectrum or with Language Delays (IY-ASD*; Webster-Stratton, 2014).

*IY-ASD* aims to promote parenting competence and child development by providing strategies that target social skills, communication and language, emotion regulation, and school readiness in children with ASD or social communication delays. To our knowledge, there is only one published study evaluating *IY-ASD*. A UK-based pilot trial of *IY-ASD* reported preliminary support for the program among a small group of eight parents of children with ASD (Hutchings, Pearson-Blunt, Pasteur, Healy, & Williams, 2016). Yet, to date, no known studies have formally assessed *IY-ASD*'s feasibility in the U.S. Thus, the current study describes a pilot trial of *IY-ASD* in two U.S. sites, based on Eldridge and colleagues' (2016) characterization of pilot trials as a subset of feasibility studies. Specifically, we aimed to describe our process of delivering *IY-ASD* in the Northwestern and Southeastern U.S., and assessed 1) participant retention rates and reasons for program/research discontinuation; 2) caregiver acceptability of *IY-ASD*; and 3) pre- and post-intervention measures of parent and child outcomes, including parenting stress, caregiver coping, and child behavior. Data from this pilot trial could inform a larger randomized controlled trial rigorously testing *IY-ASD*.

# 2. Methods

We utilized a one-group, pre-post design to assess our research aims. Although we did not randomize our participants to groups, we have included a modified version of a CONSORT flow chart (Fig. 1) and reviewed the CONSORT checklist for randomized pilot and feasibility trials (Eldridge et al., 2016). We conducted our study in collaboration with two sites in the Southeastern and Northwestern U.S. The Southeastern site is a community-based agency serving families of children with and without special needs. The Northwestern site is a hospital-based outpatient neurodevelopmental clinic. Staff at each of the two locations recruited local participants to *IY-ASD* through flyers, information sessions, and other standard recruitment avenues. These sites routinely provide support services to children with ASD and their caregivers and offered *Basic IY* for parents of preschool children in the past, both for children with and without ASD.

# 2.1. Intervention and group leaders

*IY-ASD* aims to build an early foundation for parents to problem solve and communicate effectively with their children and other adults. One or two professionals, generally with master's-level credentials in psychology, social work, or a related field, as well as experience working with individuals with ASD, facilitate *IY-ASD* sessions. The *IY* manual recommends two group leaders co-facilitate the sessions if resources permit (Webster-Stratton, 2008, p. 20). These group leaders receive training from official *IY* instructors over a two- to three-day period. *IY* instructors encourage group leaders to receive ongoing supervision and accreditation. *IY-ASD* teaching methods include collaborative group discussion, video modeling, practice, and reflection over 12 to 16 weekly, two-hour sessions. The *IY* website (www.incredibleyears.com) offers information on planning for expenses to set up an *IY* group, including training costs and offering supports such as childcare and meals.

In this study, all group leaders had previous experience delivering *Basic IY*. Due to staffing and funding constraints, only one group leader delivered the *IY-ASD* groups at the Northwestern site. This leader had a doctoral degree in psychology, was accredited in

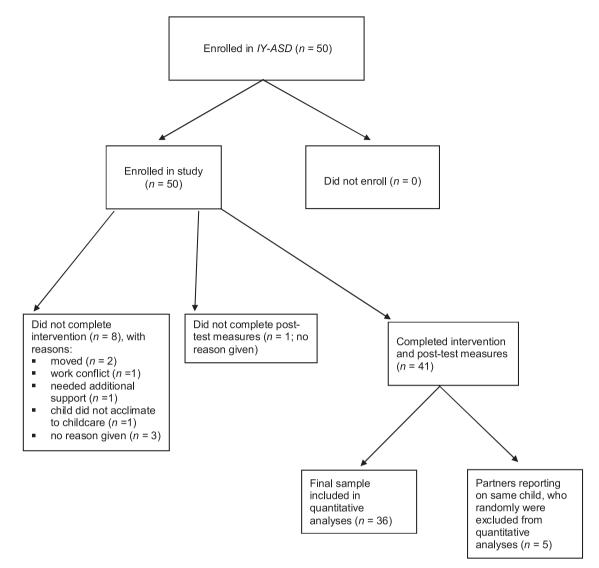


Fig. 1. Flow of participants through The Incredible Years Program for Preschool Children on the Autism Spectrum (IY-ASD).

*Basic IY*, and was in the process of pursuing *IY-ASD* accreditation during this study. She had delivered *IY-ASD* to eight cohorts of parents before facilitating *IY-ASD* for this research. This group leader was also in direct consultation with the *IY* developer as she delivered the *IY-ASD* groups.

One female and one male group leader at the Southeastern site jointly delivered the *IY-ASD* groups for this study. Both leaders at the Southeastern site had bachelor's degrees; one had a certificate and experience in early child development and home visiting. These leaders had delivered *Basic IY* previously and completed training in *IY-ASD*. However, neither had facilitated *IY-ASD* groups prior to this study, nor were they accredited in *Basic IY* or *IY-ASD*. Both leaders at the Southeastern site had experience and accreditation in another evidence-based parenting practice, *Triple P*.

While not explicitly part of the *IY-ASD* curriculum, group leaders at both sites dedicated time during the first session to offer general information about ASD and local resources, as both *IY-ASD* group leaders' training instructors and participants in our earlier *Basic IY* study recommended (Dababnah & Parish, 2016c). Staff at both sites encouraged parents to bring their partner, co-parent or another caregiver (e.g., grandmother of child) to support their learning in the group and at home, which participants in our previous research likewise requested. The Southeastern site delivered *IY-ASD* over a 15-week period. At this site, the community-based agency offered the program in the evening free-of-charge, as well as meals, transportation assistance, and childcare to facilitate participation.

The Northwestern site offered *IY-ASD* as part of a larger applied behavior analysis-based half-day program, which consisted of both direct child interventions and *IY-ASD*. Insurance reimbursed these services. Due to state implementation and duration requirements of the broader program at the Northwestern site, *IY-ASD* was delivered over a shorter 13-week time period during school hours. The Northwestern site could not provide meals due to their hospital-based setting; however, this site offered transportation assistance. Children at the Northwestern site participated in services based on their individual needs while parents were engaged in

IY-ASD. The group leader allowed siblings too young for school to attend the IY-ASD groups with their parents.

## 2.2. Program and research procedures

The Institutional Review Board at the University of Maryland, Baltimore and the Clinical Research Oversight Committee at Providence Regional Medical Center, Everett approved the study protocol. Participants could enroll in *IY-ASD* separately from the research study. It is important to note that in initial visits with participants at both sites, program staff asked parents to commit to attending all *IY-ASD* sessions, or to make up sessions with group leaders throughout the week if needed. These procedures preceded the research study, and were put into place by the coordinating agencies for all participants, regardless of whether they chose to join the research study or not. At the Northwestern site, parents were required to attend or make up at least 90% (i.e., all but one) of the *IY-ASD* sessions; those who could not were offered individualized supports in lieu of *IY-ASD*. The Southeastern site did not set a specific percentage of mandatory sessions; their average in-person attendance was 83%.

In order to be eligible for the study, participants had to be parents or other primary caregivers (e.g., grandparents) of a child between 2 and 6 years of age with an ASD diagnosis; be at least 18 years of age; and, indicate comfort reading English in order to complete research questionnaires. A study coordinator at each site assigned participants anonymous identifiers, which we used for all research-related documents. Study team members at each location obtained verbal informed consent, as the authors' Institutional Review Boards waived written consent. (Otherwise, written consent forms would be the only documents with identifiable information [i.e., names] shared with the coordinating site at the University of Maryland.) Most participants (58%) completed research measures online via REDCap (Harris et al., 2009) software. Paper copies were available if needed, and 42% of the participants chose this alternative.

Participants were required to verify they had received and understood informed consent documents before beginning research measures. Participants provided baseline data, including a background survey and three measures (described below), on average a week before they began the first *IY-ASD* session. Caregivers completed posttest data after completing the final *IY-ASD* session, approximately four months after baseline data collection. Those participants who completed the measures online had up to one week to complete the measures; the remaining participants who chose paper copies completed them at the final *IY-ASD* session. Participants received a \$25 Amazon gift card at each data collection point (up to \$50 total).

Group leaders used a combination of fidelity checklists, participant feedback surveys, and in-person/video supervision to enhance their delivery of *IY-ASD*. Throughout the program, group leaders at both sites followed and completed weekly fidelity checklists, which included a list of required video vignettes and other activities. Like *Basic IY*, fidelity checklists gave *IY-ASD* group leaders the flexibility to select video vignettes and activities that were most applicable to their cohort of parents. *IY-ASD* participants also completed short weekly feedback surveys, which the group leaders used to choose appropriate videos and activities for subsequent group sessions. At the Northwestern site, the *IY* developer periodically observed the group leader in person and provided feedback. Group leaders videotaped sessions at the Southeastern site, and a supervisor from this site with *IY-ASD* training provided weekly feedback to the group leaders on program delivery. A statewide agency also provided ongoing in-person and video consultation to the two Southeastern leaders to deliver *Basic IY;* however, the agency did not offer technical assistance specifically for *IY-ASD*.

# 2.3. Participants

Fifty participants enrolled in the *IY-ASD* program across the two sites. All of these individuals joined the research study (see Fig. 1 for CONSORT flow diagram). One participant completed the program, but did not finish online posttest measures despite reminders. Eight participants did not complete the program, and 41 completed the program and all outcome measures. Five parents provided reasons for discontinuing the program, which included moving (n = 2), work conflicts (n = 1), need for additional support (n = 1), and, a child who did not acclimate to childcare (n = 1). Individuals who discontinued the program completed an average of 1.6 sessions (range = 0-4).

The Southeastern site hosted three *IY-ASD* groups (average group size = 8.7; range = 5–15), whereas the Northwestern site hosted five groups (average group size = 4.8; range = 3–7). Five pairs from the same family (four mother-father couples, and one mother-grandmother pair) participated in *IY-ASD*. The sample size precluded multilevel analyses that could control for couples reporting data on the same child. Thus, we randomly selected one member of each dyad using SPSS v25 (IBM Corp, 2017) for inclusion in the final sample. The final analytic sample was 36 participants (18 from each site).

# 2.4. Measures

All outcome measures were caregiver self-reports. For families with more than one child with ASD, we advised caregivers to choose the target child within the intervention age range for reporting purposes (ages 2–6 years old). If more than one child with ASD in the family fell in this age range, we requested the caregiver report on the youngest child. We did not independently verify ASD diagnoses at the Southeastern site. At this site, caregivers provided external documentation of the child's diagnosis, such as an Individualized Education Program document. All children at the Northwestern site were participants in a clinical applied behavior analysis program for children with ASD. Clinicians independently assessed children at this site to verify an ASD diagnosis.

## 2.4.1. Background survey

The background survey collected both demographic and ASD-related information. Demographic characteristics included variables

such as age, marital status, race, ethnicity, income status, and number of children. We measured age and number of children as continuous variables. Categorical variables included marital status, race, ethnicity, primary language, and income. ASD-related, caregiver-reported characteristics included age of diagnosis with ASD, language ability (nonverbal, minimally verbal, verbal), and receipt of support services (physical therapy, occupational therapy, applied behavior analysis, speech therapy, or other services).

## 2.4.2. Program satisfaction questionnaire (acceptability)

Webster-Stratton (2014) developed the Parent Program Satisfaction Questionnaire – Autism Spectrum and Language Delays Program in order to assess participants' perspectives regarding *IY-ASD* program delivery and outcomes. The questionnaire consists of 34 seven-point Likert scale ratings and 3 open-ended questions. Items address parents' perspectives of their child's behavior, parenting competence, program implementation strategies, utility of parenting techniques, effectiveness of the group leaders, and group format. The questionnaire also asked participants to provide open-ended feedback on needed program improvement, the main program benefit, and whether respondents wanted additional parenting assistance.

# 2.4.3. Parenting stress index-4th edition (PSI)

The PSI (Abidin, 2012) contains 120 items that assess the level of stress in the parent-child relationship. The PSI includes both child- and parent-related stress domains, which are summed to generate a total stress score. Caregivers rate their level of agreement on a 5-point Likert scale, from 1 = strongly disagree to 5 = strongly agree. The PSI has been used in numerous studies of parents of children with ASD (Hayes & Watson, 2013), as well as research evaluating *Basic IY* (Webster-Stratton, 2011). Alpha reliability for the three summary scores is as follows: child domain = .89; parent domain = .93; total stress = .95 (Amaral, Geschwind, & Dawson, 2011). We used the raw PSI scores for statistical significance testing. We also calculated the number of respondents scoring above the 85<sup>th</sup> percentile, the recommended cutoff for clinical significance (Abidin, 2012).

### 2.4.4. Ways of coping questionnaire (WOC)

The WOC (Folkman & Lazarus, 1988) is a 66-item measure that assesses the coping processes one used in a recent stressful encounter. The WOC instructs respondents to reflect on their most stressful encounter within the past week and to answer the questions with this stressful encounter in mind. Caregivers reported how often they used certain coping strategies on a 4-point Likert scale, from 0 = does not apply or not used to 3 = used a great deal. Coping processes are grouped into eight subscales: confrontation, distancing, self-control, seeking social support, accepting responsibility, escape/avoidance, planful problem solving, and positive reappraisal. Previous research focusing on parents of children with ASD has used the WOC (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Pisula & Kossakowska, 2010). One study found the subscales have alpha reliability levels among parents of children with developmental disabilities ranging from 0.64 to 0.83, although the authors did not specify each subscale's alpha level (Glidden, Billings, & Jobe, 2006).

## 2.4.5. Aberrant behavior checklist (ABC) - community

The ABC (Aman & Singh, 1994) is a 58-item symptom checklist used to assess the severity of problem behaviors in both children and adults with developmental disabilities. The ABC has been widely used in ASD research addressing treatment outcomes (Aman et al., 2004) and contains five subscales: irritability, lethargy, stereotypic behavior, hyperactivity/noncompliance, and inappropriate speech. Caregivers rate their child's behavior over the past four weeks on a 4-point Likert scale, from 0 = not at all a problem to 3 =*the problem is severe in degree.* While the ABC manual recommends its use for ages 5 and above, studies have reported this five-factor structure was robust in samples of children and adolescents (ages 3 to 21) with ASD (Brinkley et al., 2007), with good to excellent alpha reliability across subscales for a sample of children ages 2 to 18 (e.g., irritability = 0.92, lethargy = 0.89, stereotypic behavior = 0.85, hyperactivity/noncompliance = 0.93, and inappropriate speech = 0.77; Kaat, Lecavalier, & Aman, 2014). Additionally, the ABC has good convergent and divergent validity in samples of children and adolescents with ASD (Kaat et al., 2014).

## 2.4.6. Missing data

For the PSI, we used mean imputation in cases where three items or fewer were missing from the child or parent domain; no more than one item was missing from a specific subscale; and, no more than five items were missing from the total stress summary items. In the absence of specific guidance in the ABC and WOC manuals, we addressed missing data on these measures by also using mean imputation for each subscale, provided there was no more than one missing item per subscale. All cases analyzed (N = 36) were missing less than 15% total data.

# 2.5. Data analyses

We used descriptive statistics to summarize the background survey and Program Satisfaction Questionnaire; and chi-square and two-tailed independent samples *t*-tests to identify demographic characteristic differences between respondents at each site. We conducted two-tailed paired sample *t*-tests to evaluate pre-post changes in child behavior, parenting stress, and caregivers' coping mechanisms. We also calculated 95% confidence intervals and effect sizes (Cohen, 1994). We considered a *d* of 0.20 a small effect, 0.50 a medium effect, and 0.80 a large effect (Cohen, 1988). We used the Bonferroni method to correct *p*-values for multiple *t*-tests and determined that p < .0031 indicated statistical significance.

To further investigate potential site-level differences, we used two-way repeated measures analysis of variance (ANOVA) for the child behavior, parenting stress, and coping outcomes. We created a dichotomous site variable, such that two groups were formed: 1

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#### Table 1

Sample Characteristics (N = 36).

Variable	Total % (N)	$\frac{\text{Site 1: Northwest}}{(n = 18)}$ % (n)	$\frac{\text{Site 2: Southeast}}{(n = 18)}$ % (n)	X <sup>2</sup> Statistic
Race/Ethnicity of Parent				1.37
White	57.1 (20)	47.0 (8)	66.7 (12)	
Latinx	20.0 (7)	29.4 (5)	11.1 (2)	
African American/Black	8.6 (3)	0.0 (0)	16.7 (3)	
Multiracial	8.6 (3)	11.8 (2)	5.6 (1)	
Asian American	5.7 (2)	11.8 (2)	0.0 (0)	
Race/Ethnicity of Child	0,, (2)	1110 (2)	0.0 (0)	2.33
White	48.6 (17)	35.3 (6)	61.1 (11)	2.00
Latinx	17.1 (6)	11.8 (2)	22.2 (4)	
African American/Black	2.9 (1)	0.0 (0)	5.6 (1)	
Multiracial	14.3 (5)	23.5 (4)	5.6 (1)	
Asian American	17.1 (6)	29.4 (5)	5.6 (1)	
Marital Status	17.1 (0)	29.4 (3)	5.0 (1)	0.52
Married/Partnered	77.4 (24)	82.4 (14)	71.4 (10)	0.52
Not Married/Partnered	22.6 (7)	17.6 (3)	28.6 (4)	
Highest Level of Education	22.0 (7)	17.0 (3)	20.0 (4)	0.15
High School or Less	26.7 (8)	29.4 (5)	23.1 (3)	0.15
College Graduate or Higher	73.3 (22)	70.6 (12)	76.9 (10)	
Annual Household Income	73.3 (22)	70.0 (12)	70.9 (10)	8.08*
\$0 to \$24,999	20.7 (6)	17.6 (3)	25.0 (3)	8.08"
\$0 to \$24,999 \$25,000 to \$74,999	41.4 (12)	23.5 (4)	25.0 (3) 66.7 (8)	
\$25,000 to \$74,999 \$75,000 or more	37.9 (11)	23.5 (4) 58.8 (10)	8.3 (1)	
	37.9 (11)	58.8 (10)	8.3 (1)	0.26
Language Ability Nonverbal		17 ( (2)	00.0 (4)	0.26
	20.0 (7)	17.6 (3)	22.2 (4)	
Minimally verbal	42.9 (15)	41.2 (7)	44.4 (8)	
Verbal	37.1 (13)	41.2 (7)	33.3 (6)	
Support Services Received	25.0 (2)	22.2 (1)		1.00
Physical therapy	25.0 (9)	22.2 (4)	27.8 (5)	1.00
Occupational therapy	75.0 (27)	83.3 (15)	66.7 (12)	0.44
Speech therapy	83.3 (30)	83.3 (15)	83.3 (15)	1.00
Applied behavior analysis (ABA)	30.6 (11)	38.9 (7)	22.2 (4)	0.47
	<i>M</i> (SD)	<i>M</i> (SD)	<i>M</i> (SD)	t-test statisti
Age of Child at Pre-test	3.86 (0.93)	3.83 (0.79)	3.88 (1.08)	-0.15
Age of Child at Diagnosis	2.87 (0.96)	2.88 (0.89)	2.87 (1.05)	0.02
Number of Children in Family	2.47 (1.66)	2.33 (0.59)	2.61 (2.30)	-0.05

Notes: Sample sizes range from 29 to 36 due to occasional missing data; \*p < .05, \*\*p < .01, \*\*\*p < .001. We calculated  $X^2$  test values to assess site differences in race/ethnicity for both caregivers and children using a dichotomous White or non-White variable. Caregivers rated language ability on a 5-point Likert scale, from 1 = nonverbal to 5 = complex sentences.

= Northwestern (Site 1) and 2 = Southeastern (Site 2). This bivariate site variable became the between-subjects factor and time (pre/post) was the within-subjects factor.

We conducted an a priori power analysis using G\*Power. We based the analysis on our primary outcome, total parenting stress as measured by the *PSI*. We estimated the sample size using a medium effect size, which we found in our earlier study of *Basic IY* on the total parenting stress outcome (Dababnah & Parish, 2016a). For a paired sample *t*-test, with power of 0.80, medium effect size (d = 0.50), and alpha = .05, the target sample size was N = 34. We note a power analysis based on a repeated measures ANOVA (medium effect size [f = 0.25]) estimated the same minimum N of 34.

# 3. Results

Most participants completed the program (84%). We used chi-square and two-tailed independent samples *t*-tests to investigate differences between those who did and did not complete the *IY-ASD* program. Children whose caregivers did not complete the program had a significantly lower mean age of ASD diagnosis (M = 1.6 years), versus children whose caregivers did complete the program (M = 2.9 years; p = .003). We did not find any other significant differences between these groups.

Table 1 depicts sample characteristics. Approximately half of the caregivers identified as White (57%) and 20% as Latinx. The majority of children were also White (49%), and 17% were Latinx. Most caregivers were married/partnered (77%) and had graduated college (73%). The mean child age at the start of the intervention was 3.9 years (SD = 0.93); and their mean age at ASD diagnosis was 2.9 years (SD = 0.96). One-fifth of the participants reported their child was nonverbal; 43% were minimally verbal (single words or simple phrases); and, 37% were verbal (simple or complex sentences). The majority of respondents at both sites received support services outside of the *IY*-ASD program, including speech therapy (83%), occupational therapy (75%), and physical therapy (25%). All children at the Northwestern site were engaged in an applied behavior analysis-based program; and 22% of the participants at the

Southeastern site reported receiving applied behavior analysis services. The only statistically significant difference between the two study sites was annual household income, with 59% of respondents from the Northwestern site reporting incomes of \$75,000 or more, compared to only 8% of respondents from the Southeastern site.

# 3.1. Intervention acceptability

Nearly 90% of participants (n = 32) reported that the approach used in the *IY-ASD* program was "greatly appropriate" or "appropriate" to strengthen their child's social and emotional behaviors. All participants reported that they would recommend *IY-ASD* to a friend or relative. Over 90% of participants (n = 33) felt "very positive" or "positive" about achieving their goals using *IY-ASD*, and the vast majority of participants found the program content (97%; n = 35), video vignette demonstrations (97%; n = 35), and group discussions (92%; n = 33) to be "extremely useful" or "useful."

When questioned about the main benefit of the *IY-ASD* program, 12 participants identified a general improvement in their skills addressing challenging child behaviors. As one parent said, "I learned how to teach and work with my child. It took the fear out of not fully understanding brain function, learning, and how to teach [and] play to get learning accomplished and behaviors managed." Other caregivers focused on specific techniques they learned as the main benefit of the *IY-ASD* program, including engaging children with ASD (n = 6); utilizing parent self-regulation in stressful situations (n = 6); and, promoting social-emotional development (n = 3). Some caregivers noted *IY-ASD* components, such as group discussions and support (n = 10); staff support and consistency (n = 4); video vignettes (n = 3); and, role plays (n = 2) as the most beneficial aspect of the program. Factors endorsed by one parent each included the use of props (e.g., puppets), home-based activities, individualized program content, and "everything" about the program.

While 13 caregivers indicated they would not change anything about the program (and two did not respond), the remaining participants (n = 21) offered several suggestions to improve *IY-ASD*. Most commonly, ten caregivers requested a longer program or more time on program content, as one parent noted, "For our family, emotion self-regulation skills and managing misbehavior was central and these were not addressed until late into the class and these were not developed as much as we had hoped when presented." Three participants requested improvement in role plays, with one recommending children's presence during these activities. Other recommendations endorsed by one participant each included increased focus on non-verbal toddlers, minimization of group discussions about tangential topics, slower session pace, simplified weekly lesson reminders, earlier discussion of child transition issues, and an evening session option for working parents.

Finally, when questioned about their need for additional parenting assistance, 12 indicated they wished to engage in more advanced training and support. One participant explained, "[I] would like quarterly or half yearly follow-ups with group and group leader. I would feel more comfortable making sure we are staying on track. Really would like a follow-up class." An additional participant specifically mentioned a desire for continued assistance with self-regulation for both parent and child, while another wanted training in applied behavior analysis and American Sign Language. Other needs expressed were a parent support group (n = 2); additional information on parenting and ASD (n = 2); and, social work services (n = 1). Ten caregivers indicated they did not require additional parenting assistance; the remaining participants did not respond to the question.

# 3.2. Parent stress, caregiver coping, and child behavior outcomes

We used two-way repeated measures ANOVA to investigate differential outcomes by site over time. No interactions between site and time for any outcomes were statistically significant. Thus, Tables 2, 3 show mean pre-post intervention changes in parent stress, coping, and child behavior for the combined sample.

We found significant changes in mean summary scores measuring child-related parenting stress (p < .001, 95% CI [5.73, 16.43]) and total parenting stress (p = .002, 95% CI [6.36, 27.20]), decreasing an average of approximately 11 and 17 points, respectively (see Table 2). The intervention had a medium effect on the summary scores assessing levels of child-related parenting stress (d = 0.55) and total stress (d = 0.54). While average parent-related stress decreased, we detected no significant change on this summary domain or its subscales. Finally, the percentage of participants with scores above the 85<sup>th</sup> percentile (clinical significance) decreased for the parent, child, and total stress domains.

# Table 2

Pre-Post Change ir	Parenting	Stress	(N =	36).
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Parenting Stress Index Summary Scores	% ( <i>n</i> ) with Baseline Percentile Scores > 85%	% ( <i>n</i> ) with Posttest Percentile Scores > 85%	Pre-Test Raw Score M (SD)	Post-Test Raw Score M (SD)	<i>M</i> Difference	95% CI of the Difference	Cohen's d
Child Domain	55.6 (20)	33.3 (12)	148.03 (20.12)	136.94 (20.44)	11.08*	[5.73, 16.43]	0.55
Parent Domain	13.9 (5)	11.1 (4)	(30.34)	(20.44) 129.64 (28.82)	5.69	[-0.92, 12.31]	0.29
Total Stress	22.2 (8)	13.9 (5)	283.36 (44.13)	266.58 (44.40)	16.78*	[6.36, 27.20]	0.54

Notes: p < .0031; CI = confidence interval; M = mean; SD = standard deviation.

#### Table 3

Pre-Post Changes in Coping and Child Behavior (N = 36).

Variable	Pre-Test M (SD)	Post-Test M (SD)	M Difference	95% CI of the Difference	Cohen's d
Aberrant Behavior Checklist					
Irritability	16.94 (10.78)	12.86 (10.23)	4.08	[1.41, 6.76]	0.52
Lethargy	12.28 (9.00)	10.28 (7.99)	2.00	[-0.16, 4.16]	0.31
Stereotypical Behavior	5.31 (5.01)	4.47 (4.93)	0.83	[-0.87, 2.54]	0.17
Hyperactivity/ Noncompliance	23.03 (11.79)	18.36 (11.03)	4.67	[1.16, 8.17]	0.45
Inappropriate Speech	3.00 (2.81)	2.86 (2.50)	0.14	[-0.59, 0.86]	0.07
Ways of Coping					
Confrontive Coping	6.64 (3.16)	7.31 (3.81)	-0.67	[-1.75, 0.42]	0.21
Distancing	6.69 (3.17)	6.78 (3.91)	-0.08	[-0.96, 0.79]	0.03
Self-Controlling	8.92 (3.71)	9.44 (4.21)	-0.53	[-1.76, 0.71]	0.14
Seeking Social Support	8.36 (4.46)	7.89 (3.35)	0.47	[-0.62, 1.56]	0.15
Accepting Responsibility	4.31 (3.00)	4.50 (2.74)	-0.19	[-1.14, 0.75]	0.07
Escape-Avoidance	6.89 (4.93)	6.36 (3.73)	0.53	[-1.07, 2.12]	0.11
Planful Problem Solving	9.64 (3.94)	10.17 (3.47)	-0.53	[-1.67, 0.61]	0.16
Positive Reappraisal	9.22 (4.95)	9.72 (5.87)	-0.50	[-2.36, 1.36]	0.09

*Note:* \*p < .0031; CI = confidence interval; M = mean; SD = standard deviation.

Table 3 shows mean changes in caregiver coping and challenging child behavior between pre- and post-intervention. We did not detect any significant changes in caregiver coping. On the ABC subscales, after correcting for multiple *t*-tests (p < .0031), we did not find any significant decrease in challenging child behaviors. However, two ABC subscales approached significance with small to medium effect sizes: irritability (p = .004, 95% CI [1.41, 6.76], d = 0.52) and hyperactivity/noncompliance (p = .011, 95% CI [1.16, 8.17], d = 0.45).

# 4. Discussion

This study describes the feasibility of the *IY-ASD* program for parents and other caregivers raising children ages 2–6 with ASD in two U.S. sites. We detailed our methods of delivering the program in a pilot trial of eight *IY-ASD* cohorts (N = 36), including group leader training, fidelity checklists, and participant supports. Our research explored 1) participant retention rates and reasons for program/research discontinuation; 2) caregiver acceptability of IY-ASD; and 3) pre- and post-intervention measures of parent and child outcomes. The results provided preliminary evidence that *IY-ASD* is feasible, acceptable to caregivers raising young children with ASD, and may improve parenting stress. Despite geographic, program delivery, and demographic differences between the two U.S. locations, the outcomes were consistent between sites.

## 4.1. Program/research retention and discontinuation

All parents who agreed to participate in the *IY-ASD* program also consented to join the research study. Furthermore, all but one parent who graduated from the program completed follow-up data. It is possible the small incentives and paper/online data collection options we offered increased research participation, although we did not specifically explore this question.

The majority of parents completed the program (84%). This rate is comparable to our previous *Basic IY* study (92%; Dababnah & Parish, 2016c), and recent *Stepping Stones Triple P* trials for parents of children with ASD (75%; Tellegen & Sanders, 2014). Given only five out of the eight people who left the program provided reasons (63%), we cautiously note that none of the reasons were research-related, and four of the five were not related to the program itself. Nonetheless, it is important in future studies to be aware some participants, like one in this study, might need support beyond that offered in *IY-ASD*. Furthermore, all eight participants who discontinued the program left in the first four sessions, highlighting the importance of early program engagement.

We found no differences between those who completed *IY-ASD* and those who discontinued, with one exception. Those who completed the program had, on average, children who were diagnosed at 2.9 years old, compared to the children of those who discontinued (1.6 years old). It is possible that those parents who discontinued the program had more time to intervene with their children and address emerging behavioral challenges; thus, finding the *IY-ASD* material less relevant for their families. Certainly, we need to explore this finding more in future studies.

#### 4.2. Program delivery and supports

Most of the participants in this study were highly educated and partnered. However, nearly one in five caregivers in this study identified as Latinx and one in four caregivers had a high school education or less; both groups that are underrepresented in ASD research (Jamison et al., 2017; Lord et al., 2005; Magaña & Ghosh, 2010). Furthermore, the majority of parents reported their children were nonverbal or minimally verbal, a group of children whose needs have not been adequately explored in the literature

(Maglione, Gans, Das, Timbie, & Kasari, 2012; Tager-Flusberg & Kasari, 2013). As recommended by parents in our earlier research with *Basic IY* (Dababnah & Parish, 2016c), we provided various supports such as inclusion of partners, childcare, meals, and transportation assistance. It is possible that these efforts to reduce program participation barriers facilitated the inclusion of traditionally underserved children and their families. Nonetheless, clearly more work must be done to increase the diversity of children and their families in ASD interventions. For example, *IY-ASD* could incorporate some in-home sessions, which have been used in other studies with families with limited resources (Carr & Lord, 2016; Carr et al., 2016). In-home sessions might also align with participants' suggestions in this study to involve their children in the role plays.

The majority of caregivers in this study reported their children were receiving other services besides *IY-ASD*. Larger trials should consider the impact of these services on *IY-ASD* outcomes. We believe these findings support our earlier conclusions (Dababnah & Parish, 2016c) that *IY-ASD* can be a complement to other ASD interventions specifically for the child. Thus, more work is needed to understand how *IY-ASD* can be used effectively as part of a comprehensive service plan for children with ASD and their families.

In addition to supports for parents, the group leaders also received extensive support to deliver the program with fidelity, including pre-intervention *IY-ASD* training and consultation during program delivery. We highly recommend future group leaders have prior experience with *Basic IY* and knowledge of ASD before beginning *IY-ASD* training. Agencies planning to offer *IY-ASD* should consider the initial training and ongoing supervision involved in carrying out *IY-ASD*, along with the associated costs. Furthermore, as each site will serve different populations with diverse needs, we recommend a planning and community engagement phase to consider options such as group size, number of group leaders, availability of program supports, and other factors.

### 4.3. Intervention acceptability

Program participants overall reported high acceptability of *IY-ASD*. Nearly all of the caregivers were satisfied with program content and methods. Many parents identified specific behavior management skills, as well as program components such as group discussions and role plays, that were useful. Some parents requested programming that extended beyond 13–15 weeks. This suggestion for improvement aligned with participants' requests for more advanced training and support, as well as with the recommendations in our previous research that adapted *Basic IY* for caregivers of children with ASD (Dababnah & Parish, 2016c). Furthermore, in our experience delivering the program, we have found the needs of children with ASD can be complex and difficult to address in shorter periods. Nonetheless, cost and logistical barriers can be prohibitive to longer program periods. Future research should examine program length and its association with parent/child outcomes. Regardless of program length, we believe it is critical that future *IY-ASD* group leaders intentionally connect families with ongoing support as caregivers transition out of the program.

#### 4.4. Pre-post intervention changes in parent and child outcomes

Consistent with our earlier research of *Basic IY* adapted for caregivers of preschoolers with ASD (Dababnah & Parish, 2016a), we found statistically significant improvements in total and child-related parenting stress scores, but no significant changes in parent-related stress. One potential reason for the lack of significant change in parent-related stress was low baseline levels on this domain, which suggests parents' stress originated from primarily child-related factors. Only five out of the 36 participants (14%) in this study reported clinically significant parent-related stress scores at baseline, compared to the 20 (56%) participants who reported clinically significant child-related stress at baseline. Due to the limited number of participants in our study with elevated baseline levels of parent-related stress, we could not evaluate differences between this subgroup's outcomes and those with lower levels of parent-related stress. However, a randomized controlled trial of a training program for caregivers of young children with ASD found intervention effects only for those parents with preexisting mental health issues (Tonge et al., 2006). Thus, future *IY-ASD* research with larger samples should investigate potential differential effects for caregivers reporting elevated baseline levels of stress, depression, and other parent characteristics.

Despite addressing parent coping strategies within the program, we did not find any significant changes in coping as measured by the WOC. In addition to the possibility that *IY-ASD* simply did not affect parents' coping skills, it is also feasible the follow-up time was not long enough to allow us to detect significant changes. Further, while studies have used the WOC measure for parents of children with ASD (Pisula & Kossakowska, 2010), the instructions do not request that respondents reflect on stressful situations specifically related to their children. Future studies involving this population should consider directly soliciting caregiver' coping strategies related to their child.

Similarly, we detected no significant decreases in child behavior challenges. Like the coping measure, it is possible the ABC was not sensitive enough to detect pre/post intervention changes, or this measure did not accurately capture challenging child behaviors in this population of children ages 2–6. Subsequent studies involving young children could consider using measures specifically developed for this developmental period. We note, however, the hyperactivity/noncompliance and irritability subscales approached significance. Future research should explore if *IY-ASD* can promote children's accommodation of parents' requests, and decrease children's instances of agitation, crying, and other irritable behaviors. Nevertheless, it is also feasible that *IY-ASD*, which focuses primarily on social communication and self-regulation, did not impact the behavioral challenges measured by the ABC. These findings suggest individualized interventions might be needed to address certain ASD-related symptoms, such as stereotypies, which can identify and demonstrate appropriate replacement behaviors (Wacker, Peck, Derby, Berg, & Harding, 2006).

# 4.5. Limitations

We caution readers to consider this study's limitations when interpreting its results. These limitations include the small sample size, which precluded our ability to examine outcomes between specific subgroups of caregivers and their children, including potential differential effects based on race, ethnicity, gender, language ability, and other factors. The small sample size also prevented us from conducting analyses that could control for multiple sample differences simultaneously. We only collected acceptability data related to *IY-ASD*, and thus could not directly explore participants' acceptability of the research processes. Also, while somewhat ethnically diverse, the majority of participants were highly educated and married, limiting the generalizability of our findings. Furthermore, all the outcome measures were parent self-report, which could lead to social-desirability and/or recall bias. The prepost design limits examination of changes to those immediately following the intervention. Moreover, the one-group design did not allow us to control for selection bias or other potential factors that influenced pre-post changes. Finally, none of the group leaders were accredited *IY-ASD* facilitators at the time of the study. Despite these limitations, experienced leaders, who used fidelity checklists and weekly participant feedback to ensure consistent program delivery while customizing to parents' individual needs, carried out the groups. Our findings related to program delivery, acceptability, outcome measures can inform larger trials to rigorously examine the effectiveness of *IY-ASD* to improve parent and child outcomes.

## 5. Implications

We piloted a recently adapted intervention, originally developed for children with conduct disorders. The adapted intervention, *IY-ASD*, aims to improve both child and caregiver outcomes in families raising preschoolers with ASD. This research conducted in two U.S. sites provided initial evidence that the intervention is feasible and acceptable, and holds promise in reducing parenting stress. A randomized controlled trial is needed to rigorously test the outcomes of *IY-ASD*. While outside of the scope of this research, it would be useful to conduct cost-effectiveness analyses as part of larger trials. Future research should also consider testing longer-term follow-up beyond post-intervention to ascertain if improvements are maintained. It is particularly important to include families who might be especially vulnerable to stress and other poor outcomes, including those caregivers with preexisting mental health issues, single parents, and those with limited education. Despite high levels of parenting stress, empirically supported interventions for caregivers of children with ASD continue to be scarce in the current service array. Thus, evidence to support *IY-ASD* or other parenting interventions are critically needed to promote positive outcomes for young children with ASD and their families.

# Conflict of interest statement

The Authors declare they have no conflicts of interest relevant to this study to disclose.

## Acknowledgements

The Authors are grateful to the families who participated in this research. Further, we are indebted to our colleagues at the Onslow County Partnership for Children, particularly Stacie Huntington, Seth Allen, and Molly DeWitt. We thank Dr. Fernando Wagner and Dr. Paul Sacco for their helpful comments on an earlier version of this manuscript. We acknowledge the support of a Competitive Innovative Research Award from the University of Maryland, Baltimore for funding research costs associated with this study (PI: Dababnah). We also appreciate the support of Smart Start North Carolina and Providence General Foundation, who partially funded program implementation costs. We are also grateful to The Duke Endowment for partially funding Dr. Dababnah's and Dr. Nichols' time during the preparation of this manuscript. No funders had any role in the study design; the collection, analysis or interpretation of data; the manuscript preparation; or, the decision to submit the article for publication. Finally, we appreciate Carolyn Webster-Stratton for providing training and consultation on program implementation. Dr. Webster-Stratton was not involved in any aspects of the research, including the data collection, analyses, or manuscript preparation.

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