

PILOT TRIAL OF *THE INCREDIBLE YEARS* FOR PARENTS OF PRESCHOOL CHILDREN
WITH AUTISM SPECTRUM DISORDER

Sarah Dababnah

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Approved by:

Natasha K. Bowen

Susan L. Parish

Kathleen A. Rounds

Joan Yoo

Irene N. Zipper

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ABSTRACT

Sarah Dababnah: Pilot Trial of *The Incredible Years* for
Parents of Preschool Children with Autism Spectrum Disorder
(Under the direction of Susan L. Parish)

Parents raising young children with Autism Spectrum Disorder (ASD) experience disproportionately high levels of stress and burden, which are associated with a plethora of other negative child and family outcomes. Yet, few interventions address parent mental health or related outcomes in this population.

Chapter 1 describes a comprehensive review of randomized controlled trials which included parents of preschool-age children with ASD. Seven interventions met the review criteria. The studies were strengthened by the use of fidelity measures and developmentally-appropriate interventions. However, while all of the studies collected parent measures, none reported significant posttest improvements in parent mental health or other outcomes. Furthermore, numerous issues, such as unclear randomization strategies, small sample sizes, and poor external validity further limited the ability to draw significant conclusions regarding the promise of the interventions. The chapter concludes with a call to develop and rigorously test family-centered interventions aimed at improving both child and parent outcomes.

Chapter 2 highlights the feasibility of implementing an existing evidence-based practice, *The Incredible Years*, tailored to parents of children with ASD. Two groups of parents raising preschool-age children (ages 3 to 6) with ASD ($N=17$) participated in a 15-week pilot trial of the intervention. The fidelity of the program was generally maintained, with the exception of

program-specific videos. Qualitative data from individual post-intervention interviews reported parents benefited most from child emotion regulation strategies, parent stress management, social support, and visual resources.

Chapter 3 reports on a mixed method test of the acceptability and results from the trial described in Chapter 2. Attendance was high (88% to 100% weekly) and attrition was modest (18%). Participants reported high acceptability of all aspects of the program (mean 3.3 out of 4). Parent stress decreased significantly after program completion, as compared to baseline. Parents highlighted several barriers to their success in the program, including trouble finding time to focus on their own needs and difficulty applying some program content (e.g., time-out for noncompliance) to children with sensory or self-regulation challenges. However, parents reportedly enjoyed the strengths-based, play-based approach of the program, as well as opportunities for social support and peer learning.

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CHAPTER 1

A COMPREHENSIVE LITERATURE REVIEW OF INTERVENTIONS FOR PARENTS OF YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDER

An Autism Spectrum Disorder (ASD) is a complex neurodevelopmental problem characterized by social communication challenges (both verbal and non-verbal) and restricted or repetitive behaviors or interests (American Psychiatric Association, 2013). The Centers for Disease Control and Prevention (CDC) estimate an average of 1 in 68 children have ASD (Centers for Disease Control and Prevention, 2014). Approximately 31% of children with ASD have a co-occurring intellectual disability (IQ of 70 or below) (CDC, 2014). Male children are at higher risk, with prevalence rates at 1 in 42 versus 1 in 189 for females (CDC, 2014).

Given the nature of a spectrum disorder, individuals with ASD can exhibit mild to severe symptoms. A child who displays the primary hallmarks of ASD (difficulty with communication/language and social interactions, and repetitive behaviors and routines) is inherently challenged to express his/her needs to others. Consequently, the prevalence of anxiety or externalizing behaviors such as aggression or conduct issues among children with ASD is high (Barnhill & Horrigan, 2002; Kanne & Mazurek, 2011; Lainhart, 1999; Mandell, 2008). Self-injurious behaviors, often used to satisfy heightened needs for stimulation, are also common in this population (Baghdadli, Pascal, Grisi, & Aussiloux, 2003; McClintock, Hall, & Oliver, 2003; Symons, Sperry, Dropik, & Bodfish, 2005).

In May 2013, the American Psychiatric Association released the fifth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), which eliminated past

subcategories such as Asperger syndrome and Autistic Disorder. The core change in the DSM-V is the combination of communication and social challenges into one dimension of the diagnostic criteria. In addition to the new umbrella category of ASD, a new diagnosis similar to ASD, Social (Pragmatic) Communication Disorder was added. A recent study found about 32% of children previously diagnosed with Pervasive Developmental Disorder – Not Otherwise Specified and 8% of children previously diagnosed with Asperger syndrome would now receive the diagnosis of Social Communication Disorder (Kim et al., 2014). While the remainder of this paper cites research using previous DSM criteria, Kim and colleagues emphasize that the prevalence of children with either ASD or Social Communication Disorder (DSM-V) is nearly identical to the autism subtypes as specified in the previous DSM.

Raising a Young Child with ASD: Parent Stress and Well-Being

Parents raising children with ASD, particularly children under age 5, encounter disproportionately high levels of stress (Baker, Blacher, Crnic, & Edelbrock, 2002; Herring et al., 2006; Keogh, Garnier, Bernheimer, & Gallimore, 2000). Parenting stress and psychological distress are higher among mothers of preschool children with ASD, compared to mothers of children with other developmental disabilities (Estes et al., 2009). Some studies have noted mothers and fathers with preschool children with ASD do not differ significantly on reports of stress, although researchers found significantly higher levels of maternal anxiety and depression (Hastings, 2003; Hastings et al., 2005). However, a more recent study found mothers of children with ASD experience more stress than fathers (Dabrowska & Pisula, 2010), suggesting an area in need of further inquiry.

Stress related to raising a child with ASD is associated with a variety of negative child, parent, and family outcomes. For example, community-based research on children with ASD

found parent stress had an inverse association with effectiveness of early child learning (Osborne, McHugh, Saunders, & Reed, 2008). Furthermore, parent stress in mothers of children with ASD has been strongly correlated with more depressive symptoms and lower levels of well-being (Phetrasuwan & Shandor Miles, 2009). Finally, researchers have reported an association between parent stress and poor mental and physical health-related quality of life for families raising children with high-functioning ASD (Lee et al., 2009).

Research has focused mostly on child outcomes related to parent stress. In particular, the association between parent stress and problem behaviors of children with ASD has been well established (Bromley, Hare, Davison, & Emerson, 2004; Estes et al., 2009; Hastings & Brown, 2002; Phetrasuwan & Shandor Miles, 2009; Tomanik, 2004). Moreover, the relationship between child behavior and parent well-being begins early. In one study of families of 123 preschoolers with ASD and other developmental disabilities, parent stress, mental health, and family dysfunction were associated with emotional and child behavior problems from young ages, and these findings were sustained at one-year follow-up (Herring et al., 2006). In total, these findings suggest the importance of early intervention to reduce both child behavioral challenges and parent stress.

Despite compelling findings of extraordinarily high levels of parent stress and challenging child behaviors in this population, many interventions aimed at young children with ASD do not include their parents (Boyd, Odom, Humphreys, & Sam, 2010). Furthermore, a review of parent-implemented early interventions for young children with ASD reported only four treatments met their full criteria (McConachie & Diggle, 2007). All of these interventions were directed exclusively towards the indicated child's behavior, and did not include aspects to directly address parent stress or well-being.

In light of family stress theories, which consider the child within his or her family, the lack of such interventions is concerning. For example, Boss' Contextual Model of Family Stress (2002) emphasized individual responses to stress are heavily influenced by their family system and environment. This theory also highlighted the importance of understanding a family's developmental stage, and how times of transition can be especially vulnerable times for family crisis. Boss' family stress theory is well-supported by the ASD literature on the interrelationship between parent stress and various child, parent, and family outcomes.

In the context of the Contextual Model of Family Stress (Boss, 2002), the aim of the current paper is to review published studies of interventions over a twelve-year period that target both young children under age five with ASD and their parents. McConachie and Diggle (2007) highlighted the lack of rigorous intervention research in the field, including poor external validity, use of nonstandardized diagnostic and measurement tools, and lack of long-term follow-up. In a review of education programs aimed at parents of children ages 3 to 5 with ASD, Schultz and colleagues (2011) reported 70% of reviewed studies used single-case designs. Thus, the current review is focused on randomized controlled trials, specifically their samples, study designs, analytic methods, measures, and generalizability.

Method

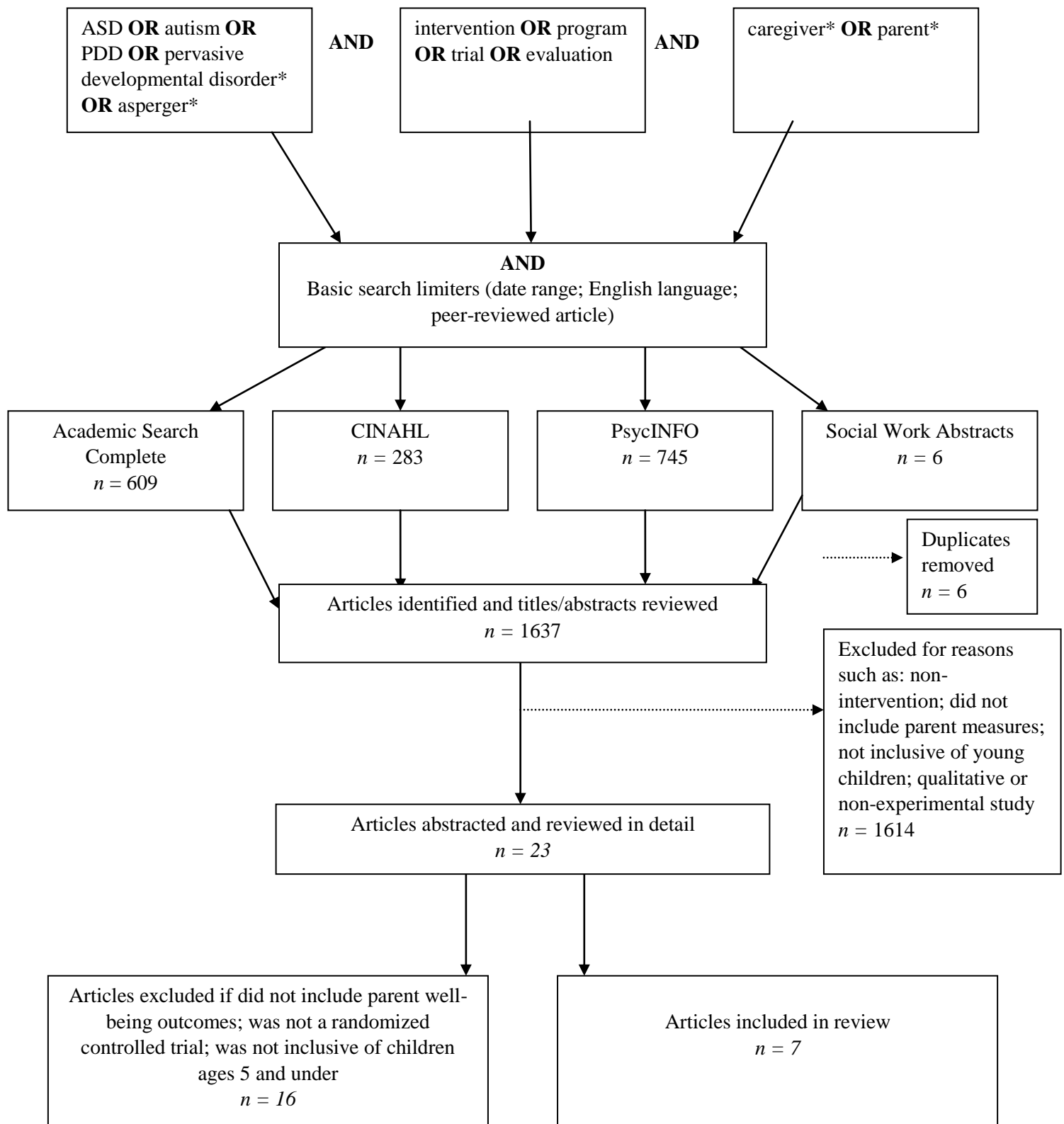
To determine the quantity and quality of available early intervention programs geared to improve child behavioral outcomes and parent well-being, including stress, depression and coping mechanisms, a comprehensive search of the international research literature was conducted. Peer-reviewed intervention studies published in English between January 2000 and December 2012 were included, based on the following criteria:

- Detailed an ASD-specific behavioral or educational program involving parents, including those developed for a specific autism subtype under previous DSM criteria (e.g., Asperger's syndrome)
- Involved children ages 5 and under with ASD and their caregivers
- Employed a randomized experimental design (random assignment to treatment and control or comparison groups)
- Explicitly tested the impact of the intervention on at least one parent outcome of well-being (e.g., stress, depression, coping skills) or parent adaptation (e.g., parent-professional alliance), not including parent-report measures of child characteristics (e.g. Child Behavior Checklist) or parent satisfaction surveys.

A broad search of Academic Search Complete, CINAHL with Full Text, PsycINFO, and Social Work Abstracts databases for autism-related intervention studies published from January 2000 to December 2012 was conducted. The title must have included one of the following words: “ASD,” “autism,” “PDD,” “pervasive developmental disorder*,” or “asperger*.” The search also included keywords “intervention,” “program,” “trial,” “evaluation,” “parent*,” or “caregiver*.” Reference lists of review articles and other relevant study reports were also inspected. Abstracts were reviewed to determine basic eligibility, and potential articles were then examined in more detail, including references. Dissertations, book chapters and publications that did not undergo peer review were excluded. See Figure 1.1 for a depiction of the search strategy.

Figure 1.1

Article Review Flow Diagram



Results

Sample

In total, 1637 articles were retrieved with these broad search keywords. Once abstracts and full articles were reviewed, seven articles met the full selection criteria described above (Aldred, Green, & Adams, 2004; Drew et al., 2002; Roberts et al., 2011; Rogers et al., 2012; Smith, Groen, & Wynn, 2000; Tonge et al., 2006; Welterlin, Turner-Brown, Harris, Mesibov, & Delmolino, 2012). Key findings extracted from each article are detailed, within the framework of their sampling methods, study design and analytic strategies, measures of parent outcomes and fidelity, and generalizability. The findings are summarized in Tables 1.1 and 1.2.

Description of Interventions

All seven article described interventions which were child-focused with a parent training component. (See Table 1.1.) Because children under age 5 and their families were of interest, interventions were evaluated to determine if they were developed specifically for that population. One intervention was for children of any age, although the upper age limit in this sample was 5 years, 11 months (Aldred et al., 2004). The remaining six interventions targeted children ages 6 and under (Aldred et al., 2004; Drew et al., 2002; Roberts et al., 2011; Rogers et al., 2012; Smith et al., 2000; Tonge et al., 2006; Welterlin et al., 2012). Drew and colleagues (2002) and Rogers et al. (2012) concentrated specifically on children under age 2, while Welterlin et al. (2012) studied children between 2 and 3 years of age.

The intervention types were diverse. Two studies utilized child-parent social communication training (Aldred et al., 2004; Drew et al., 2002), which entails the promotion of joint attention skills, a general precursor to language development (Charman et al., 2003). A second type of intervention, presented by Smith, Groen, and Wynn (2000), was a modification of

Table 1.1

Interventions and Measures

First Author and Year	Intervention	Participants	Parent Measures	Parent-related Findings
Aldred 2004	Clinic-based social communication training (child directed)	$N = 28$; median child age: 48/ 51 months (treatment/ control)	Parenting Stress Index; Parent-child interaction videotapes	No significant differences in stress; significant increase in synchronous and child communication acts
Drew 2002	Home-based social communication training (adult directed)	$N = 24$; mean child age: 21/24 months (treatment/ control)	Parenting Stress Index	No significant differences in stress
Roberts 2011	Home- and clinic-based Building Blocks (early intervention program using a variety of modalities, including structured teaching)	$N = 84$; mean child age: 3.5 years	Beach Center Family Quality of Life Scale; Parenting Stress Index - Short Form; Parent Perception Questionnaire	No significant between-group stress findings; mixed findings on Quality of Life and Parent Perception questionnaires
Rogers 2012	Clinic-based, parent-delivered Early Start Denver Model	$N = 98$; mean child age: 21 months	Symptom Checklist-90-R; Working Alliance Scale for Intervention with Children	Symptom Checklist only collected at baseline; treatment group reported stronger working alliances with therapists compared to control
Smith 2000	Home/school-based version of Applied Behavior Analysis	$N = 28$; mean child age: 36 months	Family Satisfaction Questionnaire	No significant between-group findings
Tonge 2006	Parent Education and Behavior Management training package	$N=135$; mean child age: approx. 45 months+	General Health Questionnaire; Parenting Stress Thermometer; McMaster Family Assessment Device	No significant findings; authors found an interaction between level of parent symptomology and treatment effect
Welterlin 2012	Home TEACCHing Program (home-based structured teaching model)	$N=20$; mean child age: 30 months	Parenting Stress Index	No significant differences in stress

Applied Behavior Analysis pioneered by Lovaas et al. (1981) called Early Intensive Behavioral Intervention. Rogers and colleagues (2012) reported the results of an intervention study which used components of Applied Behavior Analysis, The Early Start Denver Model. Two studies (Roberts et al., 2011; Welterlin et al., 2012) employed components of structured teaching approaches, pioneered by Schopler, Mesibov, and their colleagues (Mesibov et al., 2004). Finally, Tonge et al. (2006) reported findings from a parent education training program. The Tonge et al. research was the sole study in this review whose primary outcome was parent mental health. The seven interventions are briefly summarized below.

Aldred and colleagues (2004) aimed to improve parents' communication with their children. They utilized a clinic-based approach, in which both randomly-assigned groups received treatment as usual (routine local care) ($N=28$). In addition, the treatment group received a series of psycho-educational workshops, followed by six monthly parent-child sessions, and finally six months of individualized maintenance. The training was child-directed, in which parents were encouraged to respond to any attempt on the part of the child to communicate.

Similar to Aldred et al.'s (2004) study, Drew and colleagues (2002) developed a home-based program focused on joint attention. All children in the study received local services ($N=24$). The randomly-assigned treatment group received an intervention in which consultants visited families' homes every six weeks for three hours. Parents were encouraged to promote adult-directed games, joint attention routines, and behavior management into everyday activities.

Roberts et al. (2011) analyzed the results of a 40-week program, Building Blocks, with both clinic-based and home-based conditions ($N=56$). Those families on the waitlist ($N=29$) were invited to be part of a (nonrandomized) comparison group. For families randomized to the clinic-

based condition, each two-hour weekly session engaged children and their parents in separate group-based instruction. The children's program was partly staff-directed, with a focus on their integration into school. The parents' groups focused on a wide range of factors relating to caring for children with ASD, such as sensory issues. Families in the home-based condition received half of the services the clinic-based families received. The home-based program involved a program staff member visiting families' homes for two hours every two weeks (20 sessions).

Rogers and colleagues (2012) analyzed the results of a parent-implemented version of the Early Start Denver Model. Families in three sites were randomized to a treatment or treatment as usual (community services) group ($N=98$). The intervention consisted of a 12-week, clinic-based program in which a therapist coached parents in a range of skills, including joint attention and Applied Behavior Analysis techniques. The child attended the hour-long sessions, and parents were given feedback from therapists based on parent-child play.

Smith and colleagues (2000) implemented a three-year, home-based program, Early Intensive Behavioral Intervention, modeled on Lovaas' Method of Applied Behavior Analysis. The Lovaas Method of Applied Behavior Analysis for children with ASD entails a play-based, child-directed, individualized one-on-one therapy in which the therapists (including parents-as-therapists) reinforce and prompt positive social or communicative behaviors. Smith et al. (2000) aimed to improve children's cognitive, adaptive, and socioemotional skills, although parents were heavily involved in the intervention. Families in the treatment group ($N=15$) received 25 to 30 hours of in-home training per week for the first year, with gradual reductions over the following two years. Once children mastered basic skills at home, the intervention was shifted to naturalistic locations such as classrooms. Parents in the control group ($N=13$) participated in 3 to 9 months of in-home training for an average of 5 hours per week. Both treatment and control

conditions relied on the fundamental concepts of Early Intensive Behavioral Intervention; thus, the differences in the conditions were the intensity and duration of the treatments.

Tonge et al. (2006) investigated the effects of a parent education and behavior management program over four sites ($N=105$). The authors grouped parents into three conditions: Parent Education and Behavior Management ($N=35$), Parent Education and Counseling ($N=35$), and control (no treatment; $N=35$). Parents in the behavior management condition received group- and individual-based instruction in specific skills, such as features of ASD and issues related to parent stress. A variety of teaching modalities were used, including videos, role plays, and homework. Parents in the counseling condition received a similar program as those in the behavior management groups, except the individual sessions were less directive and contained no homework or skills training. Both treatments were delivered by therapists over a 20-week period, with alternating weeks of 90-minute group sessions and 60-minute individual family sessions.

Welterlin and colleagues (2012) examined a home-based TEACCH (Treatment of Autistic and Related Communication Handicapped Children) program for very young children. The structured teaching approach involves various strategies such as visual prompts, highly individualized goals, and structured work spaces. Families were assigned to treatment or waitlist control ($N=20$). Parents in the treatment condition received instruction from a therapist in 1.5-hour sessions for 12 weeks.

Intervention Manualization and Fidelity

Important prerequisites of measuring the efficacy and effectiveness of interventions are the manualization of interventions and collection of fidelity measures (Fraser, Richman, Galinsky, & Day, 2009). All but one of the seven studies (Drew et al., 2002) reported

manualization of their interventions. In particular, Early Intensive Behavioral Intervention, utilized by Smith and colleagues (2000), has been manualized and used extensively (e.g., see comprehensive review, Reichow & Wolery, 2009). Notably, while the center-based Building Blocks intervention cited by Roberts et al. (2011) is manualized, it is not clear if the home-based condition is as well. Finally, while Welterlin and colleagues (2012) utilized a home-based version of a manualized intervention (TEACCH), it is not clear if the home-based condition was manualized.

Two studies did not report the use of fidelity measures (Aldred et al., 2004; Drew et al., 2002). The remaining five articles reported assessing fidelity (Roberts et al., 2011; Rogers, et al., 2012; Smith et al., 2000; Tonge et al., 2006; Welterlin et al., 2012), although generally it was not clear if these measures were adequate based on the descriptions provided.

Sampling Strategies

ASD represents a diverse range of symptoms, including intellectual disabilities. The studies ranged in their characterizations of how researchers recruited and included (and excluded) children across the spectrum and their families. In turn, these sampling decisions affect how one can generalize causal inferences from these studies to broader populations. Five studies (Aldred et al., 2004; Drew et al., 2002; Roberts et al., 2011; Rogers et al., 2012; Tonge et al., 2006) used at least one of the following standardized instruments to diagnose ASD: Autism Diagnostic Observation Schedule (Lord, Rutter, DiLavore, & Risi, 1999), Autism Diagnostic Interview (Le Couteur et al., 1989), Autism Diagnostic Interview – Revised (Rutter, Le Couteur, & Lord, 2003), or Autism Diagnostic Observation Scale for Toddlers (Luyster et al., 2009). Smith and colleagues (2000) determined ASD diagnoses by two sets of clinical psychologists independent of the research study. Welterlin and colleagues (2012) provided little

information about the diagnostic method used to assess participants. Rather, children were eligible if they had “a clinical diagnosis of autism” (p. 1829).

Despite the use of standardized assessment tools, not all children met the instruments’ clinical cut-offs for ASD. For example, four children in Aldred et al.’s study (2004) and 10 children in Roberts et al.’s study (2011) did not have ASD per the Autism Diagnostic Observation Schedule. Furthermore, Aldred et al. (2004) excluded children with severe developmental delays; visual or hearing impairments; “severe environmental deprivation in infancy” and those with “no evidence of any desire to interact with adults” (p. 1423). This exclusion criteria likely excluded families of children with the most significant needs. Roberts et al. (2011) also excluded children who were determined to be unready for a center-based program by parents or staff. In another example, Drew and colleagues (2002) reported their entire sample did not meet the clinical cut-off for ASD on the Autism Diagnostic Interview – Revised.

Most authors did not include sufficient information to determine if children with co-occurring intellectual disabilities were included in the samples. Smith et al. (2000) noted children with low IQs were not excluded. However, children with co-occurring medical or developmental issues (e.g. blindness, Down syndrome) were not eligible, which could be significant. For example, the prevalence of children dually diagnosed with Down syndrome and ASD is five percent (DiGuseppi et al., 2010). Matson and Shoemaker (2009) provide a thorough overview of the overlap between ASD and intellectual disabilities, and highlight research on the tendency to focus on children without cognitive impairments. Thus, the lack of information on the inclusion of children with both ASD and intellectual disabilities limits understanding of the full spectrum of children in these studies.

Generalizability of Samples

The generalizability of a study, or its external validity, largely depends on how well a study sample reflects the broader population. ASD is a diagnosis which affects individuals regardless of ethnicity or socioeconomic status. Yet, the interventions varied in the diversity of their samples. (See Table 1.2.) Below, the studies' sample characteristics are summarized by the racial and ethnic makeup of the samples, socioeconomic status, and inclusion of fathers.

Race and ethnicity. There was little racial or ethnic diversity in the samples for which racial/ethnic information was provided. Three studies did not report the racial and ethnic backgrounds of their participants (Drew et al., 2002; Roberts et al., 2011; Tonge et al., 2006). However, Roberts et al. (2011) did report that two participants (3%) exclusively spoke a language other than English at home and 12 (15%) spoke a language in addition to English. Another study included mostly White participants, with only two African-Caribbean children out of a total of 28 (Aldred et al., 2004). Rogers and colleagues (2012) reported 69% of intervention group and 76% of control group were White. Smith et al. (2000) reported a majority of the participating children were non-Hispanic White, but children from Hispanic, non-Hispanic Black, and Asian backgrounds were all represented. Welterlin and colleagues (2012) reported 90% of their intervention group and 70% of their control group was White.

Socioeconomic status. In general, if reported, the samples were not diverse in terms of socioeconomic status. Aldred and her colleagues (2004) had a highly-educated sample, with a range of years of education from 16 to 21. They reported their sample was “predominantly middle class” (p. 1423) in terms of income. Likewise, Smith and his colleagues (2000) reported their sample was largely average income and highly-educated. Roberts et al. (2011) had a sample with predominantly high incomes, although maternal education was more diverse than other

Table 1.2

Interventions and Diversity

First Author and Year	Inclusion of Fathers	Race & Ethnicity	Socioeconomic Status
Aldred 2004	Included; composition unclear; response to intervention unclear	Sample White with exception of 2 African-Caribbean children	Sample highly-educated; majority "middle class" income
Drew 2002	Included; composition unclear; response to intervention unclear	Not reported	Not reported
Roberts 2011	Not reported	Not reported (reported 18% of sample spoke language other than English at home)	Sample reported diverse range of maternal education; predominantly high incomes
Rogers 2012	Not reported	Sample White toddlers: 69% (treatment) and 76% (control)	Sample reported range of maternal education and household income
Smith 2000	Not reported	Sample majority White, with small representation of Hispanic, non-Hispanic Black, and Asian children	Sample majority highly-educated and average income
Tonge 2006	Included; precise composition unclear; response to intervention unclear	Not reported	Sample reported range of socioeconomic status
Welterlin 2012	Included; precise composition unclear; response to intervention unclear	Sample majority White: 90% (treatment) and 70% (control)	Sample reported majority maternal education high; household income not reported

studies (14% with high school education versus 16% with postgraduate education). Tonge et al. (2006) reported a range of principal caregivers' socioeconomic status. While Welterlin et al. (2012) did not report socioeconomic status, 90% of their sample reported maternal education to be "some college or more." Rogers et al.'s (2012) community sample was more diverse in terms of household income than other studies (approximately 1/3 had a household income of \$50,000 or less), as well as compared to their treatment group (22% had similar incomes). Their sample reported a range of maternal education as well, but the community sample had fewer highly-educated individuals. One study did not describe participants' socioeconomic status (Drew et al., 2002).

Inclusion of fathers. Given some research has found mothers and fathers of children with ASD vary in levels of stress and mental health (Dabrowska & Pisula, 2010; R. P. Hastings, 2003), caregivers could potentially respond quite differently to the same intervention. Nonetheless, the studies widely varied in their report of the number of fathers and mothers in the surveys, as well as their differential outcomes.

Aldred et al. (2004) included both fathers and mothers, but did not report on their numbers or composition in the study. They only included mothers in videotaped parent-child interactions, but gave no explanation for this choice. Further, there was no indication of which parent completed the Parenting Stress Index. Similarly, Drew et al. (2002) included both fathers and mothers, but omitted information on their numbers and composition in the study. From their report, it appears both mother and fathers completed the Parenting Stress Index, but results did not differentiate between mothers' and fathers' responses. Finally, Tonge and colleagues (2006) collected information from the "principal caregiver," which they reported in all but four cases were the mothers of the children. However, other caregivers were allowed to attend the program

and did so half of the time. The findings did not differentiate between mothers', fathers', or other caregivers' responses.

Roberts et al. (2011), Rogers et al. (2012), and Smith et al. (2000) did not report on the number of mothers or fathers in their studies, nor if there were different intervention responses by gender. While Welterlin and colleagues (2012) did not report on the differential outcomes of mothers and fathers in their research, they did indicate which parent participated in the single-subject design part of their study. In all but one of the six cases, the participant was the mother.

Study Design and Analytic Methods

Consistent with the inclusion criteria, all of the studies reviewed here were randomized controlled trials. The randomization process is intended to minimize most threats to internal validity, such as selection bias or maturation. However, one significant threat to internal validity that randomized controlled trials do not avoid is attrition, which can change the nature of the sample after randomization (Shadish, Cook, & Campbell, 2002). Another possible confounder to causal inference which a randomized controlled trial cannot mitigate is differential receipt of alternate therapies in treatment versus control groups. Finally, unclear analytic methods create difficulty in statistically assessing a causal relationship between intervention and outcomes. These major design and analytic themes are summarized below.

Unclear randomization methods and attrition challenges. Proper randomization is a critical first step to promote similarity between treatment and control groups (Shadish et al., 2002). Drew et al. (2002), Rogers et al. (2012), and Welterlin et al. (2012) all reported clear randomization strategies to assign individuals to groups and adequately described their analytic methods. However, as detailed in the current and following sections, the remaining four studies

insufficiently explained their randomization or analytic methods, or had relatively high rates of attrition which significantly weakened the studies and the robustness of the findings.

Aldred et al. (2004) collected baseline data and stratified the sample by child age and severity of ASD (four strata). However, attrition was a significant problem, as 14% ($n=4$) of the sample of 28 children dropped out after randomization, but before treatment. In what the authors (incorrectly, Shadish et al., 2002) termed a “strict intention-to-treat basis” the missing children were replaced by “equivalent cases” (p. 1423). It is not clear how these cases were recruited.

Roberts and colleagues (2011) randomized parents to one of the two treatment conditions. However, the authors introduced a third waitlist control group to their analysis, which was not part of the randomization process. Eleven participants (13% of sample) withdrew from the study and thus were not included in the analysis.

Smith et al. (2000) reported randomly matching pairs of children based on IQ and ASD diagnosis (DSM-IV criteria). Originally, four children with intellectual disabilities, but without ASD, were included in the study. One was assigned to the treatment group and three were assigned to the control group. However, the authors reported they subsequently dropped the children with intellectual disabilities from the analysis. The researchers reported these changes did not affect significance testing.

Imprecise description of analytic methods. To permit readers to assess the quality of a study and its outcomes, authors are expected to fully explain their analytic procedures. Threats to statistical conclusion validity (i.e., correct use of statistics to make inferences) include violated assumptions of statistical tests and low statistical power (Shadish et al., 2002). Examples of these threats are below.

Tonge and colleagues (2006) used a site-level randomization strategy. Researchers first randomly assigned two of the four sites to a treatment or control condition. Then, individuals within the treatment sites were randomly assigned to one of the two treatment conditions. However, the authors did not delineate their attempts to control for site-level factors (given their site-level randomization strategy), but reported groups were not significantly different at pretest on mean individual demographic characteristics. Furthermore, the interventions were delivered in small groups of four to five families. Yet, the authors did not report accounting for group-level variations or group characteristics in their analysis, which is a clear violation of OLS regression. The preferred approach in this situation is some form of multilevel modeling (Raudenbush & Bryk, 2002). Similarly, it was not clear if Roberts et al. (2011) controlled for the small group-level aspect of their intervention (i.e., parents in the center-based treatment conditions met in groups of six). Thus, these studies were at risk for misestimation of their treatment effects.

The remaining studies described appropriate use of statistics, yet several had small sample sizes. An adequate sample size is a primary consideration to ensure studies have enough power to detect treatment effects. Welterlin and colleagues (2012) acknowledged their study was likely underpowered ($N=20$) and thus unable to find a relationship between the intervention and the specified outcomes.

Differential receipt of alternate therapies. Even when a study is properly randomized, treatment and control groups can change in different ways over the course of an intervention. All of the seven studies reported issues with children receiving therapies in addition to the targeted intervention. Researchers varied in their reports of the amount of outside therapies received by families, and how these differed between treatment and control groups.

Three studies found the control groups received a different number of therapies (external to the intervention under study) as compared to the treatment groups. The studies by Drew et al. (2000), Roberts et al. (2011), and Rogers et al. (2012) all reported children in their control groups utilized significantly more ASD-specific therapies, such as Applied Behavior Analysis, than those children in the experimental groups, who were receiving the interventions. Conversely, Aldred et al. (2004) noted during the course of their year-long study, only one control and two treatment children did *not* receive some sort of outside speech/language therapy. Nine treatment and eight control children in this study also received a local autism-specific therapy during the treatment period.

The remaining three studies did not report enough information to assess if the comparison groups were similar to the treatment groups throughout the research period. For example, Tonge et al. (2006) reported children in treatment and control groups received a similar number of early intervention hours; yet, it is not clear if the treatment hours differed post-intervention. Welterlin et al. (2012) did not find any differences between treatment and control groups regarding receipt of occupational or speech therapies, although this information was only collected from 50% of participants. No other therapies were noted in the study. Finally, Smith and colleagues (2000) provided no information regarding alternate treatments that participants received during the course of the study.

Measures of Parent Outcomes

Past research has had a limited focus on parent outcomes, as noted in the literature review above. As such, only the study findings for parent outcomes are summarized below. (Recall that the study inclusion criteria required studies to report parent measures in order to be included in

the review.) Measures and parent-related findings from the seven studies are detailed in Table 1.1.

Four studies used the Parenting Stress Index (full or short forms) (Aldred et al., 2004; Drew et al., 2002; Roberts et al., 2011; Welterlin et al., 2012). None of these studies reported significant between-group differences in parent stress, although Roberts et al. (2011) found the waitlist group had a significant decrease in scores on the Parenting Stress Index over the course of the intervention.

Roberts and colleagues (2011) also collected two additional parent measures, the Beach Center Family Quality of Life Scale and Parental Perception Questionnaire (a measure of competence and autism knowledge, for which no psychometric properties were reported). Their results were mixed. Center-based and waitlist groups experienced improvement on certain subscales of the Quality of Life Scale and Parent Perception Questionnaire, for example family interaction, knowledge and coping. There were few significant between-group findings. Compared to the home-based condition, center-based participants scored higher on the parenting subscale of the Quality of Life Scale and knowledge subscale of the Parental Perception Questionnaire; whereas home-based participants scored higher than their center-based counterparts on the disability support subscale of the Quality of Life Scale.

Rogers et al. (2012) utilized one parent measure, the Symptom Checklist-90-R, which was only collected at baseline. The research team also collected data with the Working Alliance Scale for Intervention with Children. Intervention group parents had stronger working alliances with their therapists after program completion, as compared to parents in the control group.

Smith and colleagues (2000) collected data on one parent measure, the Family Satisfaction Questionnaire. The instrument measured satisfaction with the intervention,

particularly with regard to the child's outcomes, but also family or parent impact and the relationship between parents and therapists. There were no differences between the groups, with the exception of parent stress related to the treatment (higher in control group). Nonetheless, only one parent in the control condition reported a stressful outcome.

Tonge and colleagues (2006) studied how their education and skills program affected parent mental health and used the General Health Questionnaire, Parenting Stress Thermometer, and McMaster Family Assessment Device. They did not find significant effects of either of their two intervention conditions, compared to the control group at posttest. However, they analyzed interactions between pretest measures of mental health and group and found significant treatment effects on General Health Questionnaire subscales for both treatment groups, as compared to controls. By six-month follow-up, a higher percentage of participants in the intervention groups experienced an effect. They found similar trends with the Stress Thermometer and Family Assessment Device.

Two studies also collected child-parent interaction data. Aldred et al. (2004) reported an increase in synchronous communication and child communication acts from interaction videotapes. Rogers et al. (2012) measured parent use of child-centered interaction skills with the Early Start Denver Module Parent Fidelity Tool, but found no significant pre-post group differences.

Discussion

This review summarized intervention studies that employed randomized controlled trial designs to evaluate training programs for parents of preschool children with ASD. Few interventions published within the past twelve years met this design criterion. For many of the studies, the parent outcome findings were too ambiguous to draw any significant conclusions

regarding the promise of the interventions. Finally, a general problem across the current review was the insufficient description of research methods in the studies.

To fairly assess the findings discussed in this review, the review's own methodological weaknesses are noted. First, despite a wide search of four databases, the review potentially failed to include relevant studies. This review also had a highly specific interest in young children with ASD and their parents. Thus, interventions outside of these search parameters, despite potential value to children with ASD and their families, were excluded. Third, it is important to recognize that while randomized controlled trials are considered to be the gold standard of intervention research, qualitative and quasi-experimental designs play an important role in the development and testing of social interventions. Finally, although all of the studies and their strengths and weaknesses were carefully reviewed, it is possible some of the studies' methods or findings were unintentionally misinterpreted. Thus, readers are advised to read those studies which are of particular interest to them, and independently assess their merits.

The studies' sampling strategies in some cases strengthened, and in others weakened the research findings. The focus on young children allowed nearly all research teams whose work was reviewed here to administer developmentally-appropriate interventions. On the other hand, the studies in general did not present a clear decision-making process for the exclusion of certain individuals. In some cases, although the rationale was presented, the decision-making process appeared subjective and unsystematic. Some studies' exclusion of certain children and their families (e.g., those with significant developmental delays or co-occurring developmental disabilities such as Down syndrome) makes it difficult to compare findings across studies, particularly when coupled with the wide spectrum of ASD diagnoses among participants.

Given the sampling limitations, external validity was generally weak. When reported, the samples had little racial, ethnic and socioeconomic diversity. These disparities are mirrored by research finding one state's Medicaid-funded ASD intervention disproportionately served White, upper-middle class families (Shattuck, Grosse, Parish, & Bier, 2009). Part of the lack of representation in these studies might be related to the intervention type (e.g., it would be difficult for a single parent with limited financial means to take off enough work to participate in a time-intensive intervention). Nonetheless, it is important for intervention researchers to ensure their interventions are accessible. The studies reviewed here did not include samples that reflect the diversity of parents raising children with ASD.

Furthermore, while at least half of the studies included fathers as well as mothers in the research (the others did not report), the authors were not clear regarding their differential impact, if any. While it is likely none of the studies would have had statistical power to analyze such differences, at a minimum the numbers of mothers and fathers in the study and any preliminary findings of differences could inform future research.

With regard to study design, the use of randomized controlled trials was an important strength. Another strength was the fact that many of the reviewed studies used assessors who were blinded to treatment conditions, which added rigor. However, it is not clear if the randomization employed in some studies resulted in truly randomized samples.

In light of the modifications to their designs, some authors did not adequately describe their analytic procedures. In addition to unclear methods to control for group-level effects in some of the studies, low statistical power threatened statistical conclusion validity in several reviewed studies. Small samples were likely in part due to the intensity of some of the interventions. Interventions which required parents to dedicate 25 to 30 hours per week result in

substantial costs to both investigators (i.e., time, personnel) and parents (i.e., lost work hours and other burdens). Furthermore, the costs and logistics of implementing such interventions are likely prohibitive for large-scale trials.

Further weakening some of the studies' internal validity was the issue of alternate therapies. Five of the studies were potentially compromised by the participants' receipt of alternate treatments in one or both experimental conditions, which is a major confounder of the relationship between the intervention and the outcomes. The two remaining studies did not adequately report participants' use of other services. However, while some researchers have asked parents involved in ASD early intervention programs to abstain from additional interventions during the duration of the study (e.g., see Silva, Schalock, & Gabrielsen, 2011), withholding potentially useful treatments during children's critical early years is unethical.

Fidelity measurement and manualization were points of strength in this review. In the event any of these interventions showed potential for large-scale dissemination, six of the studies are properly positioned in terms of intervention manual development. Five of the studies evaluated the fidelity with which the interventions were implemented.

Parent measures of well-being and their outcomes were the focus of this review. Parents raising young children with ASD are especially vulnerable to stress and other poor outcomes. Although these studies all used at least one parent measure and had a parent training component, parent outcomes were not central to the studies, with one exception (Tonge et al., 2006). For example, Rogers et al. (2012) collected the Symptom Checklist-90-R only at baseline, suggesting they were not interested in observing changes in parent mental health post-intervention. The majority of studies relied on parent stress, satisfaction or parent-child interaction instruments. However, none of the studies reported significant reductions in parent stress, and other parent

outcomes were mixed. Tonge and colleagues (2006) suggested their intervention was more effective for parents with higher baseline mental health issues. More rigorous research should investigate this hypothesis. Given the body of evidence regarding parent stress and its harmful effect on well-being, research is urgently needed to address this significant service gap.

Conclusion

Family stress theories and decades of empirical studies support the contention that parent stress, depression and coping strategies are critically important to the well-being and adaptation of the entire family. Despite consensus on this point in the field, intervention research is far from adequate in meeting the needs of the whole family, rather than only the child with ASD. While the emergence of randomized controlled trials that include parent measures are a positive step, this review demonstrated significant work remains in terms of more rigorous randomization strategies; greater attempts at inclusivity related to socioeconomic status, race and ethnicity; heightened recognition of the role that both mothers and fathers play in the future success of their children; and increased awareness of the importance of rigorous methods to replicate and sustain promising interventions.

CHAPTER 2

FEASIBILITY OF *THE INCREDIBLE YEARS* PROGRAM FOR PARENTS OF PRESCHOOLERS WITH AUTISM SPECTRUM DISORDER

The evidence demonstrating a strong association between Autism Spectrum Disorder (ASD) and parent stress and depression is vast (e.g., see Boyd, 2002; Bromley et al., 2004; Phetrasuwan & Shandor Miles, 2009; Pisula, 2007; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Parents of younger children with ASD are particularly vulnerable to stress. Estes and colleagues (2009) reported a high prevalence of parenting stress and psychological distress among mothers of preschool children with ASD, as well as a relationship between children's problem behaviors and maternal stress and distress. Davis and Carter (2008) found an association between the social delays of toddlers with ASD and maternal and paternal stress and parent-child relationship challenges. Furthermore, emotion regulation, one of the earliest challenges parents identify for children with ASD (Gomez & Baird, 2005), has also been associated with maternal stress (Davis & Carter, 2008). Notably, parent emotion regulation has been identified as a coping mechanism associated with parent daily stress and well-being (Pottie & Ingram, 2008).

Early intervention can reduce parent stress. For example, mothers of children with ASD reported a reduction in child-related stress after their children participated in an inclusive toddler program (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005). Hastings and Beck (2004) noted the value of peer support groups in reducing the stress of mothers parenting children with intellectual disabilities. Given the association between parent stress and child behavior, researchers recommend parent stress levels be regularly evaluated as part of ASD interventions for children (Lessenberry & Rehfeldt, 2004). Nonetheless, as highlighted in Chapter 1 and by

Karst and Van Hecke (2012), few interventions for young children with ASD assess parent outcomes, and even a smaller number directly address parent well-being in general. The findings reported in Chapter 1 did not identify any evidence-based early intervention programs that address stress, depression, or other parent- or family-related outcomes in the ASD population.

Despite the lack of interventions focused on parents raising young children with ASD, there are various evidence-based parenting programs that have been developed for other populations; particularly parents of children with behavioral challenges (e.g., conduct disorder). Whittingham and colleagues (2006; 2009) have made preliminary efforts to adapt *Stepping Stones Triple P* to parents raising children ages 2 to 9 with ASD. The family behavioral intervention targets challenging child behaviors with positive attention and non-violent discipline strategies. The authors found the program to be a promising option to reduce both problem child behaviors and dysfunctional parenting practices. Similarly, researchers have used another evidence-based parenting program, *The Incredible Years*, with parents of school-age children with ASD (Garcia & Turk, 2007; Roberts & Pickering, 2010). Roberts and Pickering (2010) reported a positive impact on child behavior and parent mental health. Furthermore, a randomized controlled trial of *The Incredible Years* with parents of preschoolers with developmental disabilities has been conducted, with positive results (McIntyre, 2008). The developer of *The Incredible Years* offered guidance on adapting the child version of the program for the needs of children with ASD (Webster-Stratton & Reid, 2008). Webster-Stratton (2007) further outlined how *The Incredible Years* Parent Program can be optimized to improve both child and parent outcomes. The present research describes a feasibility trial of *The Incredible Years* tailored to meet the needs of parents who are raising preschoolers (ages 3 to 6) with ASD. The next section describes *The Incredible Years* and current study in more detail.

***The Incredible Years* Preschool Basic Parent Program**

The Incredible Years Preschool Basic Parent Program (Webster-Stratton, 2001) is a group-based intervention intended to strengthen the parent-child relationship, encourage use of positive discipline practices, develop children's social and emotional skills, expand parents' support networks and communication skills, and improve parent mental health. The developer provides both a treatment 20-week protocol for children with children with diagnosed behavioral problems such as oppositional defiant disorder, as well as a 14-week prevention protocol. The current study focuses on the 14-week program.

The Incredible Years is informed by multiple theoretical perspectives related to child development and parent functioning (Webster-Stratton, 2011). The importance of the parent-child interaction is highlighted by attachment theories (e.g., Ainsworth, 1974; Bowlby, 1980). Developmental stage theories (e.g., Piaget & Inhelder, 1962) inform age-appropriate expectations of child behavior in the program. Social learning theory (Patterson, Reid, & Dishion, 1992) and social cognitive theory (Bandura, 1986) reinforce *The Incredible Years* strategies of parents modeling appropriate behaviors and social interactions. Finally, parents' negative cognitions, problem solving skills, partner communication strategies, and confidence are addressed based on theories outlined by Beck (1979), D'Zurilla and Nezu (1982), and Jacobson and Margolin (1979).

The Incredible Years has been tested rigorously in numerous randomized controlled trials (reviewed in Webster-Stratton & Reid, 2003). While originally developed for parents of children with oppositional defiant disorder, the program has since been tested in many populations, including with culturally-specific parent groups (e.g., Korean-American mothers as described in Kim, Cain, & Webster-Stratton, 2008); with families involved in the foster care system (Linares,

Montalto, Li, & Oza, 2006); and, low-income, culturally diverse groups (e.g., see Reid, Webster-Stratton, & Beauchaine, 2001). It also has been tested, with positive outcomes, using an abbreviated (12 week) protocol for children at risk of developing behavioral issues (Jones, Daley, Hutchings, Bywater, & Eames, 2007).

Although *The Incredible Years* has been used extensively both in the United States and globally, the program has not been rigorously tested with families of children with ASD. As described above, the school-age program (ages 5 to 11) has been piloted with promising reductions in challenging child behaviors and parent mental health (Roberts & Pickering, 2010). However, more research is needed to rigorously test the school-age basic program, as well as to examine the preschool basic program with this population.

Given *The Incredible Years* is an established evidence-based practice developed for a non-ASD population, it is important to consider the issue of fidelity. Treatment fidelity is the degree to which intervention researchers follow an established protocol or manual (Sussman, Valente, Rohrbach, Skara, & Pentz, 2006). Fraser and colleagues (2009) emphasize the tension that exists between achieving fidelity to an established treatment model and adaptation to meet the needs of a new population. In addition, programs are impacted by the “dosage” received by parents, as effects of *The Incredible Years* have been shown to be related to number of attended sessions (Baydar, et al., 2003). While treatment fidelity is central to proper implementation of evidence-based practices (Fraser et al., 2009), Webster-Stratton (2007) argues such interventions must have enough flexibility to allow group leaders to adapt the program to each individual parent. Thus, group leaders must possess adequate training and experience to successfully match parents’ individual goals with program content. Thus, Webster-Stratton (2004) outlined five keys to use *The Incredible Years* in community settings with fidelity: 1) standard treatment manual

and materials; 2) standard training for group leaders; 3) ongoing supervision for group leaders; 4) ongoing monitoring of fidelity; and, 5) organizational support.

As described above, extant research suggests parents raising preschool children with ASD experience significant levels of stress and poor outcomes. Yet, there are few interventions which address the needs of these caregivers. *The Incredible Years* is a program which has had success reducing children's problems behaviors, improve children's social skills and self-regulation, and addressing parent stress and coping methods. Thus, the current research proposed a two-group pilot study to test the feasibility of *The Incredible Years* with parents of children with ASD (ages 3 to 6 years old). In addition to the theories used to develop *Incredible Years*, the present research was guided by the Contextual Model on Family Stress (Boss, 2002), which situates parent stress within a strengths-based, family-focused, and developmentally-appropriate framework. In this framework, the degree of stress a family experiences and their vulnerability to crisis are related to multiple factors, including the family's "resources" (i.e., family resiliency and ability to manage stressors). In this context, the theory hypothesizes that despite the potential for increased stress in families of children with ASDs, family resources (in the form of social support and positive coping mechanism) can diminish the risk of stress and subsequent crisis.

The research aims for the study were to: (1) assess program fidelity while tailoring the program to ASD-specific needs of parents; and (2) gather information on strategies to recruit, retain and meet the needs of parents of children with ASD in *The Incredible Years* program. The current paper presents findings on program fidelity, recruitment, retention, and parents' recommendations to improve the intervention with parents raising preschoolers with ASD.

Method

The pilot study tested the feasibility of *The Incredible Years* Preschool Basic Parent Program with two groups of parents with preschool children with ASD (ages 3 to 6). The study utilized a pretest-posttest design with no control group to collect parent stress outcomes (reported in Chapter 3). Data were also collected after each weekly session and after program completion.

The two groups ($N=17$) were composed of eight and nine parents, respectively, who met in a community setting convenient to public transportation and parking. Dinner, childcare and transportation support were available for all participants. At the baseline and post-intervention data collection points, modest cash incentives were provided (up to \$75 in total). The author's Institutional Review Board approved the current study.

Intervention Design

The Incredible Years is a play-based intervention that incorporates skill building to improve child and adult emotional regulation, communication skills and parent-child relationships. For purposes of the present study, the intervention was delivered as specified in *The Incredible Years* Preschool Basic Parent Program manual (Webster-Stratton, 2001), using the 14-week protocol. Each of the 2.5-hour weekly sessions were led by two master's-level clinicians who had extensive professional experience in the ASD field. Additionally, the group leaders were trained and certified in the program, and received ongoing professional support in the intervention implementation.

The details of *The Incredible Years* program can be found elsewhere (Webster-Stratton, 2001; Webster-Stratton & Reid, 2003; Webster-Stratton, 2007). In summary, the intervention includes four modules focused on child-directed play, praise and incentives, household routines, and positive discipline. Following a half-hour informal dinner, a two-hour session begins with a

“check-in” in which each parent shares his/her experiences from the previous week with the group. Then, the two group leaders introduce the day’s content, through videos, group discussions, and interactive teaching (e.g., group brainstorming of key points). After the content is presented, participants discuss and role play new skills in small and large groups. Finally, parents set goals for the following week and provide written feedback to group leaders on the current session. (These written comments are used by group leaders to plan subsequent sessions.) After four sessions, each parent is assigned a “buddy” in the group who they can contact during the week for support. While *The Incredible Years* developer recommends inclusion of other caregivers in the group sessions, only one parent from each family was invited to participate in the pilot groups.

In the current study, group leaders relied on their own professional experience as well as weekly participant feedback to tailor the program to parents raising preschoolers with ASD. It is important to note many of these components are already part of *The Incredible Years*. Thus, tailoring the program to parents of children with ASD often meant emphasizing certain components. The group leaders augmented the program in the following ways:

Supplemental ASD parent advocate meeting. Before the actual program began, participants met once as a group. A parent of a teenager with ASD led this initial meeting and provided information on community resources and supports.

Adaptation to unique play behaviors of children with ASD. Children with ASD often play in dissimilar ways compared to typically-developing children. For example, lack of imaginative play, rigidity, restricted interests, lack of engagement, and anxiety are often issues which arise. Consequently, group leaders devoted extensive time during the initial sessions to “troubleshoot” these various issues with parents.

Extensive use of visual resources and simple, concrete language. Many children in the groups had limited verbal or communication abilities. Thus, group leaders presented additional visual prompts (e.g., picture cards) to illustrate desired commands, emotions, social skills, routines, and tasks. Furthermore, although positively-stated, direct commands are integrated into the existing program, group leaders stressed to parents the importance of limiting the number and complexity of child-directed requests.

Dedication of additional time to discuss videos. Notably, *Incredible Years* videos do not depict any children with ASD. Thus, group leaders showed fewer videos and devoted more time to debrief the vignettes and their applicability to children with ASD.

Increased focus on the development of emotional regulation skills for children. Emotion regulation is often a significant challenge for children with ASD. Thus, group leaders dedicated additional time on “emotion coaching” of children, in which parents labeled emotions with words (and pictures, if necessary). Parents also received information on how to help children identify their own emotions based on how their children’s bodies look and feel (e.g., “I can see you are feeling angry because your hands are clenched.”) and strategies in which children could calm down (e.g., deep breathing).

Emotion coaching, introduced in the first module, was revisited again in detail during the final module when time-out to calm down was presented. Typically, *The Incredible Years* dedicates approximately one session each to time-out to calm down and time-out for noncompliance (the latter being more of a punitive measure for misbehavior). However, group leaders focused more on calming down and ensuring children possessed the requisite self-regulation skills to respond to time-out methods. Thus, although the manual discusses time-out as an “extended ignore” of the child while s/he is in time-out, the groups discussed how parents

could assist their children to calm down (e.g., rubbing their backs, allowing them a “sensory” break to jump on a trampoline).

Sensitivity to the additional stress and burden experienced by families of children with ASD. *The Incredible Years* Basic program is focused primarily on child behavior. Yet, as Table 2.1 describes, nearly all of the children were receiving direct services (e.g., speech therapy). Accordingly, group leaders devoted more time for parents to process their own concerns and family needs. For example, because several of the skills presented in class were more difficult for some children, parents were provided more time to discuss various coping and anger management strategies. These were individual to each participant, but included listening to music, repeating a calming phrase to oneself, meditation and deep breathing.

Awareness of heightened need for social support in and out of class sessions. Many of the parents desired more interaction with fellow group members outside of class. One group created a class email list and corresponded about different behavioral and coping strategies between class sessions. Additionally, group leaders periodically sent out emails to the group and to individual parents to “check in” and alert parents to local resources.

Participants

Recruitment procedures. The author partnered with four community collaborators to recruit families in a suburban area of one southeastern state in the United States. Through these collaborators, parents of children aged 3 to 6 years with ASD were invited to participate in the study through fliers, listserv announcements, and postings on the websites of local ASD and developmental disability service agencies, local preschools, and parent support groups.

Table 2.1

Description of Sample (N=17)

Parent Characteristics	<i>N</i>	%
Marital Status		
Single	1	5.9%
Married/Partnered	16	94.1%
Racial or ethnic group		
African American	2	11.8%
Asian	2	11.8%
White	10	58.8%
Other	3	17.6%
Education		
High School/GED	2	5.9%
Associate Degree	3	17.6%
Bachelor Degree	5	29.4%
Graduate Degree	4	23.5%
Professional/Doctoral Degree	3	17.6%
Child Characteristics		
Mean age in years (SD)	3.7	0.92
Mean age at diagnosis in years (SD)	2.9	0.91
Mean time since diagnosis at program initiation in months (SD)	13.5	9.46
Gender		
Female	5	29.4%
Male	12	70.6%
Siblings		
None	6	35.3%
One	10	58.8%
Two	1	5.9%
Receipt of other services		
Occupational therapy	12	70.6%
Specialized preschool/educational services	12	70.6%
Speech therapy	10	58.8%
Structured teaching	4	23.5%
Hippotherapy	2	11.8%
Other	3	17.6%
Parent's characterization of child's verbal ability		
Verbal (typical)	7	41.2%
Verbal (delayed)	5	29.4%
Nonverbal	5	29.4%

Researchers did not interact with potential participants until the author was contacted directly by parents via email or telephone. To participate, parents had to be at least 18 years old and have currently lived with the child for at least 6 months. The author assessed eligibility through a series of questions. Potential participants were then invited to learn more about the program through correspondence from and discussion with the author. Before entry into the program, all participants met with the author individually to review informed consent documents. Parents who joined the program were asked to fill out a form collecting demographic data. All individuals who did not join the program were asked to list reasons they chose not to participate.

Description of sample. A total of 49 potential participants contacted the author to learn more about the study. Of these individuals, 32 parents reported not joining the program for multiple reasons (see Table 2.2.) Seven parents did not meet study eligibility criteria. Two eligible parents were placed on a waitlist due to group space restrictions. The majority of the remaining parents ($n=23$) were eligible to join, but chose not to do so. With the exception of two parents who did not report a reason for declining to participate, most individuals reported they did not enter the program because they could not commit to the entire 15-week program. Four parents did not want to take their children out in the evening and disrupt their schedules. Another four individuals were unable to attend in the evening due to their jobs. Four potential participants reported the distance from their homes to the program site was too far. One of these individuals also said she chose not to join because she wanted to attend with her husband. (Only one caregiver from each family was eligible to attend.) Two individuals felt their pregnancies would preclude them from regularly attending. Seven parents had various other commitments (e.g., Bible study) which would have prohibited them from attending regularly.

Table 2.2

Reasons for Not Joining Program (N=32)

Number	Reason
7	General scheduling conflicts
7	Did not meet study eligibility criteria
4	Did not want to take children out in evening
4	Work-related conflicts
2	Uncertain of time commitment due to pregnancy
4	Distance between home and program site
2	Reasons for not joining not reported
2	On waitlist due to group space restrictions

The remaining 17 parents enrolled in one of the two *Incredible Years* groups. (Table 2.1 summarizes the sample of participating parents.) The majority of the program participants were married/partnered (94%; $n=16$), White (59%; $n=10$), and college-educated (71%; $n=12$). The majority of the participants' children were male (70%) and their average age was 3.7 years old. The children were approximately 3 years old at ASD diagnosis and had received this diagnosis just over a year before the program began. Nearly all of the parents report their children received an ASD-related service. (One parent did not report.) The three most common services were specialized preschool, occupational therapy, and speech therapy. Over 40% of the children had typical verbal abilities, based on parent report. The remainder of the children had verbal skills considered by parents to be delayed or nonverbal (29% each).

Parents' attendance ranged between 88% and 100% per session (mean of 92%). Parents reported missing class because they or their children were sick, or they had business trips or family vacations.

Attrition. Fourteen (82%) of the initial 17 participants finished the program. The other three parents cited moving ($n=1$) and dissatisfaction with program ($n=2$) for withdrawal from the program. Reasons for dissatisfaction included the need for more one-on-one assistance with child behavior, interference with children's bedtime schedules, distance to program site, and desire to bring partner to group.

Statistical tests (2-tailed t-tests and Fisher's exact tests, as appropriate) were performed to examine differences between the individuals who completed the program versus those who withdrew. A p -value of .05 or less was considered to be significant. (See Table 2.3.) With regard to the parents' characteristics, there were no significant differences between groups. Yet, as

Table 2.3 outlines, the average child age at baseline and the average child age at ASD diagnosis were significantly older among the group of parents who withdrew from the program.

Furthermore, significantly more parents reported their children received speech therapy in the group that completed the program. There were no other significant differences in child characteristics between groups.

Measures

In addition to baseline descriptive data (see Table 2.1), two measures were collected in this study and are described below. In addition, pretest-posttest parent stress outcomes were assessed and described in Chapter 3. The author supervised or personally collected all of the measures described below. She was trained in the intervention and observed all of the sessions.

Fidelity checklists. Adherence to the standard treatment model was measured through completion of weekly, session-specific fidelity checklists. These checklists are available in *The Incredible Years* manual and are not validated measures. The checklists, completed by the group leaders during each week's session, are lists of specified activities and include the recommended video vignettes, specific tasks for group work (i.e., group process goals), and required handouts. The group leaders and author debriefed after each session and discussed plans for the subsequent session. These meetings included discussion of which videos and activities would be appropriate, based on weekly feedback from the participants and leaders' observations of group and individual needs. In addition to the fidelity checklists jointly completed by the group leaders, the author recorded her own observations of each session and completed checklists.

Table 2.3

Attrition Analysis

Child Characteristics	Completer Group (<i>n</i> = 14)	Withdrawal Group (<i>n</i> = 3)	<i>p</i> -value
Mean age in years (SD)	3.5 (0.85)	4.7 (0.58)	0.042
Mean age at diagnosis in years (SD)	2.7 (0.88)	3.8 (0.29)	0.053
Number children receiving speech therapy	10	0	0.051

Exit interviews. The author completed an in-person, one-on-one interview with each participant after completion of the program or withdrawal. All interviews took place approximately an average of 12 days after the last session (range, 1 to 24 days). The interviews were digitally recorded. The author used a semi-structured interview questionnaire to guide the conversation. The interviews focused on participants' engagement with the program and suggestions for how the intervention could better meet the needs of parents of children with ASD.

Analyses

Baseline descriptive data were summarized in Excel and reported as percentages or means and standard deviations, as appropriate. The fidelity checklists were evaluated to ensure the recommended videos were shown, the group leader tasks were completed, and the required handouts were distributed. These elements were summarized using percentages for each module, as well as the entire program.

Digital audio files of the individual exit interviews were transcribed, twice-verified for accuracy and uploaded to Atlas.ti Version 7 (ATLAS.ti Scientific Software Development GmbH, 2011). Participant responses were labeled using open coding of words or short segments of narrative. The interview guides were used to develop the initial codebook, which in turn was used for the first round of open coding. For example, interviewees were specifically questioned on particular aspects of the program leading to their decision to join the program, ways in which the program could initially engage them during the first session and maintain their participation throughout the program, and necessary supports provided such as food or childcare. Thus, responses were initially assigned codes that were derived from these broad categories. Then, one researcher examined and categorized the codes into subcategories, based on patterns from the

data related to program feasibility and participants' suggestions for future programmatic changes. Once subcategories were established, the researcher examined the broad categories and subcategories, in order to draw conclusions on specific themes and trends from the data. Along with common trends and themes, the researcher sought disconfirmatory responses to expose understanding of the diversity of opinions presented by the program participants. Finally, the interviewer maintained field notes to record short memos and impressions from each interview. These memos were reviewed throughout the coding process to assist in drawing themes from the data.

Results

Fidelity

One study goal was to determine if intervention components prescribed in the manual could be implemented with the ASD population. As Table 2.4 reports, required handouts were distributed to participants 100% of the time. (The handouts were prepared in advance and distributed to parents each week.) Over the course of the program, group leaders reported completing the required activities specified in the manual an average of 91% of the time. The average for both groups was the same. Finally, the recommended videos were shown 68% of the time in one group and 76% of the time in the second group. Fidelity reports of the group leaders were confirmed by the author's observations and notes at each session.

Fidelity ranged by module, although the activities across the course of the program were implemented more often than the videos. (See Table 2.4.) The group leaders completed the majority of required activities in Module 1 (Child-Directed Play). Across both groups, the leaders spent more time on emotion, social and persistence coaching, as opposed to coaching

Table 2.4

Fidelity Results

	Group 1 Average	Group 2 Average	Two-Group Average
Overall Program			
Completion of Videos	68%	76%	72%
Completion of Activities	91%	91%	91%
Distribution of Handouts	100%	100%	100%
Module 1: Child-Directed Play			
Completion of Videos	82%	93%	88%
Completion of Activities	90%	91%	91%
Module 2: Praise and Incentives			
Completion of Videos	63%	94%	78%
Completion of Activities	91%	94%	92%
Module 3: Household Rules and Routines			
Completion of Videos	82%	78%	80%
Completion of Activities	97%	96%	97%
Module 4: Handling Misbehavior			
Completion of Videos	58%	54%	56%
Completion of Activities	87%	87%	87%

academic concepts (e.g., reading skills). Recommended videos were shown at a high rate in Module 1 (average of 88%), which led to extensive group discussion. In this module, the missing activities were primarily role plays. Less time was available for these lengthier activities due to longer time spent on videos and discussion.

Similarly, more activities were completed in Module 2 (Praise and Incentives) than videos. Group 1 in particular consistently preferred to spend less time watching videos and more time on discussions. Across both groups, more time was spent on the topic of praise (recognizing child, self, partner, and professionals) than on incentives. Notably, both groups spent more time on the content regarding incentives for children, which decreased the amount of time available to discuss rewarding oneself.

The content in Module 3 (Household Rules, Routines and Limits), particularly the activities, was completed at a relatively high rate. Many of the group members had already been exposed to concepts such as household routines and schedules, due to their access of ASD-related services for children (e.g., structured teaching). Conversely, the content in Module 4 (Handling Misbehavior) was reportedly the most difficult for parents in both groups, and more time was accordingly spent debriefing videos and activities. Thus, recommended videos were only shown in Module 4 about half the time. As noted in the Method section, considerably more time was devoted to “time-out to calm down” for the children and coping strategies to calm parents, rather than time-out for aggression and noncompliance. Lastly, little time was available for the final session’s content on child problem solving.

Exit Interview Findings: Considerations for Future Use of *Incredible Years*

The exit interviews highlighted multiple challenges to consider for using *The Incredible Years* with parents of preschoolers with ASD. All 17 of the original participants completed an

exit interview, including the 3 who withdrew early from the program. To protect the confidentiality of the participants who withdrew from the program, their suggestions are only described in aggregate. Parents offered various suggestions for planning *The Incredible Years*, laying the groundwork for the first session, retaining families and encouraging participation, and additional supports. Specific subthemes within these broader suggestions included ways in which program planners can improve supports for working parents, consider group diversity related to children's functioning levels, dedicate more time and resources to promoting parent self-care, and include partners and other caregivers. The full array of themes is described in detail below. Summaries of participants' recommendations related to the logistics and content of *The Incredible Years* are outlined in Tables 2.5 and 2.6, respectively.

Planning *The Incredible Years*. Recruiting and setting up supports for families to enable them to participate in the intervention required months of preparation. Food and childcare were offered to all participants and children. The food included gluten- and dairy-free options for children on restricted diets. Monetary incentives of up to \$75 were distributed to participants to encourage questionnaire completion. The incentives were also intended to offset participants' transportation costs. The following two subsections outline participants' suggestions to plan groups for children with ASD and their parents.

Build in supports for working parents and parents in need of childcare. Six participants regularly used the childcare provided by the program, while the children of two others attended occasionally. Childcare was provided by individuals with previous experience with children with ASD. Providers were matched 1:1 or 1:2 with children, depending on the children's needs. Four children were regularly accompanied by siblings who ranged in age from 2 to 6 years.

Table 2.6

Logistical Considerations to Plan ASD-Specific Incredible Years Groups

Logistical Issue	Recommendation
Meals	<ul style="list-style-type: none"> ▪ provide options for individuals with gluten, casein, or other allergies
Specialized childcare	<ul style="list-style-type: none"> ▪ ensure low provider-child ratios ▪ offer structured activities and opportunities for social interaction ▪ make appropriate settings for children with hypersensitivities available ▪ consider vouchers for in-home childcare
Group considerations	<ul style="list-style-type: none"> ▪ maintain small group sizes (6-10 parents) ▪ include partners and other caregivers ▪ consider specific groups for parents of children with similar verbal, behavioral, or sensory profiles ▪ expand group meetings to more geographic locations ▪ offer daytime, weekday evening, and weekend group meetings
Pre-intervention session	<ul style="list-style-type: none"> ▪ invite ASD parent advocate to introduce program and share resources ▪ establish group leaders as knowledgeable in ASD practice ▪ assure participants program will be tailored to their specific needs
Resources	<ul style="list-style-type: none"> ▪ streamline and organize take-home resources ▪ offer more information on public and/or local programs, therapies, and ASD-specific supports (e.g., social stories)

Table 2.7

Tailoring Incredible Years Content to Parents of Preschool Children with ASD

Content Area Recommendation	Specific Activity
Dedicate more time to skills in first module	<ul style="list-style-type: none"> ▪ assist parents to understand child-directed play in the context of ASD through discussion and role plays ▪ practice and troubleshoot emotion regulation strategies and social skills
Develop appropriate program resources for children with ASD	<ul style="list-style-type: none"> ▪ identify alternative incentives to motivate children with ASD (e.g., “sensory” rewards such as jumping on trampoline) ▪ consider an optional “peer sharing night” in which parents create picture schedules and other supports together ▪ increase access to visual resources (e.g., photos of emotions)
Refine activities and videos	<ul style="list-style-type: none"> ▪ reduce time on videos ▪ redirect focus to role plays and class discussions
Modify sessions on handling misbehavior	<ul style="list-style-type: none"> ▪ reduce focus on ignoring children’s negative behaviors ▪ assist children to develop self-regulation skills through “time-out to calm down” ▪ abbreviate or omit session on “time-out for noncompliance” ▪ allow for time to address children’s problem solving skills
Encourage parent self-care and stress reduction strategies	<ul style="list-style-type: none"> ▪ gradually increase focus on parent stress and well-being over course of program ▪ incorporate small “rewards” for parents into each module to model self-care ▪ offer targeted stress-related resources outside of program ▪ expand opportunities for peer social support and group leader “check-in” between group sessions ▪ consider additional sessions to dedicate more time to parent-specific issues ▪ process family needs and anger management strategies

All of the parents who utilized childcare reported they would not have been able to participate without it. In the future, one parent suggested more structured activities and opportunities to engage children in social interactions. A parent of a child with hypersensitivity to auditory stimuli requested a separate room with low noise levels. Some parents noted that if partners are invited to attend in the future, the need for childcare will increase. However, many parents reported it would have been difficult to bring children to evening meetings due to their children's reliance on schedules. (Notably, one reason cited for not joining and also for withdrawal from the program was the disruption it created for children's nighttime routines.)

For parents who worked outside of the home, all said the program was manageable. Two noted childcare had been a critical support. Reported barriers to completing the program while working included limited amount of time to complete homework, missing classes, and class location too far from their homes.

Consider group size and diversity. Parents reported group size and composition were important considerations for program planning. Each group had between 7 to 9 parents participating at one time. While *Incredible Years* groups typically accommodate up to 14 individuals, all of the parents agreed a group size of 6 to 8, and no more than 10 was appropriate. They noted the smaller size allowed them to adequately discuss their specific concerns in detail. Furthermore, two participants said the size was large enough to include individuals with a diversity of opinions and experiences. Many parents were interested in participating with their partners; yet, some recognized the groups would accordingly expand if partners were included. Those questioned agreed 12 should be the maximum size of the group if other caregivers were invited to participate.

Parents had differing opinions on whether the program was appropriate for families whose children had recently received an ASD diagnosis. Parents of children with more recent diagnoses commonly cited needing more one-on-one support, whereas some parents whose children had the ASD diagnosis for longer noted needing less intensive support due to their receipt of early intervention services. One parent, however, said it would have been difficult to participate in the intervention immediately after her child's diagnosis:

You're trying to deal with that term, "autism."... What does that mean? Where are we going to go? How do we get treatment? Then, there are sensory issues. What are sensory issues? What does that mean? How are we going to deal with it? I think it would have been more overwhelming with this program if I'd done it earlier on, because it really relied on understanding what sensory seeking was, and that our [child] had it, what to look for, and how to achieve that "what is and what isn't."

Conversely, a parent of an older child emphasized her opinion that it was important to give timely support to parents of recently-diagnosed or young children, saying:

[The ages of] 3 to 4 years [old] are really hard with a child on the [autism] spectrum...so much is coming in and if they have sensory issues, there's just too darn much... Things felt very hard at 3 and things felt really hard at 4, and they didn't by 4 and a half and 5 and 6 for us...[For] a lot of parents who are in this real 3 to 4 [year old stage], they can't see where their child is yet. I still can't. I don't know that my child will live independently. I don't know that my child will get through high school. I do not know, but I have lot more confidence that we will figure out a plan for him. So, I feel like when you're still in the semi-verbal but not really, or needing a lot of emotional support, and the child is still really "meltdowning" a lot, or you're so restrictive of what [you] do

because the [child] can't handle much more, you can't see your way over that hump [without support].

The program included a mix of parents of children with different behavioral and communication challenges, ages 3 to 6. There was no consensus as to whether a more homogenous group regarding behavior or age was needed. Two parents of older children stated they regretted not being able to pursue the problem solving content in Module 4 in detail, due to spending more time on earlier sessions. However, one parent noted she enjoyed sharing her perspective, saying, “I was really excited about being able to share some of my stories. It seems like a lot of [other parents’ challenges]... sound exactly where we were a year ago. [My child] was a firecracker and I never thought we would be where we are now. [The diversity] was a really good thing.” Many parents of younger children reported they appreciated having the insight of more experienced parents.

Two parents reported feeling guilty about their children’s progress in the program, relative to other parents’ challenges with their children’s behavior. One parent said:

I really felt bad for some of the parents whose kids were really behind. Honestly, I know that [my child] has come really far. I don’t think [the other parents] fully understand that either I've been in their shoes, which I have, or that...I've really thought about what my homework was.

Thus, both of these parents suggested it might have been useful for them to be in groups with other parents whose children had similar behavioral challenges as their own, or were as focused on the homework as they reported to be. Another parent of a highly verbal child, whose quote was representative of two others in the groups, said:

In the class from what I sensed, I had a very, very verbal child and it was almost something I didn't want to bring up very often because I felt like I didn't want to just take away from the parents that needed to learn from that information for their children. Thus, this parent would have preferred a more homogenous group of families raising verbal children with ASD, in order to shift the focus away from nonverbal strategies to those for children with verbal abilities.

Three parents discussed the challenge of separating groups based on children's diagnosis or age alone. One noted the new Diagnostic and Statistical Manual – Version 5 guidelines, with its umbrella category of Autism Spectrum Disorder, no longer distinguishes between former categories such as Autistic Disorder or Asperger syndrome. Furthermore, the parent said chronological age is not an accurate predictor of children's developmental or skill level. One parent reported it was helpful to have a diversity of child behavioral challenges represented in the group, because the sensory- or transition-related causes of challenging behaviors are common to children with ASD, regardless of their "functioning level."

Lastly, while some participants enjoyed the diversity of parents representing various cities and towns, one noted it might have been more helpful to offer the program in more geographical locations. Then, parents could form support networks with individuals who live closer and share similar resources. One parent mentioned the lack of socioeconomic diversity in the group and advocated for reaching underserved populations, saying:

[A]utism is one of those things that is colorblind, and moneyblind.... the only reason that I'd think about [socioeconomic diversity], or bring it up, is because I want [low-income] people to know the doctor in that way. They are going through very similar things, and to feel supported, because it's a lonely place in a lot of ways to have a child with a special

need...[A] gift would be to feel like you were part of the community of people who might be stronger than you financially...and you are all supportive of each other.

Setting the stage: The first session. Interviewees reported diverse opinions on how group leaders could begin the program effectively. In the current two groups, the parent of an older child with ASD shared her story and local resources with participants in a pre-intervention session. While two of the parents felt it was unnecessary for them because they were already “tapped in,” the remainder of the participants reported it was helpful to hear the perspective of someone “further down the road.” One parent noted it made her more willing to share her own experience and struggles. Another parent said it was a positive beginning to the program, saying:

It seems extraneous. Let’s just get to the nitty gritty and start learning stuff. But when you think about where most of your parents are coming from, or even those who have been living with the diagnosis...it’s been 5 years, or whatever, it’s always nice to have a welcoming into the program by someone who has a child [with ASD]. We’re all on the same footing, we are where we are. It’s all good, and it’s a safe place to be, instead of just jumping in and starting to talk about stuff.

The only suggestion parents had was to structure some of the pre-intervention session to introduce common ASD terms such as “sensory seeking” or “stimming” (i.e., self-stimulation, or a repetitive movement, such as hand flapping) in order for parents to begin on “common ground.”

After the parent advocate spoke, the group leaders explained that while *The Incredible Years* was not developed specifically for parenting a child with ASD, the leaders had extensive experience in the ASD field and would assist participants to achieve their goals. However, some

parents reported they needed more reassurance the program would be tailored to their needs from the beginning. One parent said:

That assumption that we're going to...encourage pretend play automatically kicks the bucket for some of these families...and makes you feel like, "Oh my God! My kid's not doing this. How are we even going to complete this program?" This is happening the first week. Some parents in our group [in the] first two weeks had some knee-jerk reactions. I think it's feeling out the landscape, and getting comfortable with where things are.

Obviously, as we moved on these were not issues...but earlier on, I [thought], "Am I going to walk away from this group feeling like my child is completely inadequate, even in an autism-specific [group]?" which I know is not the intention, ever, but I think parents, especially mothers, internalize a lot of that very easily, inadvertently, and they see it as somehow a failure on themselves as a parent.

The videos had the potential to be off-putting to parents because children with ASD were not depicted. One participant suggested future group leaders should acknowledge this problem at the outset of the program:

Say, "We realize this. The program originally was not made for kids that have autism, but we can take a lot of these fundamental ideas, and still apply them, and really these videos are used as examples of positive things or things that you could change in modeling parent behavior, and it's not so much a reflection of the children"... at the end I was... looking at the parents first....You don't need to be fixated on the children, really. They're just there as props. The parents in the video, that's what we're here for.

Optimizing parent learning throughout the program. Participants had many opinions on how to retain families in the program, encourage participation, and increase parent success.

Offer appropriate in-class and take-home resources. All of the parents received an *Incredible Years* book, which they reported was a good reference. While three of the parents found the number of take-home handouts appropriate, the majority of participants reported they were confused or overwhelmed by the amount. This was due in part to also receiving resources from schools and therapists, as one parent explained, “Right now I’m getting [handouts] from [my child’s] teacher. I get it from the [therapist] and then I had it from this class too. I just need to find a way that I can merge it all together where I can get the big picture from all of them together.” While two parents requested fewer handouts, most of the parents made suggestions for managing the resources. Six parents proposed providing three-ring binders so participants could organize their handouts weekly. Other parents suggested group leaders point out which homework was most critical, to help parents to prioritize. Finally, one parent noted that beginning the homework in class would have been helpful to reduce at-home work.

Group leaders also sent out regular emails to participants with links to resources in the area. If needed, group leaders would send out an individualized email if a specific parent seemed to be in need of additional assistance. One of the two groups also created an email list of all of the parents, to provide a forum for contact when classes were not in session. Parents reportedly enjoyed these various ways to learn more about resources, particularly those whose children had recently received the ASD diagnosis. Some parents who traveled from areas distant from the program site requested more local resources, whereas most of the parents reported they could always use more information on public programs, picture schedules, social stories, and occupational therapy.

Plan for adequate time on each program module. In general, parents wished the entire program was longer, particularly the first module (Child-Directed Play). An exception was two

parents with older children, who were ready to move on to the second module and set of skills. Another parent said, “Looking back on [the beginning], it probably helped me because it helped me learn how to play with [my child] more, but I remember feeling...because I was working too and I felt overwhelmed sometimes that I had to do all that homework.”

For nearly all of the parents, beginning with play was reportedly a critical foundation point for their understanding of the entire program and, as one parent noted, “built confidence.” Three parents requested more opportunities to practice the content in class through role plays and discussion, since play for many children with ASD differs from play with typically-developing children. A common suggestion from multiple parents was to spend more time on social and emotional coaching. One parent suggested introducing the coaching skills earlier, in order to spend a full week each on emotion and social coaching. The additional time on emotion coaching in particular would allow parents to practice and troubleshoot self regulation strategies for themselves and their children.

Over half of the participants felt the time spent on Module Two was appropriate. For those for whom the rewards did not work well, they felt it gave them an opportunity to try out the strategy without spending too much time on it. Another parent pointed out the first session of the second module (Praise) was the point where the content started to get “harder,” leading to the potential for parents to become overwhelmed.

Approximately half of the parents felt the time spent on the “Rules, Routines and Limits” Module was sufficient. The remainder reported the concepts were difficult for them and they could have benefited from more time on the picture schedules in particular. One challenge highlighted by one parent was that some families had already accessed ASD-related services, which typically demonstrate concepts such as visuals to parents. Thus, extended time on visual

prompts and picture schedules would be boring to some. She suggested a peer sharing night, where those parents who have already been exposed to teaching on visual strategies were paired with those who had not.

Finally, most parents reported the time spent on the final module was adequate. However, three requested the “time-out to calm down” session to be lengthened. One individual felt the focus on time-out be dedicated solely to self-regulation strategies (i.e., time-out to calm down, rather than time-out for noncompliance). Other parents recommended an extra session be added to the final module to provide adequate time to fully understand child problem solving.

All of the parents who completed the program either believed 15 weeks was an appropriate amount of time ($n=3$) or too short ($n=11$). Those who wanted to lengthen the entire program reported the weekly meetings had become part of their families’ routines, so extra weeks would not have been a burden. However, two parents cautioned the program should not overlap too much with summer vacations and another that parents might need to miss more classes. Additionally, the initial “buy-in” of parents to commit to a 20+ week program might have been difficult, as one parent said, “At the beginning, I was very doubtful if I can stick with it and if [my child] would like the [childcare], because I was very worried. As I did week after week, I felt better and better. [By the end], I think everybody wanted to stay. They [said], ‘We don't want to graduate. We want to have more time.’”

Parents generally felt the time allotted each night (half-hour for dinner and informal socialization, plus two hours for actual class content) was appropriate. Most parents were concerned longer sessions might make it even more difficult for families to participate on weeknights. Additionally, parents might “burn out” from longer sessions. Participants offered suggestions, such as using the dinner “social” time in a more structured way to share resources

and discuss the previous week's activities; or holding these sessions on a Saturday to extend the time in class.

Recognize parent self-care is underutilized. Some parents became emotional when asked about content regarding self-care and stress reduction. All participants reported understanding its importance; yet, very few actively indicated they could set aside time to focus on their own needs. Many parents said if the program was presented to them at the beginning as having too much of a focus on parents' needs, they would not have joined. One parent explained:

Market [the program] as how to help your children. You'd have to trick us into [focusing on ourselves]!.... Yeah, it feels so selfish, but let me tell you, when you get on the scale and you gained 40 pounds, or when you realize you've been collecting records and you haven't listened to them in over a year... That's pretty depressing. That's exactly what happens, and it shouldn't. Then for me, you get resentful of your life, resentful of your partner. When you see your partner doing something enjoyable, you're like, "How dare you? What are you doing? You must think I'm ugly!" Just all of this stuff, please include it more.

Another parent suggested slowly building in more content on self-care after participants felt they have made progress and "conquered" some of the struggles with their children. A third parent recommended incorporating small "rewards" for parents within each module. Finally, one parent emphasized her belief that one program was not enough, saying:

I liked that [parent stress] was brought up, the idea that the seed was planted...and it was a discussion point that came up over and over again. So, at least I'm aware of it. I should be doing things... But at least I know there are these strategies that might help, and there are these handouts with stuff on there. So, that was good, I appreciated that. But for me,

it's just such a big thing that I would need a separate program dedicated [to stress], so I wouldn't be trying to switch gears... I know it's not really healthy, but it's easier for me to deal with problem solving for my child. It's harder for me to problem solve for myself. Which is not the way it should be, but that's just the reality of it. I know everyone's needs are so varied. But, I think what would be nice, in a perfect world, if you could do this for them, is to bring it up like you've done, and then at the end say, if you as a parent need or want to explore more of this wellness and mindfulness sort of thing, there's this other program and here's the information for it, or a scholarship for it.

She suggested collaborating with an existing program to provide parents with more stress-related resources once they “graduate” from *The Incredible Years*.

Thinking to the future: Additional supports for ASD-specific groups. Parents felt the program could be enhanced with the addition of five key supports, outlined below.

Check in regularly via email or phone. Some parents reported that the amount of attention from group leaders was adequate. However, three parents reported needing more intensive feedback and they suggested group leaders check in regularly with participants on their goals and progress. One parent emphasized the check-in must be leader-driven, as some parents might be reluctant to initiate contact.

Present more visual resources. Many parents craved additional visual materials to accompany *The Incredible Years* materials, such as “first-then”/“when-then” cards, photos of emotions, and picture schedules. While these ideas were discussed in group sessions, a parent said, “A lot of families either don't know how to make it, they don't know what to make, or they can't find the time to make it, or they just...don't have the materials [and] time to shop for

them.” Three parents suggested a “make it and take it” night in which participants could share supplies and develop visual materials for their children.

Create additional social support. Peer-to-peer support is integrated into *The Incredible Years* program, such as an informal dinner each night, the group format, and a “buddy system.” However, five parents requested more time to socialize and share ideas. The email support strategy implemented by one of the groups would be a potential way in which parents could connect outside of the formal group sessions.

Include partners and other caregivers. Most participants ($n=10$) expressed a desire to bring their partners or other caregivers (e.g., grandparents) to the group meetings. One parent explained:

[My partner attending] would’ve helped me to feel more supported....it’s certainly not marriage counseling. But, I feel like for our family, that’s something that’s been put on the back burner...In class when we talked about partner support, I was always the one who was like, “Yeah!”...I wouldn’t say every family is like our family, but a lot of the moms I met are the ones doing the up-front work, on the autism front. I feel like if the other spouse or partner was involved...it would lend some credence to some of the stuff on the autism front. That you are being sane, that you are not crazy. That’s what I get at home....I feel that sometimes that exposure to someone other than your spouse relaying all of this information, getting the ideas from other people...can be a nice way to bring couples closer together, or at least more on the same page, inadvertently.

Nonetheless, participants identified multiple barriers to having partners’ attend. The most commonly-reported issue was regarding childcare and breaking children’s night routines in order for all caregivers to attend. One parent suggested the program provide “vouchers” for in-home

childcare so parents would not have to bring their children out. Other parents remained concerned a babysitter would disrupt evening routines too dramatically. Weekend or daytime meetings were an option for some families, although one noted that giving up 15 Saturdays in a row might have been a problem. Other participants had spouses who wished to attend, but could not regularly attend due to heavy work schedules or physically strenuous jobs. Finally, one parent was concerned the dynamics of the group would be changed too dramatically and parents would not be willing to share disagreements in front of the group. Two parents who did not wish to bring their partners said it would have been acceptable to be in a group with a mixture of parents attending alone, and those with partners or other caregivers. However, they preferred to have couples- and singles-only groups.

Offer “advanced” program. As discussed above, parents reported they might have been reluctant to commit to such a long program at the beginning. Yet, once they completed the Preschool Basic program, they reported desiring additional weeks. Thus, one parent suggested the program be offered as an initial 15-week program, then give participants the option to continue for additional weeks with an intensive focus on partner relationships and stress management in particular. *The Incredible Years* does have an advanced program. This preliminary evidence from parents suggested that it would likely be well-received.

Discussion of Lessons Learned

This study focused on the feasibility and fidelity of *The Incredible Years* for parents of preschoolers with ASD, based on process data from group leaders and exit interviews with 17 program participants. Results demonstrate *The Incredible Years* program is feasible with this population. Fidelity to the complete protocol of the original *Incredible Years* model was generally maintained. An important exception was that videos were shown less frequently than

recommended by the program developer. Furthermore, the additional time needed to debrief videos and troubleshoot ASD-related behavioral challenges often resulted in less time available for role plays and other activities.

One important finding from this study was the challenge parents faced to focus on their own self-care. While parent stress, depression, and poor coping in this population are highly prevalent, participants reportedly dedicated nearly all of their time to child-related issues. The Contextual Model of Family Stress (Boss, 2002) clearly delineates the direct link between parent coping resources – how parents manage stress and promote family resiliency – and family well-being. Thus, considerably more work must be done to identify how *The Incredible Years* can better meet the direct needs of parents raising children with ASD.

In exit interviews, participants outlined various challenges in the recruitment and implementation of the program. These lessons are outlined below, with recommendations for future use of *The Incredible Years* with ASD-specific groups. Summaries of the recommendations are delineated in Tables 2.5 and 2.6.

Recruiting a Diverse Group of Parents

Despite wide outreach and multiple supports (e.g., childcare, free dinner, cash incentives), the majority of participants in the two groups were college-educated, White, and partnered. Based on participants' feedback and recruitment data from this study, future programs should offer the following to increase the diversity of participating families:

- Group meetings in more dispersed geographical locations, to reduce travel burden;
- In-home childcare vouchers or provisions for families who do not wish to disrupt their children's evening schedules; and

- Options for timing of group meetings (i.e., Saturday, weekday evening, or daytime groups) to accommodate more work and family life schedules.

These recommendations have the potential to increase program accessibility for more socioeconomically diverse groups of families.

Implementing the Program to Maximize Parent Success

Supports such as childcare, meals, and transportation were critical to facilitating participation in this lengthy program. However, parents raising children with ASD often require additional supports such as gluten/dairy-free foods and specialized childcare with low child-caregiver ratios. Furthermore, group leaders must have extensive professional experience in ASD services and supports for them to be effective and for them to have credibility with participants.

Parents identified several components as “active ingredients” to their success and satisfaction with the current program, particularly emotion regulation skills for children *and* parents, social support, and family-focused, strengths-based content. Furthermore, parents highlighted other recommendations to consider in the future, including the following:

- Longer program, potentially with use of *The Incredible Years* Advanced Parent Program, in order to spend more time on parent-specific issues;
- Ongoing, individualized support (possibly, in-home) for parents of recently-diagnosed children, due to increased stress at this developmental period;
- Partner/other caregiver participation, in order for parents to feel more supported in implementing program strategies at home; and,
- Opportunities for additional sessions in which parents can create and share resources.

It is important to recognize the current and proposed methods to tailor *The Incredible Years* to the ASD population will likely increase planning and implementation time and costs

(particularly, the hiring of sufficient number of experienced personnel to lead groups and provide childcare). However, these strategies have the potential to maximize the capacity of an evidence-based intervention to promote the well-being of children with ASD and their families. Further research is urgently needed to test this program rigorously using a randomized controlled trial.

Conclusion

Clearly, there is a gap between research on parents raising young children with ASD and available evidence-based interventions appropriate for their needs. One advantage of *The Incredible Years* is its current use and widespread acceptability in various localities in the United States and abroad. The potential for agencies in these areas to use existing resources to adopt the program and tailor it to families of children with ASD, once its efficacy and effectiveness have been established through more rigorous research, is high. The question for communities currently not using *The Incredible Years* or other evidence-based parenting programs suitable for this population is: is it worthwhile to invest the often constrained resources of agencies to provide such services to families? Also, how do service providers bridge the tension between maintaining fidelity to an evidence-based practice, while still meeting the unique needs of the ASD community? Further research is needed to answer these questions.

CHAPTER 3
THE INCREDIBLE YEARS PROGRAM TAILORED TO PARENTS OF
PRESCHOOLERS WITH AUTISM SPECTRUM DISORDER:
RESULTS FROM A PILOT TRIAL

An Autism Spectrum Disorder (ASD) is a neurodevelopmental disability with unclear etiology. The Centers for Disease Control and Prevention estimate approximately 1 in 68 children have ASD, with a higher prevalence of males affected (Centers for Disease Control and Prevention, 2014). The newly-released Diagnostic and Statistical Manual – Version 5 (American Psychiatric Association, 2013) eliminated past subcategories of ASD (e.g., Asperger’s syndrome) and characterized ASD based on two primary criteria: social communication challenges, and restricted or repetitive behaviors or interests. Children with ASD often have various comorbidities, such as cognitive delays, language deficits, hyperactivity, anxiety, sensitivity to tactile and auditory stimuli, gastrointestinal problems, and difficulty sleeping (Limoges, Mottron, Bolduc, Berthiaume, & Godbout, 2005; Newschaffer et al., 2007; Nikolov et al., 2009; Rogers, Hepburn, & Wehner, 2003; Simonoff et al., 2008). Furthermore, children with ASD often display emotion regulation challenges from an early age (Gomez & Baird, 2005) in addition to significant behavioral issues (Hartley, Sikora, & McCoy, 2008).

Parent strain and burden are high in families raising children with ASD. In addition to significant financial strain (Liptak, Stuart, & Auinger, 2006; Parish, Thomas, Rose, Kilany, & McConville, 2012), parents of young children in particular encounter disproportionate levels of stress and depression (Baker et al., 2002; Herring et al., 2006; Keogh et al., 2000). Research has

found maternal depressive symptoms in this population persist over time and exacerbate other stressors (Benson & Karlof, 2009; Carter, Martínez-Pedraza, & Gray, 2009). While ASD represents a wide range of symptoms and functioning levels, Herring et al. (2006) noted child behavioral problems impact parent stress more than a child's diagnosis. High parent stress and depression are associated with several negative outcomes, including child social difficulties (Neece & Baker, 2008), strained parent-child attachment (Sexton, Burrell, Thompson, & Sharpton, 1992), and marital unhappiness (Sher & Baucom, 1993).

Reviews have found parent training programs have numerous benefits to children with ASD (Matson, Mahan, & Matson, 2009; McConachie & Diggle, 2007). Researchers have highlighted reductions in child-related challenges through improving parent-child interactions, parent responsiveness during play, and verbal/nonverbal communication skills in early childhood (Mahoney & Perales, 2003; Siller & Sigman, 2008; Vismara, Colombi, & Rogers, 2009). A recent meta analysis found general (non-ASD) parent training programs led to significant improvements in parent depression and confidence at six-month follow-up (Barlow, Smailagic, Huband, Roloff, & Bennett, 2012). Yet, despite a preponderance of evidence demonstrating the prevalence of poor parent mental health and related outcomes in families of young children with ASD, few interventions have been developed to address parent outcomes (see Chapter 1 and Karst & Van Hecke, 2012).

Researchers have investigated ways in which parents of children with ASD receive support. Mandell and Salzer (2007) highlight the importance of support groups for parents raising children with ASD, particularly those with challenging behaviors. Steiner (2011) also noted a strengths-based approach to ASD parent education could facilitate parent adjustment to child-related challenges. Nonetheless, comprehensive, rigorous efforts to address parent well-

being along with child behavior related to ASD have not been described in the literature. However, one program, *The Incredible Years*, has been successfully tested in a randomized controlled trial with parents of preschoolers with developmental disabilities (McIntyre, 2008). Furthermore, a case study (Garcia & Turk, 2007) and a pilot test with eight parents (Roberts & Pickering, 2010) provide initial support to the use of *The Incredible Years* with parents of school-age children with ASD. Yet, the program's capacity to serve the needs of families of preschool children with ASD is unknown, despite evidence of the particularly high level of needs of this population. The following sections describe *The Incredible Years* and a pilot test with parents raising preschool children with ASD.

The Incredible Years Parent Program

The Incredible Years is a group-based early program that offers a number of developmentally-appropriate interventions to parents, children, and teachers. The program is based on several theoretical perspectives, including attachment theories (Ainsworth, 1974; Bowlby, 1980) and cognitive development theory (Piaget & Inhelder, 1962). The program is also heavily influenced by social cognitive theory (Bandura, 1986) and social learning theory (Patterson et al., 1992). Together, these theories form the foundation of developmentally-appropriate interventions focused on fostering positive child-parent interactions and improved child emotion regulation and social skills.

The focus of the current study is the Preschool Basic Parent Program, which uses a straightforward, collaborative and low-cost format to develop skills in problem-solving coping methods, stress management, and communication. Decades of evidence indicate that *The Incredible Years* improves parent stress, depression, and coping skills, and decreases negative child outcomes, such as aggressive behavior, in a broad array of diverse populations (Jones et al.,

2007; Kim et al., 2008; Linares et al., 2006; Reid et al., 2001; Webster-Stratton & Reid, 2003).

The program has been recognized in the United States by, among others, the U.S. Department of Health and Human Service's (2007) National Registry of Evidence-based Programs and Practices and Institute of Behavioral Science at University of Colorado at Boulder's Blueprints Model Program (Webster-Stratton et al., 2001). The program has been used extensively in the United States, United Kingdom (Melhuish, 2007), Sweden (Axberg, 2007), and other international sites. Cost-effectiveness analyses have been performed with positive results in England (Edwards, Ceilleachair, Bywater, Hughes, & Hutchings, 2007).

The goals of *The Incredible Years* parent intervention – communication, problem-solving, stress management, reduction in challenging behaviors, and improvement in school readiness – are partly informed by theories emphasizing the importance of adults addressing their own negative cognitions and improving interactions with others (Beck, 1979; D'Zurilla & Nezu, 1982; Jacobson & Margolin, 1979). In addition, the Contextual Model of Family Stress (Boss, 2002), while not referenced as a basis for *The Incredible Years*, provides a framework in which stress and crisis are influenced by families' balance between perception of stressors and their ability to manage such stressors.

The stated goals of *The Incredible Years* are critically important to families with children with ASD. Parents of children with special needs tend to interact with teachers, healthcare professionals, and other adults more often than parents of typically-developing children (Parish, Saville, & Swaine, 2011). Thus, building a strong foundation early to address challenging behaviors and navigate healthcare and special education systems has important potential to reduce parent stress.

Given the potential of *The Incredible Years* to create positive outcomes for parents of young children with ASD (ages 3 to 6 years old), a pilot study was undertaken. The research aims for the study were as follows:

- 1) Decrease parent-reported stress from baseline to post-intervention; and,
- 2) Assess participant acceptability, and parent, child and family outcomes from each of the four *Incredible Years* modules (described below).

The current paper uses a mixed methods approach to investigate parent, child, and family outcomes and acceptability of *The Incredible Years* with two groups of parents raising preschool-age children (ages 3 to 6 years old) with ASD.

Method

Participants

The current study was approved by the author's Institutional Review Board. Participants were recruited through fliers, listservs, and website announcements distributed by local ASD support groups, community agencies and public schools in a southeastern suburban area of the United States. Interested individuals contacted the author directly by phone or email. The inclusion criteria permitted participation of biological or adoptive parents of a child with ASD who was aged 3 to 6 years, or who would turn 3 during the course of the program. Only one parent per family was allowed to participate. Additionally, the parent had to have currently lived with the child for at least 6 months and be at least 18 years of age at baseline.

In total, 17 parents participated in the two *Incredible Years* groups. (See Table 3.1 for a description of the sample.) The majority of the sample (94%; $n=16$) was married/partnered. Furthermore, more than half of the participants self-reported as White (59%; $n=10$), while African American, Asian American, and other ethnicities comprised the remainder of the sample.

Table 3.1

Description of Sample (N=17)

Parent Characteristics	<i>N</i>	%
Marital Status		
Single	1	5.9%
Married/Partnered	16	94.1%
Racial or ethnic group		
African American	2	11.8%
Asian	2	11.8%
White	10	58.8%
Other	3	17.6%
Education		
High School/GED	2	5.9%
Associate Degree	3	17.6%
Bachelor Degree	5	29.4%
Graduate Degree	4	23.5%
Professional/Doctoral Degree	3	17.6%
Child Characteristics		
Mean age in years (SD)	3.7	0.92
Mean age at diagnosis in years (SD)	2.9	0.91
Mean time since diagnosis at program initiation in months (SD)	13.5	9.46
Gender		
Female	5	29.4%
Male	12	70.6%
Siblings		
None	6	35.3%
One	10	58.8%
Two	1	5.9%
Receipt of other services		
Occupational therapy	12	70.6%
Specialized preschool/educational services	12	70.6%
Speech therapy	10	58.8%
Structured teaching	4	23.5%
Hippotherapy	2	11.8%
Other	3	17.6%
Parent's characterization of child's verbal ability		
Verbal (typical)	7	41.2%
Verbal (delayed)	5	29.4%
Nonverbal	5	29.4%

Nearly three-quarters of the parents reported they had a bachelor's degree or higher (71%; $n=12$). The mean age of the participants' children with ASD was 3.7 years old at the beginning of the program. The children were diagnosed with ASD at a mean age of 2.9 years old, and a mean time of 13.5 months had elapsed from diagnosis to program initiation. Approximately 70% of the children were male. The most common therapy children received were specialized preschool/educational services and occupational therapy (71% each). Nearly 60% of the children also received speech therapy. Parents had between one to three children in their households, with the majority of participants reporting they had two or more children (65%; $n=11$). Finally, parents characterized their children's verbal abilities as typical (41%; $n=7$), delayed (29%; $n=5$) or nonverbal (29%; $n=5$).

Of the 17 original participants, 14 parents (82.4%) completed the program. The reasons for discontinuation were moving out of state and dissatisfaction with program. Reasons for dissatisfaction included disruption in children's nighttime schedules, distance to class, need for more one-on-one support, and inability to bring partner to group. Participation ranged from 88% to 100% at each session. The mean participation per session was 92%.

Research Design

The current study utilized a mixed methods design with no comparison group to assess the acceptability of *The Incredible Years* Preschool Basic Parent Program with two groups of parents with young children with ASD. The author, who was also trained in the intervention, attended (but did not participate in) all intervention sessions and collected the measures described below.

Research Procedures

Each potential participant met with a researcher to review eligibility and program information and to provide informed consent. Childcare, dinner, and transportation support were offered to all participants. Cash incentives were provided to participants in exchange for completion of measures (up to \$75 for completion of all measures). Data were collected an average of 10 days before program initiation (range, 1 to 18 days), on a weekly basis during the 15-week program, and after program completion. All posttest measures were collected an average of 12 days after program completion (range, 1 to 24 days.)

Intervention Procedures

The Incredible Years program met for 15 two-hour weekly sessions. Dinner was provided 30 minutes before each session, in order to allow parents to informally socialize, if desired. Each group, composed of up to nine parents, was held in a community setting. The first group meetings were led by an ASD parent advocate, who provided participants with information regarding ASD services and supports in the community. Subsequent meetings (i.e., weeks 2 to 15) were co-facilitated by two individuals trained and certified in *The Incredible Years* model, who also had extensive post-master's level experience working with children with ASD and their families.

The details of *The Incredible Years* program are described elsewhere (Webster-Stratton, 2001; Webster-Stratton, 2011). In summary, the intervention was divided into four modules: child-directed play; praise; limit setting; and handling misbehavior. Each module contained strategies to address the child's behavior, the parent's interaction with the child, and parent coping strategies. Each session included four parts: 1) participant "check-in," where each parent described and discussed the previous week's successes and challenges with the group;

2) facilitator teaching of new materials, which involved videos and interactive discussions; 3) small and large group practice of skills; and, 4) goal setting for the coming week and distribution of homework. The videos primarily featured typically-developing children, with the exception of some videos of children with language delays. Each parent was paired with a fellow group member in a “buddy system” after week four in order to provide additional support during the week.

Although the program was implemented according to *The Incredible Years* manual, the intervention was tailored to the specific needs of young children with ASD. In addition to the meeting with the ASD parent advocate described above, the group leaders tailored the program for families raising children with ASD by: 1) providing examples of visual prompts and schedules for children; 2) focusing more on the development of child and parent self-regulation skills; 3) encouraging self-care and coping skills for parents under stress; 4) spending more time to discuss videos and other program content in context of ASD; and, 5) sharing ASD-specific resources via email in order to facilitate community social support and service access. More information about tailoring the program for ASD-specific groups can be found in Chapter 2.

Measures

In addition to one-time baseline demographic data and weekly attendance records, three types of quantitative and qualitative measures were collected from participants in this study and are described in detail below. Quantitative data included a prepost/posttest parent stress survey and a weekly acceptability questionnaire. A mixed quantitative/qualitative comprehensive acceptability survey was administered to participants during the final session of the program. Finally, qualitative data from each parent was collected during one-on-one interviews after

program completion. In addition to the measures described below, fidelity measures were collected throughout the study period and are described elsewhere (see Chapter 2).

Acceptability. Two measures were collected to assess participants' appraisal of the acceptability of the program. Both of these questionnaires are available in *The Incredible Years* manual, and neither has established psychometric characteristics.

First, on a weekly basis throughout the duration of the program, participants were asked to complete a short satisfaction survey. The surveys included four Likert-scale questions ranging from "not helpful" to "very helpful," and focused on participants' satisfaction with the week's program content, teaching, group discussion, and videos. The surveys took less than 5 minutes to complete each week.

The second acceptability survey was collected at the end of the final program session. The survey included 46 questions and asked participants to rate their satisfaction with the program's content, teaching methods, specific techniques, and group leaders on 7-point Likert scales. Additionally, participants were asked to respond to four open-ended questions and provide additional comments. The open-ended questions asked what parents to identify the most helpful part of the program, what they enjoyed most and least, and what could be improved. The surveys took approximately 15 minutes to complete.

Parent stress. The Parenting Stress Index (PSI) – Fourth Edition (Abidin, 2012) was used to measure parent stress. Developed for parents of children ages 1 to 12, the PSI measures child-parent relationship challenges that contribute to parent stress. The PSI has been validated in over 25 languages and has been used for over 30 years with parents who have children with special needs. The PSI has a history of use in the ASD community (e.g., Dumas, 1991). The measure has strong psychometric characteristics. Loyd and Abidin (1985) reported an internal

consistency (Cronbach's alpha) of 0.95 for the Total Stress Score and 0.91 for the entire Parent Domain. The PSI is also used to determine clinically-significant levels of parent stress, based on normative samples provided in the instrument's manual.

The PSI is a 120-item, self-reported questionnaire that largely employs 5-point Likert scale answer choices (Abidin, 2012). The measure requires approximately 20 to 30 minutes to complete. It covers two major domains, which include seven child and eight parent subscales. The child scales are Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability. A sample item from this domain asks the parent to rate the statement, "My child rarely does things for me that make me feel good" as strongly agree; agree; unsure; disagree, or strongly disagree. High scores on the Child Domain suggest parent stress related to difficulty with the child. The parent scales are Depression, Competence, Social Isolation, Attachment to Child, Health, Role Restriction, and Spouse. One item from this domain is, "Since having a child I feel that I am almost never able to do things I like to do." High scores on the Parent Domain are related to parent stress resulting from parents' emotional, physical, or social functioning. The scales are summed to yield a Total Stress Score, which measures the stress of the parent-child interaction.

Exit interviews. Lastly, an exit interview was conducted with each individual participant following program completion or withdrawal. The aim of the interview was to assess overall satisfaction and obtain feedback on methods to tailor the program to parents of children with ASDs. The semi-structured interview covered topics such as the length of the modules, method of presentation, and additional topics needed. Each interview lasted approximately 60 to 120 minutes. All interviews were digitally audio-recorded, transcribed, and twice-verified for accuracy.

Data Analysis

Acceptability measures. The weekly surveys were used by group leaders to tailor the content for the following week in response to parent feedback. However, the overall purpose of the weekly surveys was to gather information on the suitability of the model to parents with children with ASD. Thus, these surveys were examined for overall themes on issues affecting this population. Similarly, the final questionnaire was tabulated and the open-ended questions were combined to look for outcomes and themes across the two groups.

Parent Stress Index. Given the relatively small sample size, basic descriptive statistical procedures were used to analyze the Parent Stress Index. Once data were entered into Microsoft Excel, two-tailed paired t-tests were used to test for significant change between baseline and post-intervention outcomes. A *p*-value of .05 or less was considered to be significant.

Exit interviews. After completion of the individual one-on-one interviews, the audio files were transcribed and transferred to Atlas.ti Version 7 (ATLAS.ti Scientific Software Development GmbH, 2011). The author read each transcript twice for accuracy before coding began. In addition, field notes from each interview were reviewed before and during the coding process. An initial codebook was developed based on the interview guide. Then, each response was labeled with an open coding approach, with additional codes developed as necessary. The codes were then organized into categories aligned with the study's research aims and interview questions. In particular, the author was interested in responses regarding outcomes and acceptability of the overall program content and specific modules. Each category was further divided into subcategories, to investigate themes based on respondent characteristics. At times, subcategories were again collapsed into larger categories as overlapping themes emerged. The

author was highly interested in trends leading to both positive and negative outcomes for parents, and potential reasons for which these outcomes occurred.

Results

Weekly and Final Acceptability Outcomes

Ratings from weekly acceptability measures were high over the duration of the program. (See Table 3.2.) Videos were rated the lowest (“helpful”; average of 3.44 out of 4 over the course of the program). Teaching, group discussion, and session content were all rated an average of 3.7 to 3.8 out of 4 (“very helpful”).

Based on the final acceptability survey administered after completion of the final session, parents’ ratings of the overall program were high. (See Table 3.3 for listing of key items and results.) Parents reported their original problem related to their child and child’s behavior was “improved” as a result of the program (mean scores of 5.9 and 5.8 out of 7, respectively). Furthermore, participants noted the program “helped” family and personal issues not directly related to the child (e.g., marriage, personal feelings) (mean score of 6.0 out of 7). Overall, parents felt the program was “appropriate” for their child (mean score of 6.3 out of 7) and would “strongly recommend” the program to a friend or relative (mean score of 6.6 out of 7).

Graduates of *The Incredible Years* program rated the teaching format as “useful” (mean score of 6.1 out of 7) and both of the group leaders as “extremely helpful” (mean score of 6.9 out of 7). Participants reported the techniques to improve child behavior discussed in the program were either “useful” or “very useful,” with the exception of tangible rewards/sticker charts (“somewhat useful”).

In the comments section of the questionnaire, most parents listed the group discussions as either the most helpful part of *The Incredible Years*, what they liked most about the program, or

Table 3.2

Mean Weekly Acceptability Results

Program Aspect	Mean Rating	SD
Session Content	3.67	0.53
Videos	3.44	0.71
Teaching	3.78	0.43
Group Discussion	3.74	0.53

Note: Ratings ranged from 1=not helpful to 4=very helpful.

Table 3.3

Selected Final Acceptability Results

Item	Mean Rating	Mean Score	SD
A1. The problem(s) that originally prompted me to take the parenting program for child is (are):	Improved	5.9	0.9
A2. My child's behavior which I have tried to change using the methods presented in this program are:	Improved	5.8	0.7
A4. To what degree has <i>The Incredible Years</i> parenting program helped with other personal or family programs not directly related to your child (e.g., your marriage, your feelings in general)?	Helped	6.0	1.0
A6. I feel the approach used to improve my child's behavior in this program is:	Appropriate	6.3	0.8
A7. Would you recommend this program to a friend or relative?	Strongly Recommend	6.6	0.5
B. Teaching Format	Useful	6.1	1.1
C1. Technique: Child-Directed Play	Extremely Useful	6.6	0.6
C2. Technique: Descriptive Commenting/Social, Emotion and Academic Coaching	Useful	6.3	0.6
C3. Technique: Praise and Encouragement	Extremely Useful	6.7	0.5
C4. Technique: Tangible Rewards (Charts)	Somewhat Useful	5.4	1.0
C5. Technique: Routines, Responsibilities	Useful	5.9	0.9
C6. Technique: Ignoring	Useful	5.7	1.1
C7. Technique: Positive Commands (e.g., "when-thens")	Useful	6.0	0.9
C8. Technique: Time Out to Calm Down	Useful	5.9	0.9
C9. Technique: Loss of Privileges, Logical Consequences	Somewhat Useful	5.4	1.0
D4. At this point, I feel the group leader (1) in the program was:	Extremely Helpful	6.9	0.5
D4. At this point, I feel the group leader (2) in the program was:	Extremely Helpful	6.9	0.4

Note: All scores ranged from 1 to 7.

both. They reported that these discussions allowed them to talk about their unique problems, specific child behavior strategies and form connections with other parents. The next two most frequently reported responses to the question about the most helpful part of *The Incredible Years* were the homework activities (particularly play-based tasks) and in-class role play exercises. The answers to the question regarding what individuals liked most about the program were similar. In addition to group discussion, participants reportedly enjoyed learning new behavioral skills and the individualized nature of the teaching format/group leaders' advice. Parents reported the videos were the least helpful aspect of the program, because they were out-of-date and did not feature children with ASD. The participants' top two suggestions for improvement were to increase the length of the entire program and add even more information on ASD.

Parent Stress

The findings from the Parent Stress Index (PSI) are detailed in Table 3.4. Mean total stress scores decreased significantly following the intervention, as compared to baseline scores (23-point decrease; $p < .01$). At baseline, 79% ($n=11$) of the 14 participants reported total stress scores at or above the 75th percentile, compared to a normative sample (Abidin, 2012). By completion of the program, 36% ($n=5$) had elevated total stress scores.

The Child Domain of the PSI similarly decreased. At baseline, 79% ($n=11$) of parents had scores at or above the 75th percentile. By the end, 43% ($n=6$) of participants reported these elevated scores. The total mean scores on the Child Domain also decreased significantly (18-point decrease; $p < .001$). Scores on five of the six Child Domain subscales decreased significantly from baseline to post-intervention, specifically Distractibility/Hyperactivity ($p < .03$; e.g., child who often fails to complete tasks), Adaptability ($p < .02$; e.g., child has difficulty adjusting to change); Reinforces Parent ($p < .05$; e.g., parent has feelings of rejection from child);

Table 3.4

Pre/Post Changes in Parent Stress

PSI Domain	Percentage (<i>n</i>) with Elevated Baseline Percentile Scores (>75%)	Percentage (<i>n</i>) with Elevated Posttest Percentile Scores (>75%)	Mean Pretest (SD)	Mean Posttest (SD)	Difference	<i>p</i> -value (2 tail)
Total Stress	79% (11)	36% (5)	298.8 (34.0)	275.4 (48.3)	-23.4	0.01
Child Domain	79% (11)	43% (6)	148.6 (21.3)	130.5 (23.1)	-18.1	0.001
Parent Domain	43% (6)	36% (5)	152.1 (23.4)	144.9 (32.2)	-7.2	NS

Note: *N* = 14 (participants who completed intervention)

Mood ($p < .02$; e.g., child seems depressed or unhappy); and, Acceptability ($p < .001$; e.g., child's personal characteristics do not meet parent expectations).

Change in total scores on the Parent Domain was not statistically significant. While the raw mean scores, as well as the number of participants with elevated percentile scores, decreased from baseline to program completion, the decreases were modest and not statistically significant. Similarly, the Parent Domain subscales were not significant, with the exception of Competence ($p < .02$; e.g., parent lacks knowledge on child behavior strategies).

Qualitative Findings from Exit Interviews

All 17 parents participated in the individual exit interviews, including the three who discontinued the program. Most of the findings from the acceptability surveys described above were consistent with the exit interviews. No themes were identified from specific subgroups of parents and/or children (e.g., children with specific behavioral challenges; parents who withdrew from the program).

All 14 participants who completed the program found the content to be appropriate for their children and families. While nearly all of the parents received at least one other service for their child outside of the program (e.g., speech therapy), parents overall reported *The Incredible Years* complemented these therapies. Although the program was not developed specifically for parents of children with ASD, the autism-specific groups were, for many of the parents who completed the program, sufficient for their satisfaction with *The Incredible Years*. One parent noted that while the content was not designed for ASD, “[The group leaders] had answers....Like if they hadn't had any experience with kids with autism then that wouldn't make any sense, but they did. So...it works for everybody.”

The biggest advantage for many of the parents was the focus of the program to meet their children where they were developmentally. One parent commented, “[E]very other therapy session we’ve ever been to is all about the autism piece and not the child as a whole. I think this [program] was a step back and it really made me reevaluate okay, maybe I don’t need to push so hard.” Other parents concurred, one saying the program forced her to “take time out” and another that it made her realize, “What was the point in making [my child] do a lot of stuff we were trying to make him do?” The following sections describe parent-reported outcomes from each of the four program modules in more detail. Then, it presents findings on parents’ satisfaction with the teaching methods. Finally, parent-reported outcomes on stress and family/professional communication skills are detailed.

Module 1: Strengthening children’s social skills, emotion regulation, and school readiness skills. The first module focused entirely on child-directed play. Two parents acknowledged they worried at first the content would not fit their unique situations, given its focus on child play. However, over time the parents who continued in *The Incredible Years* found the content beneficial, especially in terms of the children’s emotional regulation skills. One parent said, “I actually felt by starting with something that required [me] to be child-directed, and...an observer, it kind of helped me settle down in order to not feel hyped up about carrying out ...goals, and what I accomplished this week.” Important outcomes from this module for the parents included the reduction of parent stress, frustration and anger, as one mother described:

[Child-directed play] worked really well for us, actually, because it gave us something to do. But probably from [my children’s] perspective, we weren’t really doing anything. So,

it alleviated a lot of stress from both of our ends, because even if our minds were racing, we were just supposed to let them do what they were doing, without interfering.

Nearly all of the parents who completed the program felt it improved their relationship with their child. One mother said, “I used to sit and have fun with my kids, instead of worrying about disciplining them...or being distracted...[The program] made me focus on them. When I [played], they actually behaved a lot better because they were getting attention.” Other parents reported their children’s ability to self-regulate improved due to the skills parents learned in the classes. One parent observed her child became disregulated because “[He] needs to be on the go all the time... If I sit down and play with him for a while, that will chill him out usually.”

Several parents noted their children either wanted to exclude the parent from the play, or became overwhelmed with the nondirective nature of the play. Two parents cited their children’s rigidity as a barrier to play, although one noted that the play caused her to begin to read her child’s cues better. Some parents reported after they gave their children limited choices in what to play, the child was able to continue with play activities for longer, and for some to practice imaginary/pretend play. Although several children continued to engage in preferred activities, some parents reported the play became more interactive over time, as one mother discussed:

Rather than mom saying, “What color is that? What shape is that?” I just went with the flow. And, he was a little apprehensive at first and it took a while to let me in. Once he did, he got really excited and then he would engage me a lot more in his play because I think he trusted me and thought I would do things that he preferred.

However, one parent, while reporting child-directed play made her child happy, continued to struggle to engage with the child:

[I'm] just looking at her and trying to find out the ways to enter her life. Sometimes... I'm trying the same strategy again and again and it's not working, sometimes it's working...I cannot figure out the logical way of why it worked this time, why it doesn't work this time.

Descriptive commenting, in which the parent simply described verbally what the child was doing as s/he played (e.g., "Oh, the car is on the table!"), was beneficial to most parents. They found it easy to add into their play routines, as one parent noted, "They are not asking you to reinvent some tool that is going to take much time...It's such common sense and easy to do." Others found it challenging to comment rather than ask the child questions. Some parents of both verbal and minimally verbal children reported descriptive commenting improved their children's language or communication skills. A parent said:

He picked up that language pretty quickly, so talking about things like..."The blue train is going over the bridge and it's going into the tunnel." So then he started using those kinds of words and phrases when he was playing, which was good. I felt like it allowed him to be more descriptive with what he was doing, as well.

Another parent reported it caused her child to stay on task for longer, "[Commenting] was a huge turning point for our relationship, actually. The cues I got were [my child] enjoyed being appreciated for exactly what [she was] doing...It seemed [she] would do whatever [she was] doing for longer."

Four of the parents reported that descriptive commenting was not completely beneficial to their children. One parent noted that her child just repeated everything she said (echolalia),

while another parent said her child began “scripting” more (e.g., saying phrases repeatedly). Two parents said their children became irritated when they commented too much, which one speculated was due to auditory overstimulation.

The remainder of Module 1 consisted of four types of “coaching” in which the parent encouraged persistence with tasks, and labeled academic concepts, emotions, and social skills (e.g., sharing). Academic coaching was reportedly useful for most of the parents, particularly if they took into account the child’s developmental level and/or temperament assessment (provided in program handouts). One parent considered academic coaching to be too “goal-oriented,” while another found it difficult to remember to do.

Emotion coaching (labeling emotions for children, either verbally, with pictures, or modeling how one’s body looks like when s/he experiences different emotions) was useful for most of the program participants, particularly to decrease anxiety and improve emotional regulation. However, two parents felt the coaching was too developmentally advanced for their children. Others parents described how it helped to decrease tantrums, particularly if they assisted children to identify emotions before the “meltdowns” escalated. One parent of an older child explained:

[W]ith his tantrums lately, I feel like it's because he's frustrated. I said, "You're frustrated because I think you need a hug?" He'll give me a hug...and stop earlier. So that's my goal. I think...because he doesn't have the words to say what he's feeling and I know he's frustrated or mad or disappointed, but he doesn't say that and move on.

A parent described how it expanded her child’s emotional repertoire:

[My child] used "I'm sad" all the time and I think that after learning [emotion coaching] [my partner and I] were very careful to say, "Oh, you look upset" or "Oh, you look

frustrated" and...to find him when he did something that was upsetting, and comment on the facial expression to try to give him that word....It made us think of situations when he was making the face, but normally we probably wouldn't have said anything, and we said, "Oh, you look rather frustrated" you know, and then he'd tell us what was wrong.

Another significant advantage of emotion coaching for parents was to identify and regulate their own feelings. Multiple parents described situations in which they felt angry or frustrated, but used program strategies to calm themselves down. As the parents learned to express their own emotions, some began to model it for their children. One parent described a situation in which she used a deep breathing strategy when her child was screaming. Then, she taught the same technique to her child in order to regulate his emotions, as well.

Persistence coaching, for most of the parents, helped to increase their children's ability to stay on task and reduce frustration and anxiety. One participant noted that this type of coaching also assisted in daily life skills, such as toilet training. Four parents emphasized the importance of understanding their children's moods, and pairing persistence coaching with labeling of emotions.

Social coaching also was most helpful for those parents who reportedly paired it with emotion coaching. Challenges in social communication/interaction are a cornerstone to the ASD diagnosis (American Psychiatric Association, 2013); thus, parents reported this type of coaching was of particular interest. One parent reported her child did not respond to social coaching. However, others found it increased positive peer interactions and prosocial behaviors (e.g., sharing), and decreased problems between siblings. Two parents noted the coaching was most helpful when the child was in the "right mood" and when they coupled verbal coaching with nonverbal prompts (e.g., "hand over hand").

Module 2: Using praise and incentives to encourage cooperative behavior. Nearly all of the parents reported their children enjoyed receiving praise, as evidenced by an increase in positive behaviors (e.g., sharing) and social interaction (e.g., eye contact). Two parents noted their children inconsistently responded to praise, sometimes seeming to be overwhelmed by verbal praise. One parent of a minimally verbal child described utilizing nonverbal methods of praise, such as clapping. Multiple parents noted it was helpful to remember to praise good behaviors, rather than focus on challenging ones.

The session on praise also included strategies to praise oneself, as well as partners and professionals (e.g., therapists, teachers). Most of the parents struggled with self-praise in particular. One parent explained this difficulty:

I think it's because we feel that our children represent us, and...how well we are doing with them. And when your child has [ASD], part of it is that if you go to a dark place, you feel that you're responsible for it. "What am I doing wrong? I'm not doing enough!" You know, if you relax, you get worried. So, it's easy to not be able to praise yourself. But, it is important, and I think the children benefit from it, too, if you're taking care of yourself.

Two parents noted self-praise, as well as praise for partners and professionals, was challenging because it was uncommon in their cultural backgrounds. However, praise was helpful for some parents, as one described:

[Before the program began,] I do remember feeling a lot more like I suck as a parent and I have no idea what I'm doing, and this is annoying. I was much more negative. Now, I definitely don't feel that way. I feel like I'm not perfect and I don't always respond the way I'm supposed to, but I feel like I know how to respond now. I have all these tools

that I can look back on and use...the praise was good because I felt like I was getting to this point where I was just feeling angry all the time, so it was very negative. So then as soon as we changed it to more praise, it was more of a positive thing and I liked that.

Parents noted their partners, professionals, and other family members appreciated praise, although the parents reported they did not praise these individuals as much as they would have liked.

Parents were introduced to reward systems (incentives), such as sticker charts, to encourage cooperative child behavior. The parents were split as to whether these reward systems were effective with their children. For the half of parents who reported sticker charts were not motivating for their children, they explained the rewards were not developmentally appropriate for their child (i.e., the child was either too old or too young) or their child preferred other types of rewards. Other incentives parents used to successfully motivate their children included physical “sensory” rewards (e.g., hugs), bubbles, use of technology (e.g., iPad applications), food, and television shows.

Module 3: Household rules, routines, and effective limit setting. Module 3 focused on establishing household structure. The concept of routines was familiar, and generally well-established, by many families of children with ASD. For those parents who did not already use routines and prompts (e.g., picture cards), they reported these strategies led to an improvement in transitions and a decrease in misbehavior. Rules and limits, particularly the focus on positively-stated commands (e.g., rather than “No screaming!” using “Quiet voice, please”) resonated with some of the parents and their children. Positively-stated commands were more concrete than “Stop!” or “No!” and thus parents felt the commands were more helpful for children who were not abstract thinkers. However, many of the parents struggled with limit-setting. Common

barriers included maintaining parental consistency with rules and limits, as well as difficulty phrasing commands positively and with few words. Two parents detailed their children slowly, but steadily became more compliant with rules, while two others discussed incorporating strategies such as play or redirection to facilitate compliance.

Module 4: Positive discipline and handling misbehavior. Module 4 was reportedly the most difficult for some of the parents. The first session in Module 4 taught parents how to ignore inappropriate behaviors. Some parents reported being surprised to observe a decrease in negative behaviors with this strategy, given the common perception of children with ASD is that they are not attention-seeking. For most parents, ignoring behaviors that did not pose a safety risk (e.g., running away) or involve aggression was beneficial. However, two parents noted that ignoring maladaptive behaviors led to an increase in child anxiety, perhaps due to their children's inability to self-regulate. Multiple participants discussed how methods for the parents to cope when their child misbehaved (e.g., listening to music, positive self-talk) were helpful.

Module 4 also presented two “time-out” strategies: one method to help the child calm down, the other a consequence for non-compliance, particularly aggression. Three parents explicitly discussed successfully using a “calm down” method, in which they sat next to their children and did soothing activities (e.g., rubbed child's back). Two additional parents described using the strategies discussed in class to visually depict to children how their body feels when they are sad or upset (e.g., fast breathing when mad), and to then use concrete deep breathing exercises to calm their bodies down. Other parents felt the concept of having a “calm” or “safe space” where children can regulate themselves (e.g., bean bag chair, trampoline) was useful for children with sensory-seeking behaviors. However, one parent struggled to understand the distinction between time-out to calm down and time-out for noncompliance, and had trouble

implementing either with her child. Lastly, two parents found it difficult to consistently use time-out due to disagreement with other caregivers (e.g., spouse, teachers) regarding which behaviors deserve a time-out.

Time-out for noncompliance (i.e., where child sits in chair alone) was not used often by participants, many of whom felt their children's misbehavior was more often the result of sensory-related or communication issues. Only three parents reported using it regularly and with success. The other parents noted it was hard for their children to understand the concept of time-out and calm down when they were left alone. Some parents said they did not need this type of time-out because the other strategies (e.g., time-out to calm down, redirecting) worked better.

The concept of natural and logical consequences (e.g., "If you throw your toy, then I will take it away") was reportedly helpful for most of the parents and their children. These types of consequences were noted by parents to help reduce behaviors such as running away or aggression. Some parents felt their children were not able to understand the concept of consequences, or merely just "tuned out" the parent. Although the concept of explaining consequences using visuals was discussed in class, none of the parents reported using it.

Problem solving was covered in the final class, so it was difficult for parents to assess their children's response to the content. However, two parents of older children felt the strategies could be helpful for their children; whereas some parents of younger children noted the content was likely too advanced.

Teaching methods. Three primary teaching methods were used in *The Incredible Years*: group discussion, role playing, and videos. While nearly all of the parents said they learned from the videos (particularly what *not* to do), half of the parents had trouble applying information to their situations due to the fact that none of the videos had children with ASD in them. Some of

the parents noted the videos were outdated, and one felt there were too many. Although the videos lacked specificity for each parent's unique situation, some parents found the role plays and group discussions allowed parents to discuss their particular challenges in more detail. Some parents were uncomfortable with the idea of role play activities at the beginning of the program, yet after a few weeks all of the parents reporting enjoying them. Multiple parents noted role play exercises helped them to better understand their children's perspectives. Similarly, the group discussions were reportedly important to nearly all of the participants. They reported group discussions reduced isolation and stress, and increased knowledge of local resources. Three parents reported while they enjoyed the group discussion, at times the discussions were too lengthy and reduced the time spent learning new content.

Reduction of parent stress and isolation. In addition to the support provided in-class during group discussions and role play, parents overall enjoyed the "buddy system" employed by the program to create peer support between participants during the duration of the week. The opportunity to have a platform every week to discuss challenges was stress-reducing for some participants. Parents also discussed the benefits of the various types of personal coping strategies they learned to deal with frustrating or challenging child behaviors, such as distraction (e.g., singing), ignoring certain behaviors, or gaining access to information. Most parents noted they appreciated the program was child-focused, while still inclusive of parents' needs. However, one parent found it hard to remember strategies to relax and other coping mechanisms for frustration once she left the group meetings. Others reported appreciating the self-care strategies, but felt they needed more time to practice them in class.

Family and professional communication. Parents reported that while they recognized the importance of partner, family and professional communication strategies, they felt there was

an insufficient focus on these issues in the program. However, one parent discussed a positive outcome when she applied the concept of “praise” to her father: “My father and I go at it a lot. He's got the most challenging temperament....I learned in class [for this] challenging temperament, you really got to kick up the praise a lot....it worked wonders for my dad almost immediately.”

Most parents reported they were able to communicate with their partners regarding the program content; yet, there were multiple barriers. Some partners were disinterested in class content, while other participants felt unsupported by their partners or other caregivers (e.g., grandparents) in implementing changes in their households. Two parents discussed difficulty using partner praise and communication strategies due to their own preexisting anger with their partners. In addition, two parents noted their partners were resentful when the parents tried to “teach” them class content, as one parent described:

I think some of the coaching that I've done came off as criticism or I'm bossing [my partner] around or I'm blaming him. It's really hard to not blame the other parent when your child is screaming. It's really hard to be like, “Stop doing that! You're not doing it right!”

However, one parent discussed using communication strategies to impart class content with her partner effectively, “I shared [coping strategies] with [my partner] and it did wonders for him. It was just a lot easier because he gets frustrated easily with [our child]...It took a lot of pressure off.”

Lastly, for those parents with other children, the program was reportedly appropriate for the siblings as well. Many parents indicated they were able to adapt strategies for siblings, although finding time to work with each one individually was challenging. Furthermore, one

parent said it was confusing to apply concepts to different children, particularly given the focus on ASD. Two parents said they benefited from information from the videos on sibling dynamics, but desired more information on this topic.

Discussion

These findings offer promising preliminary evidence of the acceptability of *The Incredible Years* Preschool Basic Parent Program for two groups of parents of preschool-age children with ASD. This research assessed acceptability with weekly surveys, a comprehensive final questionnaire, and individual exit interviews. Finally, parents reported stress before and after program participation. This mixed method study found some improvements in parent stress and generally positive reactions of parents to the content and delivery of *The Incredible Years*.

In order to properly evaluate the outcomes of this study, its limitations must be addressed. The study sample was modest, with 17 parents, and generalizability should not be presumed. Further research with a larger sample is warranted. The study did not include a control group, so it is impossible to conclude that the program, rather than other factors such as receipt of other interventions, led to changes in parent stress and related outcomes. Furthermore, given the program was focused on measuring acceptability, few quantitative outcome measures were collected. At a minimum, understanding of child behavior and functioning level at baseline and after the program would expand understanding of the full scope of family and child outcomes. Finally, despite recruitment efforts, the sample was not diverse in terms of marital status and education in particular. This sample was advantaged compared to the general US population, but is consistent with nationally-representative analyses of children with ASD, in which relatively higher income and education are reported among parents (Parish, Thomas, Williams & Crossman, in press). In addition, the attrition analysis suggested the children of individuals who

withdrew from the intervention were significantly different on three measured characteristics from those whose parents completed the program. Finally, this study relied on self-reported information from the parents, and given their investment in the program, it is possible that they inflated the benefits (i.e., social desirability bias).

Nonetheless, the three sources of parent reports on acceptability (weekly surveys, final questionnaire, and exit interviews) indicate the program overall was appropriate for the participants and their children. Satisfaction with the program remained high over the 15-week period in both groups. While parents rated the videos lowest relative to teaching, group discussion, and session content, all of the aspects of the program were rated highly. The first module, particularly child-directed play and emotion coaching, and the session on praise (in Module 2) were reportedly of most benefit to parents. In the exit interviews, participants outlined many positive outcomes from the program, including increased child compliance, improved language, and reduced parent stress and frustration. The flexibility of the program to address ASD-specific challenges, such as sensory-seeking behaviors, was a notable positive attribute of *The Incredible Years*.

Despite the majority of parents reporting satisfaction with the overall program, there were several barriers to their success in the program. The foundation of the program, child-directed play, was not completely straightforward for some of the children. Parents reported it was at times difficult to engage with their children during play, or their children's play was rigid or stereotyped in nature. Incentives (e.g., stickers) were not motivating for some children, nor did many respond to time-out strategies. Self-regulation appeared to be a mediating factor: those parents who reported success assisting their children to calm down and reduce their frustration and anxiety were more satisfied with the latter program modules. Given emotion dysregulation

affects very young children with ASD (Gomez & Baird, 2005) and is correlated with early maternal stress (Davis & Carter, 2008), strategies which address child self-regulation are critical. Finally, although the parents reported a decrease in stress, many found it difficult to focus on their own needs, such as self-care, praise, and partner communication outside of class sessions. The vast body of research highlighting high parent stress and related outcomes in this population call for a continued focus on ways in which interventions can assist parents to improve their own well-being.

In total, the significant findings from the Parent Stress Index scores of Total Stress and in the Child Domain suggest the parents' stress emanates primarily from child-related characteristics. This hypothesis is further supported by the fact that at baseline, only 43% of parents ($n=6$) reported elevated Parent Domain scores (above the 75th percentile), as compared to the 79% of parents ($n=11$) who reported elevated Child Domain Scores. The current sample's low baseline scores of parent-related stress suggest these participants did not experience significantly elevated levels of depression and other parent-specific stress symptoms. However, ample evidence exists that the prevalence of depression in particular is high among parents raising children with ASD (e.g., see Carter et al., 2009; Phetrasuwan & Shandor Miles, 2009). Thus, future work with larger samples should investigate if *The Incredible Years* is effective in reducing parent-related stress in those with elevated baseline levels.

The encouraging results of the present pilot study can perhaps be attributed to several “active ingredients” of *The Incredible Years*. First, while nearly all of the children were engaged in direct therapies (e.g., speech therapy), parents seemed to benefit from a program which fully engaged them as caregivers and addressed some of their personal needs. Furthermore, while most therapies are highly structured, the play-based approach of *The Incredible Years* seemed to

decrease the demands on parents and children to narrowly define goals of their play. Child-directed play also provided parents with opportunities to introduce naturalistic learning opportunities through descriptive commenting and emotion coaching. Furthermore, the role of peer support (e.g., participant “check-in”/discussion, role plays) cannot be discounted, and certainly is a programmatic aspect to rigorously test (and control for) in the future. The incorporation of strategies to improve partner/professional relationships was helpful, yet insufficient for this population. Lastly, the addition of parent coping strategies seemed to be a significantly important component of the program, as it allowed parents to self-regulate and to teach these methods to their children.

Consistent with the Contextual Model of Family Stress (Boss, 2002), the ability of parents to draw upon family resources (e.g., positive coping strategies) seems to correlate with their experiences of stress and burden. However, participants in this study reported considerable challenges precluded them from devoting sufficient time to their own self-care, rather than focusing all of their efforts on their children. While the reduction in parent stress outcomes and improvement in anger management and coping strategies are positive findings, clearly more effort must be dedicated in assisting parents to improve their own well-being, along with their children’s.

Conclusion

The current study is one of the first of its kind to evaluate the acceptability of an evidence-based parenting program with groups exclusively composed of parents raising preschool children with ASD. Thus, the overall positive findings of reduced parent stress, as well as high satisfaction, attendance, and retention provide preliminary support to the hypothesis that *The Incredible Years* can be used with this unique population. Given the use of the program is

ongoing across various states, localities, and community agencies in the United States with nondisabled children and their families, the potential for expansion to children with ASD and their parents using existing resources is promising. Future research is needed to rigorously test this program with a randomized controlled trial.

CHAPTER 4

INTEGRATIVE SUMMARY

Autism awareness has dramatically increased over the past 50 years, largely through the efforts of parents of children with ASD. The focus on child outcomes has led to significant improvements in short- and long-term outcomes for those diagnosed with ASD. Yet, despite the role of these parents in advocating for their children's needs, very little progress has been made to address their own needs.

The literature is saturated with studies highlighting the struggles of families affected by ASD. Financial burdens for these families are significant and associated with a broad array of negative outcomes for parents and children. Stress and depression are highly prevalent among parents raising children with ASD, especially parents of young children, and even when compared to those parents of children with other special needs. Stress and depression are related to a host of poor child and parent outcomes, including poor child mental health, learning, and peer-related issues; increased use of emergency health care; marital dissatisfaction; and, poor physical health-related quality of life.

Despite the increased financial and emotional burdens faced by parents caring for children with ASD, some research has demonstrated they are highly resilient. Yet, very little has been done to address the high levels of burden of individuals in this population, nor to capitalize on their strengths and areas of resilience. The overall aims of the dissertation were to investigate extant literature on interventions addressing both child and parent outcomes; and then, to pilot test such an intervention with two groups of parents raising preschool-age children with ASD.

The following sections give an overview of the major findings from the research; outline the significance, strengths, and weaknesses of the studies; and, provide future directions for social workers and other professionals committed to advancing the well-being of families of children with ASD.

Overview of Major Research Findings

The first goal of the dissertation was to examine existing interventions that aimed to reduce parent stress and other negative outcomes for parents of young children with ASD. Then, it evaluated the feasibility, acceptability, and preliminary outcomes from a pilot test of *The Incredible Years* Preschool Basic Parent Program with parents of young children with ASD.

Chapter 1 demonstrated that intervention research in this field is at a standstill. Only one of the studies reviewed described an intervention specifically developed to address parent stress and coping. Moreover, the intervention studies had significant limitations. In broad terms, some of the studies did not adequately discuss their sampling, design, and analytic methods, making it difficult to assess study findings. Particularly concerning were the unclear randomization strategies and statistical conclusion validity (e.g., low statistical power; not controlling for group-level effects) of several studies. External validity was generally poor when information was provided, or otherwise difficult to ascertain, due to the limited information provided by authors on the sampling strategies and characteristics of the individuals in their studies. Of most interest to this review were parent outcomes. None of the studies reported significant improvement in key parent measures. Clearly, much more work is needed to develop effective strategies to adequately address the needs of parents in addition to those of their children who are engaged in ASD early intervention programs.

Chapters 2 and 3 described the implementation of *The Incredible Years* tailored to parents raising young children with ASD. Two groups of parents ($N=17$) raising children ages 3 to 6 with ASD participated in the program. Data were also collected from those parents who expressed interest in the program, but ultimately did not participate.

Chapter 2 describes the recruitment efforts, fidelity measures, and feasibility of *The Incredible Years* in this population. Approximately 65% of the individuals who contacted the researchers regarding the study did not join. The reasons varied from not meeting eligibility criteria, reluctance to disrupt children's evening schedules, job-related scheduling conflicts, and distance between homes and program site. Of the 17 parents who did join the study, 3 ultimately did not complete the program. One parent moved to a different state, but the remaining two reported various issues with the program, such as timing, need for more intensive support, partner exclusion, and distance to program site. There were no significant parent-related differences in the groups who completed the intervention versus those who withdrew. Yet, the average age of the children at baseline and at ASD diagnosis was significantly higher in the group who withdrew, while most of those who completed the program had children who received speech therapy.

Chapter 2 also reports on the fidelity to *The Incredible Years* model and the degree to which the program was implemented as intended with the target population. Required activities were completed approximately 90% of the time over the course of the program. However, the recommended videos were viewed at lower rates (68% to 76% of the time). The group leaders adhered to the required activities and videos the most during Module 1 (child-directed play) and least during the final module on handling misbehavior.

Finally, Chapter 2 outlined various suggestions from participants regarding future use of the program with parents of children with ASD. They advocated for a continued focus on methods in which to assist children to self-regulate and parents to manage stress; create social support; and provide visual resources. For the future, they requested additional opportunities to practice parent self-care strategies, inclusion of partners and other caregivers, a longer program, and more intensive support for individuals with recently-diagnosed children or children with exceptionally challenging behaviors.

Chapter 3 expands on Chapter 2 by presenting the acceptability of the intervention and stress outcomes for those parents who participated in the program. Parent stress (total and child-related) significantly decreased from baseline to post-intervention. Acceptability was also high over the course of the program. Parents reported the homework exercises and in-class role plays were particularly helpful for them. Weekly attendance ranged from 88% to 100%.

Chapter 3 also described outcomes collected from participants' responses during exit interviews. Overall, parents found the strength-based, whole-family approach of the program to be beneficial. Participants reportedly enjoyed the ASD-specific groups, although some would have preferred groups specific to verbal children. The first four weeks on child-directed play and emotion "coaching" in particular were popular with the parents, as it gave them new strategies to address their children's and their own challenges. Conversely, the final module on handling misbehavior was difficult for some parents, and the session on time-out for noncompliance in particular did not resonate with them. Common barriers faced by parents in the program included disagreement with partners or other caregivers regarding child behavioral management strategies; insufficient time to focus on parent self-care; and, problems in the application of strategies such as time-out to children with self-regulation or sensory issues. The most significant

benefits of the program, from the perspectives of the participants, were reduction of parent stress through acquisition of self-care and coping skills, ability to improve children's self-regulation abilities, and access to local resources and parent support.

Research Limitations

In order to assess the significance of this dissertation, its weaknesses must be acknowledged. The comprehensive literature review in Chapter 1 had a somewhat narrow focus on interventions which measured parent outcomes. Thus, interventions that did not meet search criteria (e.g., quasi-experimental studies; unpublished studies of community-based interventions), although they might positively affect parent well-being, were not included in this review. Finally, while every effort was made to fairly and impartially assess each intervention's strengths and weaknesses, the possibility exists that the authors' methods were unintentionally misinterpreted.

Chapters 2 and 3 describe a small study with a limited focus on measuring the feasibility and acceptability of an existing evidence-based practice. Thus, no effort was made to collect data using long-term measures or comprehensive questionnaires on child or family well-being. Further, the lack of a randomized control group prohibits attribution of causality to the intervention. Overall, the participants were highly invested in their groups as a means of peer learning and social support. Thus, parents could have reported overly positive or inflated outcomes due to social desirability bias. Finally, the two pilot groups did not include many individuals from low-income or low-education backgrounds. As a result, it is challenging to make assumptions about the feasibility and acceptability of this study outside of a college-educated sample.

Research Significance

Chapter 1 confirmed, despite decades of research on parent stress in families of children with ASD, little has been done to create interventions to address parent well-being along with child behavior. The research presented in Chapter 1 provides an argument not only to offer families such services, but also to ensure available interventions have been rigorously tested for positive child and parent outcomes. It is unethical to ask parents who are likely already over-scheduled with child therapy, and educational and medical appointments, to engage in a lengthy program for which there is no reasonable evidence of effectiveness.

Thus, Chapters 2 and 3 represent one of the few known evaluations of an existing evidence-based program used exclusively with parents of young children with ASD. Clearly, it is only an initial effort to examine the potential of *The Incredible Years* in this population. Future studies need to investigate the effectiveness of this program using a randomized controlled trial with additional groups and more diverse samples. Furthermore, the collection of data using various measures on child behavior, parent stress and other outcomes, and family function, are critical to understand the true value of this program to families raising young children with ASD.

How researchers can balance intervention fidelity with generalizability to the ASD population is less clear. Dingfelder and Mandell (2011) argue for the need to connect intervention researchers with community practitioners and stakeholders to promote fidelity in real-world settings. They propose that through the formation of strong collaborative relationships between researchers and communities, the external validity of research-based practices will be demonstrated more rapidly. These researchers make a strong argument to thoughtfully engage families raising children with ASD and community agencies from the beginning, in order to deliver programs in ways in which the community's needs are met.

In this way, Chapters 2 and 3 break new ground by directly eliciting participants' in-depth perspectives on what worked, and what needs to be improved, in order for *The Incredible Years* to be beneficial to parents of young children with ASD. This information can be useful not only for researchers who intend to test the program more rigorously, but also practitioners who are currently using *The Incredible Years* in their local communities. It is important to note that this program is not intended to replace direct child therapies. Rather, for this population, *The Incredible Years* offers parents a venue in which to connect with other families, learn specific play-based and emotion regulation strategies, and incorporate stress-reduction skills into their daily lives. Moreover, while the results of *The Incredible Years* pilot trial were promising, the program is only one of many which can address parent and family outcomes. Thus, this study can be used as a model of ways in which other parenting practices can be implemented with the proper supports and focus for parents of young children with ASD.

Implications for Social Work Professionals

As the incidence of ASD grows, individuals and families affected by stress and poor mental health have the potential to increase accordingly. Social workers are well-positioned, in their roles as researchers, practitioners, and policymakers, to address the needs of these vulnerable populations. Furthermore, the strengths-based social work approach aligns well with research finding families of children with ASD are often incredibly resilient to stressors. The following list details the most pressing needs for social workers and other professionals, based on the evidence presented in this paper.

Intervention research. There is a clear need for social workers and those in the disability field to develop, implement, evaluate, and disseminate interventions designed to improve the lives of families of children with ASD. Furthermore, there is a great urgency to

involve individuals previously underrepresented in research. In order to move the field forward and improve the rigor of intervention studies, the results from the literature review and pilot test support:

1. Engage individuals with ASD, their families, community advocates, and practitioners in study efforts throughout the entire research process.
2. Develop family-based interventions appropriate for this population, by limiting time-intensive treatments and addressing parent concerns in addition to those of the children.
3. Increase sample sizes of studies.
4. Improve randomization methods and other design issues.
5. Utilize analytic strategies appropriate to study designs.
6. Extend studies to individuals representing the entire ASD population, including children with challenging behaviors; fathers and other caregivers; children with intellectual disabilities or other comorbid conditions; and, families of diverse cultural and socioeconomic backgrounds.
7. Collect additional parent outcome measures, such as mental health and quality of life.
8. Add multiple and long-term data collection points.
9. Manualize, replicate and disseminate promising interventions.

Practice. It is critical for social workers in all child- and family-serving professions to understand the challenges facing families of children with ASD. Practitioners should also be aware some groups are particularly vulnerable to stress and poor mental health. They include:

Families with young children. Parents are high risk for stress during their children's early years. Practitioners should be alert to not only the signs of ASD in order to refer children

for screening, assessment, and intervention, but also note symptoms of parent distress and family dysfunction.

Underserved populations. Low-income families are underrepresented in the literature, yet they are especially susceptible to financial and work-related burdens, antecedents to stress and poor outcomes. Furthermore, special care must be taken to ensure children and their families from all socioeconomic, racial, ethnic, and linguistic backgrounds receive access to appropriate screening, assessment and intervention services.

Policy. The Combating Autism Act has added critical funding to the study of individuals with ASD and their families. It is important to continue to use this funding to create research to advance policy and practice. In addition, publicly-available services to support the emotional well-being of the whole family are essential. A public health model of early intervention will aid in the prevention of ineffective coping skills and the promotion of family strengths. Lastly, in our current economic environment, fundamental supports for children with ASDs and their families are constantly at risk or under threat of being cut. It is our role as social workers to protect the needs of vulnerable families and advocate for the well-being of all those we serve.

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