The Development and Implementation of an Early Intervention Program for Underserved Families of Children with Autism Spectrum Disorder

by

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DEDICATION

This project is dedicated to the families who participated in the ESI-CO project. Thank you for inviting us into your homes and sharing both your challenges and successes. Your stories are an inspiration to us all.

ACKNOWLEDGMENTS

PREFACE

Research on Autism Spectrum Disorder (ASD) has accelerated greatly since its first introduction in the articles presented by Leo Kanner (Kanner, 1943) and Hans Asperger (Asperger, 1944). Earliest conceptions of the disorder perceived it as only affecting White, affluent families, a public misconception that persists today. Epidemiological research, however, has demonstrated that ASD knows no barriers, affecting families across cultural, racial, ethnic, and socioeconomic levels (Centers for Disease Control and Prevention, 2009; Kogan, Blumberg, Schieve, Boyle, Perrin, Ghondour et al., 2007).

While there do not seem to be differences in the presentation of autism or in the prevalence of ASD across populations, there are significant disparities in rates of diagnosis and service utilization (Liptak, Benzomi, Mruzek, Nolan, Thingvoll, Wade et al, 2008; Mandell, Listerud, Levy, & Pinto-Martin, 2002) with families of racial/ethnic minority status, lower levels of education, and those who live in non-metropolitan areas experiencing greater limitations (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). In fact, such disparities may contribute to the misconception that autism only occurs in more affluent, highly educated families.

Little is known about the experiences of families of children with autism living in underserved (low-income, low education, racial and ethnic minority) families. We know that barriers exist in preventing these families' access to services, but we know less about

factors contributing to those barriers or what means may be employed to decrease such barriers. In recent decades, the greatest impetus in autism research has been in neurobiology and early identification and early intervention. Research showing that children who receive services early have better outcomes (National Research Council, 2001) places great urgency on developing policies to ensure that all families have early access to services that will promote optimal outcome.

This dissertation focuses on the design and implementation of an early intervention protocol—the Early Social Interaction-Community Outreach Project (ESI-CO)—for families living in the Southeast region of Michigan with limited education and limited income. Chapter 1 provides an overview of ASD and highlights growing evidence of social disparities in access to autism services. Chapter 2 utilizes research from the broader psychotherapeutic field to review existing barriers to intervention and empirically supported methods and strategies for decreasing such barriers. Chapter 3 reviews current trends in early intervention for ASD, while Chapter 4 describes the application of strategies outlined in Chapter 2 to current models of ASD intervention to develop the ESI-CO treatment model. Chapters 5 and 6 report specific methods and results of the ESI-CO project, while Chapter 7 provides a discussion of the success of the intervention, with implications for future development of ASD intervention research focusing on underserved families.

Specific Aims:

1. To apply empirically supported methods for decreasing access barriers to ASD intervention by developing a specific program targeting underserved families and to test the applicability of this intervention in the targeted population.

2. To provide preliminary outcome data on the modified intervention that includes descriptive, quantitative, and qualitative analyses of the experiences of an underserved population in early autism intervention.

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Chapter 1: Introduction

Autism Spectrum Disorder (ASD) has always been described as a disorder manifesting in childhood (Kanner, 1943), but it has not been until the past few decades that our knowledge of early indicators of ASD has significantly expanded. With this knowledge comes an urgency to develop interventions that are developmentally appropriate for very young children with autism, with the hopes that some of the most severe lifelong impacts of the disorder may be prevented. As we refine treatment programs to meet the needs of individual children, it is also important to emphasize the development of interventions to meet the needs of families from diverse backgrounds. Calls for greater inclusion of a diversity of study participants have been made across numerous groups of leading autism researchers and funding agencies (Lord & Bishop, 2010; National Research Council, 2001), but research on autism intervention is virtually nonexistent in populations that are predominantly racial or ethnic minority and of low socioeconomic status. The purpose of this dissertation is to embark on a research program to expand, adapt, and implement an early autism intervention program for families who have been traditionally underrepresented in autism research.

Background on Autism Spectrum Disorder. Autism Spectrum Disorders (ASD) are characterized by impairments in social interaction and communication, and the presence of restricted repetitive and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 1994). Individuals on the spectrum vary in

the degree to which they are impaired in each core domain. Thus there is great heterogeneity in the way that symptoms of ASD are expressed. Many individuals with ASD also present with abnormalities in cognitive functioning, learning, attention, and sensory processing (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). The diagnosis of ASD has become increasingly standardized, but at the same time, the conceptualization of the disorder has expanded.

The most recent comprehensive epidemiological studies report increases in autism prevalence over past decades, with an average of one out of every 110 children affected (CDC, 2009; Kogan et al., 2009). Increases in prevalence may be attributed to a broadening of the diagnostic category, with individuals with more subtle presentations of autism symptoms receiving diagnoses. Additionally, increased public awareness of "red flags" of autism in young has contributed to greater numbers of young children being identified on the spectrum. Claims of rising prevalence attributed to environmental exposure of toxins through vaccinations have repeatedly been unfounded (Chen, Landau, Sham, & Fombonne, 2004; Richler, Bishop, Kleinke, & Lord, 2006).

Research on the etiology of ASD is highly suggestive of a genetic component. Epidemiological, twin, and family data indicate a complex genetic contribution (Abrahams & Geschwind, 2010). Impairment across abilities within social, communication, and behavioral domains further suggests the complex involvement of very basic processes or several neural systems. As there is not yet a reliable biological marker of ASD, diagnosis of the disorder is made on the basis of behavioral assessments and interviews. The Autism Diagnostic Observation Schedule (ADOS: Lord, Risi, Lambrecht, Cook, Leventhal, DiLavore, Pickles, & Rutter, 2000) and the Autism

Diagnostic Interview – Revised (ADI-R: Le Couteur, Lord, & Rutter, 2003) are

standardized instruments used to diagnose the disorder. Used in conjunction, they have

been found to reliably diagnose ASD in children as young as two years old (Lord, Risi,

DiLavore, Shulman, Thurm, & Pickles, 2006). Research has recently focused on

developing screening and diagnostic instruments that can detect features of autism in

children at even younger ages. Specific screening instruments such as the Modified

Checklist for Autism in Toddlers (M-Chat; Robins, Fein, Barton, & Green, 2001), the

Screening Tool for Autism in Toddlers and Young Children (STAT; Stone, Coonrod, &

Ousley, 2000) and the Infant Toddler Checklist (ITC; Wetherby & Prizant, 2002) provide

a means for young toddlers to be identified and quickly referred for more thorough

diagnostic assessment. The development of the Toddler ADOS (Luyster, Gotham,

Guthrie, Coffing, Petrak, Pierce, et al., 2009) and other diagnostic tools specifically

designed for use in very young children are also increasing our sensitivity and specificity

in diagnosing children as young as 12 months.

Advancements in screening and diagnostic instruments were made possible by a

better understanding of the unfolding of ASD symptoms across the first few years of life.

Broad descriptions of deficits in social interaction can be broken down into more defined

symptoms including decreased interest in others, lack of positive affect, and abnormality

in eye-gaze and social orientation (Chawarska, Klin, Paul, & Volkmar, 2007; Osterling et

al., 2002; Wetherby et al., 2004; Zwaignbaum et al., 2005). Deficits in joint attention, the

ability to share attention with others through pointing, showing, and coordinating looks

between objects and people (Kasari, Gulsrud, Wong, Kwon, & Locke, 2010), are central

to the presentation of ASD in the early years. Communication patterns of infants and

toddlers with autism also unfold in predictable ways. Very young children with ASD use complex babbling and words less frequently and exhibit lower levels of expressive and receptive language ability (Werner & Dawson, 2005; Zwaigenbaum et al., 2005). Abnormalities in nonverbal forms of communication, such as reduced use of conventional, instrumental, or descriptive gestures, are also common (Wetherby et al., 2004). Restricted and repetitive behaviors and interests may also emerge beginning in infancy. High levels of sensory sensitivity or sensory oriented behaviors or repetitive motor actions may unfold around 12-24 months (Chawarska et al., 2007; Wetherby et al., 2004; Zwaigenbaum et al., 2005) with patterns of restricted interests and behaviors emerging more frequently during the preschool years (Charman et al. 2005; Lord, 1995).

ASD is a lifetime disorder and most individuals on the spectrum face an array of challenges and difficulties across development. There is no cure for ASD, thus treatments for the disorder are developed to reduce the severity of ASD symptoms. No single treatment approach is appropriate for all individuals or even for the same individual as he or she develops (Volkmar et al., 2004). Several variables have emerged as significant predictors of positive outcome for children on the autism spectrum. In young children who receive early intervention, higher social abilities and cognitive level before treatment have been found to predict higher scores in expressive language and play skills post treatment (Ben-Itzchak & Zachor, 2007). Some studies have found that the amount of treatment received in early years has had significant impact on outcome, particularly related to gains in cognitive ability and adaptive behavior (Woods & Wetherby, 2003). A growing body of research on early autism intervention emphasizes the use of a developmental approach in which behavioral strategies are applied to

promote change within the context of natural learning environments. Developmental

approaches are usually child-centered and utilize materials and tasks that are appropriate

for a children's developmental level (NRC, 2001). Comprehensive programs addressing

the total array of social and communication deficits are currently being tested in large-

scale randomized control trials (Dawson et al., 2010) and show promise for promoting

positive change in the lives of young children and their families.

ASD in Underserved Populations. In the broader health context, the term

"underserved" refers to an individual or family with an identifiable disorder that is

receiving no or minimal health service (Snells-Johns, Mendez, & Smith, 2004). Families

of racial/ethnic minority background, lower levels of education, lower income, or those

who live in non-metropolitan areas have been found to experience greater limitations in

accessing services for ASD (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). We

know little about experiences of these families, thus this population is greatly

underserved and understudied.

Most research examining underserved families of children with ASD has been

conducted in the context of epidemiological studies, focusing on prevalence and rates of

diagnosis. In the United States, prevalence estimates of ASD across race and ethnicity

are inconsistent (Newschaffer et al., 2007). Most recent findings report higher

prevalence rates in Caucasian children than other races (CDC, 2009; Kogan et al., 2009),

while others report no differences (Yeargin-Allsopp et al., 2003). One potential

explanation for differences in prevalence rates across race is that there are racial

differences in the phenotypic expression of the disorder. Cuccaro et al. (2007) conducted

a study comparing African American and Caucasian children across core domains of

ASD and found that while overall there were no significant differences between groups, African American parents reported significantly later acquisition of first words and phrases in their children, suggesting a more severe language phenotype. As the authors noted, however, more severe language acquisition in African American families could also be attributed to referral bias or cultural differences in reporting of symptoms. Mayes and Calhoun (2010) examined whether scores on an autism checklist varied as a function of race in addition to other sociodemographic variables (Intelligence Quotient, age, SES, and gender). Autism severity was predicted by age and IQ, but not by gender or race.

While it is not possible to rule out the possibility that the prevalence and expression of ASD varies by race or ethnicity, discrepancies in prevalence or risk rates across ethnicities may be more clearly attributable to other sociodemographic variables. In his hallmark presentation of a group of children identified with autism, Kanner (1943) described the parents of his participants as being highly intelligent, well educated and well employed, suggesting that autism only occurred in families of high social class. Prevalence of autism diagnoses has been found to vary by geographic region, parental age, parental education, family income, and parental marital status (Croen et al., 2002; Karapurkar & Schendel, 2007; Kogan et al., 2009). In a large-scale population-based study utilizing multiple source ascertainment methodology, higher family income and higher maternal education were associated with greater risk for autism (Karapurkar & Schendel, 2007). Subanalyses revealed, however, that this relationship was stronger when children had diagnoses of autism without intellectual delay and also varied by identification source (non-school versus school-based). As reported by previous researchers (Wing, 1980; Schopler, Andrews, & Strupp, 1979) these findings suggest that

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differences across ethnicities and varying level of socioeconomic status may be more a result of ascertainment bias rather than true group differences.

Reasons for ascertainment bias may be partially explained by differences in rates of diagnosis across ethnicities. ASD can be reliably diagnosed as young as age two years (Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006), yet many ethnic minority children in the United States are not diagnosed until they are school-aged, with the age of first diagnosis significantly later for African American and Hispanic than Caucasian children (Liptak, Benzomi, Mruzek, Nolan, Thingvoll, Wade, et al., 2008; Mandell, Listerud, Levy, Pinto-Martin, 2002; Mandell, Wiggins, Arnstein Carpenter, Daniels, Durkin et al., 2009). African American children are also more likely to receive a different diagnosis, such as conduct or adjustment disorder, before receiving a diagnosis of ASD (Mandell, Ittenbach, Levy, and Pinto-Martin, 2007).

Factors contributing to such disparities in diagnosis are multifaceted. Demographic factors such as maternal education, birth weight, and IQ have also been found to influence diagnostic rates of ASD (Mandell, et al., 2009). Barriers may include limited access to experienced ASD service providers (Ruble, Heflinger, Renfrew, & Saunders, 2005) and high cost of diagnostic and treatment services (Flanders, Engelhart, Pandina, & McCracken, 2007). Cultural background may also influence a parents' interpretation of the child's symptoms, the manner in which a parent responds to such symptoms, and the manner in which a parent communicates such symptoms to a professional (Mandell & Novak, 2005). Such findings highlight the importance of including families from varying degrees of socioeconomic status in ASD research to determine how disparities in diagnosis can be addressed.

One particular area in which the experiences of underserved families have not been thoroughly examined is that of autism intervention. Descriptions of participant samples in autism intervention research often do not include adequate descriptions of race, ethnicity, or social class (NRC, 2001) and most current interventions in autism have only included predominantly white, middle class populations (Lord et al., 2005). Current autism intervention research studies have direct impact on public policy determining availability and accessibility of effective treatments across the nation. School systems, insurance companies, and private agencies are responding to increasing pressure to limit support or practice of treatment programs to those that have been established as Evidence-Based Treatments (EBTs). The promotion of a few specific treatments for an entire diverse population is questionable, however, when research has only been based on predominately white, middle-class, English-speaking participants (Bernal & Scharron Del-Rio, 2001)

Description of Dissertation Agenda. Empirically supported methods for overcoming barriers to service utilization and intervention have been examined in psychotherapeutic research, but have not been specifically tested within a population of families of children with ASD. The purpose of this dissertation is to utilize research examining strategies for promoting attendance, adherence, and retention in underserved families in the application of an early intervention program for families of young children with ASD. The dissertation will combine evidence from the broader psychotherapeutic field with evidence of successful early ASD intervention programs to develop and implement an early intervention protocol in a sample of low-income families. Overall, this dissertation recognizes that families who often have the most trouble accessing ASD

services are those who are not frequently included in research examining child and family predictors of positive outcome. This project will utilize a mixed methods approach to focus on identifying factors within the treatment that may affect family attendance, adherence, and positive change. Such a focus will encourage the development of treatment services that are accessible and appropriate for families from diverse social and cultural backgrounds.

Chapter 2: Strategies for Decreasing Barriers in Service to Intervention Programs

In developing an intervention program for underserved families of children with ASD, it is important to examine barriers to service utilization and particularly, how such barriers may be decreased. Snells-John et al. (2004) employ a social-ecological framework to conceptualize factors contributing to barriers in service utilization across levels of the individual, microsystem, exosystem, and macrosystem. This framework may help us understand the occurrence of social disparities existing for families of children with autism. At the individual and microsystem levels, disparities may be related to factors of race/ethnicity, culture, education, and SES (Kilbourne, Switzer, Hyman, Crowley- Matoka, & Fine, 2006). Children of mothers with lower education levels are less likely to have documentation of ASD, suggesting that mothers with less education may be less knowledgeable of developmental milestones and less able to advocate for proper diagnosis and access to services (Mandell et al., 2009). At the exosystem level, disparities may be related to availability and affordability of services. Many families of children with ASD experience difficulty obtaining referrals for services because experienced providers are not available (Ruble, Heflinger, Renfrew, & Saunders, 2005). When providers are available, the high cost of ASD services often limits families from obtaining care (Flanders, Engelhart, Pandina, & McCracken, 2007). At the macrosystem level, cultural background may also influence a parents' interpretation of the child's symptoms, the manner in which a parent responds to such symptoms, and the

manner in which a parent communicates such symptoms to a professional (Mandell &

Novak, 2005). Findings from the few studies that have been able to include

representative samples of African American and Latino families suggest differences in

the way these cultural groups experience raising a child with ASD (Blacher & McIntyre,

2006; Magaña & Smith, 2006; Bishop et al., 2007, Carr & Lord, under review). Such

influences on perceptions of ASD may indirectly affect rates of treatment-seeking. For

some families, the conceptualization of the disorder as stigmatizing may challenge

service accessibility, while for others, the perception of health care providers as

discriminatory or culturally insensitive limits treatment advocacy (U.S. Department of

Health and Human Services, 2001). Other families may choose not to seek services as

they view their child's disability as a spiritual opportunity, gift, or test of faith (Klinger,

Blanchett, & Harry, 2007).

To date, there have been no studies directly examining how to overcome access

barriers in research specifically pertaining to autism intervention, but there have been

multiple reviews conducted across a range of family and child therapy models. Focus has

been on studies implementing strategies to promote the following constructs:

Engagement, attendance, adherence, and retention. Engagement and attendance are

highly related terms, relating to the ongoing participation of participants or the "delivery

of the agreed upon treatment participants to the treatment setting for scheduled

appointments" (Ingoldsby, 2010; Nock & Ferriter, 2005, p. 151). Adherence refers to the

voluntary, collaborative involvement of the participant in behaviors designed to achieve

the therapeutic result (Nock & Ferriter, 2005) while retention refers to the rate of

participants' program completion (Ingoldsby, 2010). In general, commonly used

strategies to increase engagement and attendance include the provision of transportation, childcare, and low-cost services. The utilization of home-based sessions in particular, reduces barriers to access. Strategies for increasing retention (i.e. decreasing attrition) include reducing time spent on waiting lists and offering incentives for ongoing attendance or completion of treatment. Attention to individual family needs and focusing on family strengths serve as particular methods for empowering families and promoting change in how families or caregivers perceive the benefits of family or child therapy. A full summary of empirically tested strategies documented as being effective in reducing barriers to services and increasing engagement, attendance, adherence, and retention are summarized in Table 1.

Table 1. Strategies to overcome access barriers, decrease attrition, and/or promote change in underserved families

Overcoming barriers to access	Decreasing attrition	Promoting change
▪ Offer transportation, child care, and low-cost services ▪ Use the telephone ▪ Provide home-based services ▪ Facilitate self-directed and video-based interventions ▪ Use Multiple-Family Groups	▪ Decrease waitlist times ▪ Monitor therapists' behaviors and expectations ▪ Offer incentives for attendance ▪ Conduct brief interventions ▪ Make therapists readily available ▪ Address parents' individual needs	▪ Prepare families for therapy and address expectations ▪ Provide culturally competent services ▪ Give family task assignments ▪ Focus on families' strengths ▪ Conduct motivational interviewing

Adapted from Snell-Johns, Mendez, & Smith, 2004

Three studies conducted within underserved populations provide some evidence for the effectiveness of such strategies in promoting attendance and adherence. Lyon and Budd (2010) investigated the effectiveness of a Parent-Child Interaction Therapy (PCIT; Zisser and Eyberg, 2008) in low-socioeconomic status, urban, ethnic minority families of children with disruptive behavior disorders. Twelve families (50% African American, 29% Multiracial, and 21% Latino) of children ages 2-7 years were enrolled in a 16-

session PCIT program offered through a Community Mental Health Clinic. Specific

strategies employed to reduce treatment barriers included provision of free transportation

to the treatment site, scheduling of evening sessions, and a commitment to continue

treatment even when families had frequent cancellations or no shows. Of the 14 families

enrolled, 12 completed at least one treatment session, 8 discontinued participating after

an average of 8 completed sessions, and only 4 completed treatment successfully,

yielding an attrition rate of 67%. In comparison to other studies examining PCIT in non-

community settings, the authors were successful in enrolling a group of families from an

underserved community. However, efforts to reduce treatment barriers and increase

engagement were only marginally successful.

Fox and Holtz (2009) examined the effectiveness of a treatment program for

toddlers with behavior and emotional problems who were also living in poverty.

Toddlers ages 1-5 years (43% African American, 21% Latino, 21% Caucasian, and 15%

Multiracial or other) and their caregivers participated in an average of 12 weekly sessions

of the Parenting Young Children Program (Fox & Nicholson, 2003). The most

significant strategy employed to reduce treatment barriers was the provision of treatment

in individual families' homes. Emphasis was also placed on increasing engagement by

establishing a trusting relationship between interventionists and caregivers. For example,

interventionists were willing to discuss issues with families that were not clinically

relevant to the behavior problems of the child. Care was taken to make sure all written

treatment materials were easily understood and small monetary incentives ($5) were

provided when caregivers completed weekly assignments. Finally, clinicians were

explicitly trained on how to interact with a diverse population and received regular

supervision to assess treatment fidelity. Of the 238 families who completed intake evaluations, 102 completed the treatment program (57% attrition rate). Families who completed treatment improved on ratings of parent-child interaction and children's disruptive behavior decreased. Though this program also yielded a high attrition rate, it was successful in disseminating an effective treatment to a large number of underserved families.

Hilton, Fitzgerald, Jackson, Maxim, Bosworth, and Shattuck, et al. (2010) utilized multiple strategies to increase the enrollment of African American families in an autism genetics registry. Information regarding the project was mailed to families and follow-up calls were made to families who did not respond to the mailing. African American members of the research team participated in recruitment efforts, including helping to design flyers and written materials distributed to families. Monetary incentives and written test results were provided for participating families, in addition to recommendations for other available autism services. For those families with limitations in schedule, available transportation, or childcare, efforts were made to accommodate their needs. Efforts were successful in increasing willingness of African American families to participate, but the majority of families were still excluded from participating due to family structure (i.e. absence of one parent, no available siblings).

In general, empirically tested strategies for decreasing access barriers to treatment show mixed results in their effectiveness. Continued investigation into family and child factors that mediate and moderate the success of such strategies is warranted. Furthermore, the application of such strategies in research pertaining to autism intervention is highly needed.

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Chapter 3: Early Intervention for Young Children with ASD

Interventions services for young children with ASD are funded by federal and state governments and private agencies (Boyd, Odom, Humphreys, & Sam, 2010). The Individuals With Disabilities Education Act provides a national agenda for early intervention for young children with disabilities. Part C, the Program for Infants and Toddlers with Disabilities, provides states with funds to implement comprehensive programs for children from birth through age two, while Part B, the Preschool Grants Program, provides special education services through free public education for children ages three to five (Trohanis, 2008). Private organizations such as specialty clinics or hospital programs also provide intervention specific to ASD.

The question of what type of intervention should be provided through these services is highly complex. The heterogeneity across ASD requires that intervention strategies and approaches are varied, with recognition that what is appropriate for one child may not be for another. As we have not identified direct biological causes for ASD, treatments must focus on the reduction of autism symptoms. Consequently, historical trends of autism intervention have involved the development and refinement of behavioral strategies to reduce the core language and social deficits that characterize ASD, as well as the cognitive deficits that accompany it. Behavioral interventions range across a continuum from those that occur under very structured and controlled environments to those that occur in naturally occurring environments. The National

Research Council (2001) conducted a thorough review of autism intervention for young children and put forth recommendation guidelines for the development of effective treatment programs. Their recommendations include:

1. Entry into treatment immediately upon diagnosis or identification as very high risk.

2. Active engagement for a substantial part of the day, most days of the week (i.e. 5 hours a day, 5 days a week).

3. Repeated presentation of brief, planned teaching opportunities aimed at the specific needs and developmental levels of the individual child.

4. Individual adult attention sufficient to meet the child's goals and to ensure engagement and learning in the targeted activities.

5. Inclusion of a family component

6. Focus on a comprehensive range of developmental skills, including communication, social engagement and interaction, play, cognitive skills, and self-help.

A growing body of research on early autism intervention emphasizes the use of a developmental approach in which behavioral strategies are applied to promote change within the context of natural learning environments. Developmental approaches are usually child-centered and see the role of treatment as facilitating normal developmental processes as opposed to teaching specific behaviors through "learning paradigms," an approach more common to strictly behavioral interventions (NRC, 2001).

One intervention program that has received significant attention is the Early Start Denver Model (ESDM; Dawson, Rogers, Munson, Smith, Winter, Greenson et al., 2010),

a comprehensive developmental behavioral intervention for toddlers with ASD. In this model, interventionists provided 20 hours per week of home-based intensive intervention for a period of two years. While parents did receive training in intervention strategies on a semi-monthly basis, treatment was primarily disseminated through interactions between the child and interventionist. In a randomized control trial comparing ESDM to community treatments, children (72.9% Caucasian, 14.6% Multiracial, 12.5% Asian, and 12.5% Latino) receiving the treatment condition showed significant improvements in cognitive ability and adaptive behavior, differences that were maintained at both 1-year and 2-year outcome assessments. Furthermore, children receiving ESDM were more likely to move from a diagnosis of autistic disorder to one of Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), indicating fewer observed features consistent with autism spectrum. This study provided promising findings for the application of an integrated behavioral, developmental, and relationship-based approach to ASD intervention. There are concerns, however, regarding the feasibility of effectively implementing such a model in a community-based setting.

For toddlers and preschool-aged children, much of their learning occurs within the context of natural environments and is transmitted through interactions with caregivers or family members. Thus, another trend in early intervention is the use of parents or caregivers as the primary medium of treatment, rather than trained interventionists. Several parent-mediated interventions have been tested in recent years. Green, Charman, McConachie, Aldred, Slonims, and Howlin et al. (2010) conducted a large-scale randomized control trial comparing the parent-mediated Preschool Autism Communication Trial (PACT) to treatment as usual from community-based centers.

Children's severity of autism symptoms in addition to the quality of parent-child interaction, child language, and adaptive functioning were assessed upon the completion of 13 months of intervention. Components of the treatment included a focus on increasing parental sensitivity and responsiveness to child communication while encouraging child communication through strategies such as action routines, familiar language, and pauses. Parents (57% Caucasian) participated in six months of biweekly clinic sessions followed by an additional six months of monthly booster sessions. Results indicated significant improvement in parent-child interactions (i.e. increased parent-child synchrony and child communication initiations), but no significant improvement in autism symptoms as measured by the ADOS.

Schertz and Odom (2007) examined the effectiveness of a joint attention parent-mediated model in children with ASD below age three. A mixed method design combining single subject multiple baseline and qualitative research designs was utilized to examine child outcome and the influence of family factors on intervention.   Three families (race/ethnicity unreported) participated in an average of 12 intervention sessions over the course of an average of 17 weeks in an intervention based on the Joint Attention Mediated Learning (JAML) program. Quantitative analyses, as measured by observations of the frequency of specified child behaviors, found that children showed improvement in targeted joint attention skills, including social orientation, turn-taking, responding, and initiating. Qualitative analyses, as measured by parent report, indicated that family factors, including co-occurring family disabilities and relationships between family members, had an effect on parents' experience of coming to terms with the diagnosis, accessing traditional treatment services, and child's progression through the

program. This study demonstrated positive outcome in a parent-mediated intervention.

The mixed methods approach also allowed the researchers to provide a preliminary

exploration of family factors affecting treatment outcome.

Kasari et al. (2010) utilized a randomized waitlist-control model to test the

effectiveness of a targeted intervention for caregivers of toddlers with autism in which

caregivers were explicitly taught skills to promote joint attention in their children. The

influence of caregiver adherence and competence was also examined in relation to

treatment outcome. Parents and their children (58% Caucasian) participated in 24

sessions led by trained interventionists over the course of 12 weeks. Children in the

immediate treatment group exhibited higher levels of joint attention (more joint

engagement, greater response to joint attention) and a wider range of functional play than

children in the waitlist group. Higher levels of caregiver involvement predicted increased

joint engagement scores at post-treatment. This study demonstrated positive outcome in

a parent-mediated study, and also highlighted the importance of examining caregiver

factors that may affect treatment outcome.

Another parent-mediated model that has been tested in the field is the Hanen

More Than Words (HMTW; Sussman, 1999) approach.   HMTW is an eight-session

group training program with three additional home visits that teaches parents to facilitate

social interaction with their child during naturally occurring daily activities

(McConachie, Randle, Hammal, & Le Couteur, 2005). Specific focus is on teaching

parents to increase their use of responsive behaviors (e.g. imitating the child's action with

a toy, responding to the child's request, describing the child's focus of attention). In a

recent randomized controlled trial, the effectiveness of HMTW was examined in

comparison to community-based treatment as usual (Carter, Messinger, Stone, Celimni, Nahmais, & Yoder, 2011). Sixty-two children with ASD and their caregivers (47.4% White, 38.6% Hispanic or Latino, 3.5% Black, 10.6% multiracial) were randomized to each condition. Outcome measures included children's communication, as well as parental responsivity. Children's gains in communication were moderated by level of object interest measured at pre-treatment. Parents demonstrated gains in responsivity that yielded clinically significant effect sizes.

With the exception of the research by Green et al., (2000), Kasari et al., (2010), and Carter et al., (2011) most of the literature outlined above and indeed, most research on autism intervention, has focused primarily on the pathway from child at pre-intervention to post-intervention outcome, with emphasis on the child's level of impairment as a moderating factor (Figure 1). Few have focused on examining the parent or caregivers' role in treatment outcome.

Figure 1. Conceptual model of autism intervention research: Child pathways

With the increased emphasis on parent-mediated models of autism intervention, it seems especially important to expand the focus to include factors related to caregiver influences and caregiver outcome. This includes not just the relationship between caregiver and child, but also the mediating pathways of caregiver well-being and family environment

(i.e. access to health, education, and community resources). Such inclusion is especially

important when applying intervention to underserved families, as there is substantial

literature supporting the cumulative effect of environmental risk factors, including family

factors, affecting children living in poverty (Bradley & Corwyn, 2002; Barnett, 2008).

Thus, it seems appropriate to expand the conceptual model of autism intervention to

include the interacting factors of caregiver and family environment (Figure 2).

Figure 2. Broader conceptual model of autism intervention research.
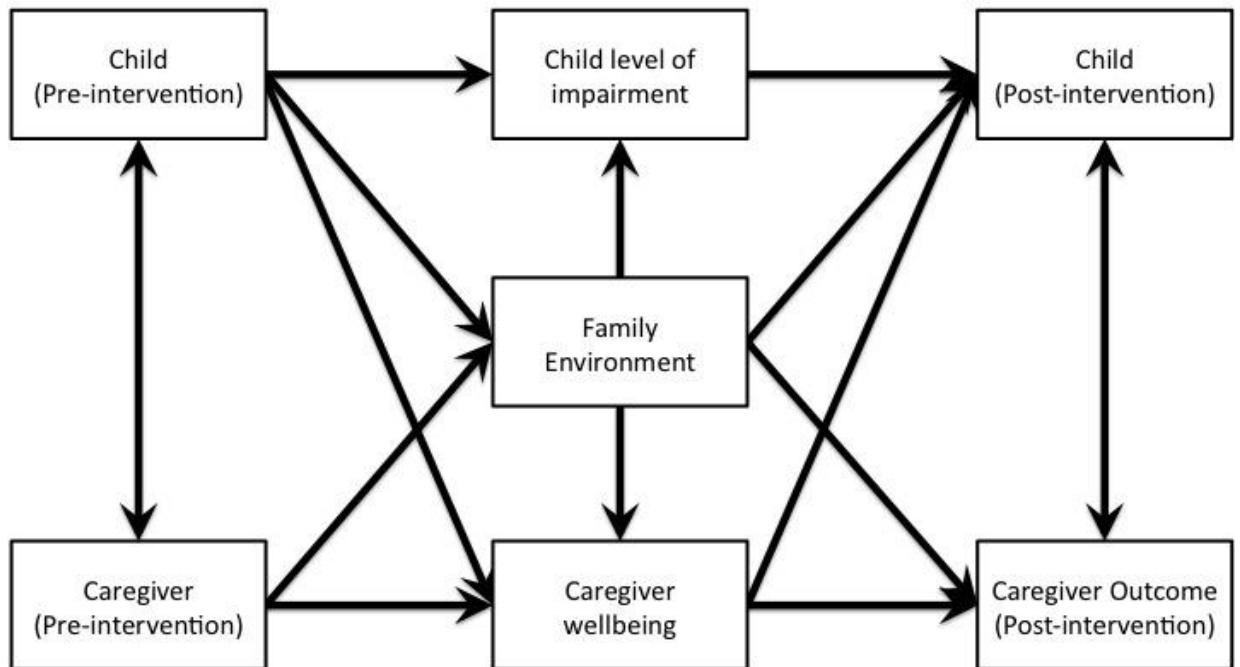
In the following chapter we describe how an existing model of a developmental

parent-mediated intervention for children with ASD, the Early Social Interaction Project

(Wetherby & Woods, 2006), was modified to place greater emphasis on the influences of

family environment, the experiences of caregivers of children with ASD, and to increase

participation from a population that historically has been underserved.

**Chapter 4: From ESI to ESI-CO: Development of the Early Social Interaction –
Community Outreach Project**

The Early Social Interaction Project. The Early Social Interaction (ESI) Project

is an intervention targeting children with ASD who are younger than three years old. It

was developed in response to NRC (2001) recommendations by addressing deficits in

social and communication skills within the context of a family-centered, natural

environment (Woods & Wetherby, 2003). Three main components comprise the ESI

model:

1. Parent-implemented intervention. Interventionists in this model collaborate
   with parents to identify social and communication objectives and develop
   opportunities for addressing objectives within everyday activities.
2. Routines-based intervention in natural environments. The intervention takes
   place in the natural environment of the child and family, primarily in the
   home, but also extending to the local community. Families play an integral
   role in identifying routines and activities that commonly occur in their home,
   which form the context of the intervention.
3. Individualized curriculum. Intervention content is tailored specifically to the
   child's strengths and weaknesses across social interaction, joint attention,
   communication, imitation, play, and emotional regulation.

Thus, in comparison to other parent-mediated models targeting one specific core

deficit of autism (i.e. joint attention), a strength of ESI is that is focuses on a variety of

social communication deficits, and is tailored to children's individual developmental profiles and families' reported needs or concerns.

The primary goal of ESI is to increase children's *Active Engagement* by teaching their caregivers *Transactional Supports*, which are behavioral strategies to support social communication.   In the ESI model, children are actively engaged when they are 1) well-regulated, 2) playing productively and flexibly, 3) socially-oriented, 4) responsive to social bids, and 5) initiating communication. Transactional Supports include strategies such as structuring an activity to promote participation, providing opportunities for initiations, and providing nonverbal and verbal models of communication. The development of home-based routines, or activities, becomes the medium of intervention in which objectives for Active Engagement are targeted through the continued application of Transactional Supports.

In the preliminary study of the implementation of ESI (Wetherby & Woods, 2006), caregivers were instructed to embed naturalistic teaching strategies within everyday routines and activities such as caregiving (e.g. getting dressed, changing diaper), play with toys (e.g. puzzles, cars and trains), and play with people (peekaboo, hide-and-seek). In a quasi-experimental, one-group pretest-posttest design, children improved on measures of social communication, including social signals (gaze shifts, shared positive affect, gaze/point follow), rate of communicating, communicative functions (behavior regulation, social interaction, joint attention), communicative means (use of gestures, sounds, and words), and symbolic capacity (receptive language, functional and symbolic play).

A large-scale multisite randomized control trial of the ESI Project is currently underway at Florida State University and the University of Michigan to compare the effectiveness of two conditions, ESI and a parent-education group, on outcome measures of social communication skills, autism symptoms, developmental levels, and adaptive behavior. Families of children between 16 and 20 months old are randomly assigned to one condition for 9 months and then crossover to the other condition for an additional 9 months. In ESI, interventionists conduct two weekly home sessions while families travel to the University of Michigan Autism and Communication Disorders Center (UMACC) for one weekly clinic session. Between sessions, parents are expected to work with their child for 25 hours or more per week on home-based routines developed with the interventionist. Families are also required to travel to UMACC for monthly assessments.

While this project provides thorough, intensive long-term care to families within southeast Michigan, some families, especially those from low-income populations, could not meet the time commitment required to participate in the two 9-month treatment conditions nor could they meet the requirement of traveling to weekly sessions and monthly assessments. These factors limited the project's accessibility to those families who are traditionally underserved in autism research and led to the development of the Early Social Interaction – Community Outreach (ESI-CO) project.

In developing the ESI-CO project, several adaptations were made from the ESI intervention protocol and research design (Table 2) to provide more focus on influences of caregiver and family environment and to be more appropriate for underserved families, with built-in strategies for increasing engagement, attendance, adherence, and retention.

Table 2. Modifications from ESI to ESI-CO

	ESI	ESI-CO
Eligibility Criteria	Child diagnosis of ASD	Child diagnosis of ASD Expanded child age eligibility Limited family income Limited caregiver education
Length of Intervention	18 months	7 months
Research Design	Randomized controlled crossover	Single subject multiple baseline
Primary Outcome Measure	Child outcome	Caregiver outcome

ESI-CO strategies for overcoming barriers to access. An important modification to ESI-CO was accommodation made for **location** and **transportation**. Families participating in ESI were required to provide their own transportation each week to attend clinic sessions and scheduled assessments at UMACC, a circumstance that can place significant financial strain on families due to the cost of transportation. ESI-CO offered families the option of receiving services at their home or locations closer to their place of residence. Families were compensated for funds spent on traveling to assessments and if needed, local cab services were provided.

An additional modification made to the ESI-CO protocol was the **age range of children** eligible to participate in the study. ESI required that children were at least 12 months and no older than 18 months at entrance into the project. ESI-CO expanded the age range to include young children up to 42 months. By expanding the age eligibility of children for ESI-CO, we hoped to reach families of children who had not yet received a diagnosis of ASD through their local early intervention program by 18 months.

In ESI, only one caregiver was identified who learned to implement strategies and who was evaluated for protocol fidelity. Another modification to ESI-CO was to encourage **additional caregivers** to participate, although one caregiver was identified as

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primary. This structure provided caregivers with the combined benefit of individual instruction from a clinician and the opportunity to work with other caregivers both within and outside the family.

Finally, in families with multiple children, we anticipated that caregivers would be implementing treatment strategies with their affected child in the presence of that child's sibling(s). To accommodate for this structure, we also committed to encouraging caregivers to **include their other children** in treatment sessions, or in the case of older siblings, to teach them to implement treatment strategies as well.

ESI-CO strategies for decreasing attrition. We elected **not to use a treatment waitlist** because of the importance of families receiving the targeted intervention immediately upon entrance to the program.

It was also decided to **limit the time spent in the project** to lessen burden placed on families who may be experiencing significant work or family stressors. Rather than have caregivers commit to 18 months of treatment, the modified study only requires a 7-month commitment. The first month and months 5-7 involved weekly or monthly home observations without intervention. During months 2- 4, families receive the home-based intervention. The number of weekly intervention sessions was reduced to two 60 to 75-minute sessions rather than three.

In ESI, participants' continued enrollment in the project is contingent on their commitment to engaging their child outside of the three weekly hour-long intervention sessions in order to accumulate the recommended 25 hours per week (NRC, 2001). While we encouraged our families to strive to spend as much time implementing treatment strategies as possible, we **did not include 25 hours as a project requirement**

in recognition that this expectation may be too demanding for families experiencing multiple stressors.

We anticipated that cancellations and no shows would occur more frequently during the course of the intervention therefore we **maintained a liberal cancellation or absence policy**. If families cancelled or were not at home for a scheduled session, we immediately contacted the family to schedule a make-up session. When families were unable to be reached by telephone, we contacted them via mail. Overall, we committed to providing each family with 24 treatment sessions, regardless of the number of cancellations or the length of time required to complete those sessions.

Similar to the ESI protocol, we provided families with a **monetary incentive for completing assessments and observations** throughout the duration of the program. A proposal was made to offer additional financial incentives for completing treatment sessions, but this was not implemented. Though monetary incentives have been supported as a means of engaging low income populations in treatment research, we had concerns that to offer financial incentive in addition to the value of free intervention was potentially detrimental to the vulnerability of our targeted population.

ESI-CO strategies for promoting change. The importance of being **aware and sensitive to the cultural values and practices of each family** was a central tenet of this intervention. Interventionists were Masters-level clinicians with backgrounds in Clinical Psychology, Developmental Psychology, and Social Work. All interventionists had received specific training on working with underserved populations in their respective programs. During the course of the intervention, interventionists participated in weekly consultation sessions to assess their experiences with each family. Salient interactions

with family members were shared and processed, providing insights for future interactions. Finally, each interventionist was encouraged to seek consultation and supervision from licensed UMACC clinicians to provide guidance on approaching each family with cultural competence and sensitivity to meet its individual needs.

An important component of the treatment program also included empowering caregivers to become stronger advocates for their children. **For the entire 7-month duration of the project, families were actively assisted in identifying and enrolling in all available autism resources for which they were eligible**. This involved a range of activities from providing families with informational handouts, assisting them in enrolling their children in Special Education services, and providing referrals for additional autism treatment programs. Each family was also provided with a resource guide to local autism services including information regarding payment requirements and available scholarships for participation.

Additional structural modifications to the ESI-CO protocol were in **research design** and **outcome measure**. We had originally intended to conduct a randomized crossover trial, but modified the design to a single subject multiple baseline research protocol. Rationale for this change was multifaceted. First, though funding for ESI-CO came from two grants (National Institutes of Mental Health and Autism Speaks) total funds available for implementing the project were not sufficient to support the logistical needs of two treatment conditions (e.g. recruitment for a large enough sample for two discrete treatment conditions, support for two separate teams of interventionists, travel expenses, etc.). This limitation is not uncommon in research on autism interventions, as most treatment studies within the field are carried out with limited funding compared to

what would be needed to conduct an RCT (Lord, Wagner, Rogers, Szatmari, Aman, Charman et al., 2005). The use of RCTs has even been questioned as the best method to examine effectiveness in underserved populations (Bernal & Scharron-Del-Rio, 2001; Lau, Chang, & Okazaki, 2010). For example, in a systematic review of sociodemographic variables in NIMH-funded clinical trials it was observed that many studies actually lack the power to conduct appropriate subgroup analyses (Mak, Law, Alvidrez, & Perez-Stable, 2007).

Second, from both ethical and practical perspectives, a crossover design would not meet the needs of our population. Given the history of underutilization of autism services within low-income, low-education, and ethnic minority populations (Mandell, Wiggins, Carpenter, Daniels, DiGuiseppi, Durkin, et al., 2009) it was important to us that all families who entered the project receive the same intensity of the intervention we thought was the most effective. Had we used a design similar to the ESI crossover design, we were concerned that families assigned to the group condition first would have a higher likelihood of discontinuing participation and consequently, lose out on the intervention we hypothesized would be the most helpful. We also realized that traveling outside of the home to attend group sessions would be difficult for families with limited transportation and that scheduling families together for group sessions would be difficult for families with variable employment schedules.

While the shift to a multiple-baseline design did allow us to better accommodate and meet the needs of our families, it resulted in a decrease of experimental control. The use of single-case research designs, however, can be used to test new intervention designs before implementing RCTs (Lord et al., 2005; Drew, Baird, Baron-Cohen, Cox, Slonims,

& Wheelright, 2002). Such designs have made substantial contributions, especially to the field of behavioral interventions (Kazdin, 2011). Furthermore, single-case research designs are particularly useful in research on underserved populations as they have great potential to generate hypotheses about factors relating to treatment and "allow for qualitative exploration of individual differences and generation of hypotheses regarding the contributions of culture or ethnicity" (Lau, et al., 2010, p. 2010). Given the novelty of implementing an autism intervention specifically for a low-income, low-education population, the benefits of a single-case research design outweighed the costs of the reduction in experimental control.

In ESI, the primary outcome measures relate to child change in autism symptoms and developmental level, which are measured over the course of 9 months. Because the intervention time in ESI-CO is significantly shorter, we hypothesized that we would be more likely to capture change in the caregiver's behavior, thus we shifted our focus in outcome to the caregivers' development in the application of Transactional Supports to promote Active Engagement. A modified version of the *Measure of Active Engagement and Transactional Supports* (Wetherby & Morgan, 2010), a 20-item Likert scale rating of child engagement and caregiver support, was utilized to measure caregivers' transactional supports over time. Thus, this measure of Transactional Supports became a featured component of our multiple baseline design, which consisted of two primary phases, Baseline, and Treatment.

Baseline Phase. Beginning in the baseline phase and continuing through treatment, caregivers were videotaped weekly engaging their children in home activities. Prior to the first taping, the interventionist collaborated with the caregiver to identify 6

preferred home activities across 6 activity categories in which they wanted to develop

routines to target their child's social and communication skills (Table 3).

Table 3. Activity categories with examples

Play with Toys	Play with People
Vehicles and people figures	Peekaboo
Puzzles	Hide and Seek
Playdoh	Ring-around-the-Rosie
Meals and Snacks	**Caregiving**
Preparing food	Hand washing
Sharing food with others	Changing diaper
Snack/Meal Time	Getting dressed
Book Sharing	**Family Chores**
Picture books	Laundry
Song books	Sweeping
Story book	Feeding pets

Adapted from the ESI project; Wetherby & Woods (2006)

Importance was placed on choosing activities that were motivating and

developmentally appropriate for the child and feasible for caregivers to implement in

their homes. Activities were expected to last three minutes or longer, depending on their

content and purpose. Two standard activities, Snack and Handwashing, formed the core

to which caregviers selected six other activities for a total of eight. Snack and

Handwashing were selected to be used for all children because they offer learning

opportunities that for most families, take place multiple times per day. Caregivers were

instructed to engage their child in all eight activities during each baseline visit. After

each baseline taping, an ESI-CO staff member coded the caregiver's behavior within

each of the eight activities using the Transactional Supports (TS) measure. A TS

percentage score was calculated by dividing the sum of all 10 items over 40 (the highest

score TS possible) and multiplying by 100. For each activity, three consecutive scores below 70% were required to establish a stable baseline.

Treatment Phase. Before the first treatment session, the interventionist selected 4 activities to be targeted. Two of these were always Snack and Handwashing. The third and fourth activities were randomly selected from the remaining six activities. Random selection of activities was completed by creating a Microsoft Excel file listing each of the six activities, using the randomization function to assign each activity a number, and then choosing the activities with the lowest numbers. During the two weekly treatment sessions, the interventionist worked on the four targeted activities with the caregiver. Interventionists were encouraged to work on each of the four targeted activities during each session, but at a minimum, were required to work on each activity at least once a week. Caregivers were encouraged to work on all four activities the rest of the week.

The weekly videotaping sessions that had begun during the baseline phase continued during the treatment phase. After the videotaping session, an ESI-CO research assistant blind to targeted vs. non-targeted activities scored each of the eight activities separately on the TS measure. An activity was considered mastered if the caregiver received a TS score of 70% or above on three consecutive caregiver fidelity tapings. When a caregiver mastered an activity, it was no longer targeted in session with the interventionist. The interventionist randomly selected an activity from the already-being-videotaped non-targeted activities to become the next targeted activity. Next, the interventionist collaborated with the caregiver to select a new activity to move into the pool of non-targeted activities. Thus, a caregiver always engaged their child in eight activities, four of which were always targeted with the interventionist. Care was taken to

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ensure that each new non-targeted activity was held in baseline for at least three consecutive tapings or until a stable baseline was achieved.

It is important to recognize that while the ESI-CO procedures involved several modifications to the ESI model, it retained the key component of the model that has been shown to promote positive outcome in young children with ASD (Wetherby and Woods, 2006). As with the ESI, an integral component of the intervention was to teach caregivers to support their child's communication, social, and play skills in the everyday routines and activities of their natural environment.

Overall, the purpose of this project was to develop the ESI-CO project and to obtain preliminary outcome data based on descriptive, quantitative, and qualitative analyses of the experiences of an underserved population in early autism intervention. In particular, we focused on the influences of the *family environments* and *caregivers*, hypothesizing that:

1. Strategies implemented to increase participation of families from low-income and low-education populations would be successful in retaining families for the duration of the intervention, but that families at higher risk (fewer resources) would be more likely to discontinue the project, or have lower treatment attendance and treatment adherence.

2. Caregivers who completed the treatment phase would demonstrate an increase in their use of strategies to promote children's social and communication skills.

Ultimately, the goal of the project was to test the applicability of the newly

developed intervention model and to use results to continue development of interventions

serving families from underserved populations

Chapter 5: Methods

Design

The application of a mixed-method research design can be advantageous in research projects in which a combination of quantitative and qualitative methods best reflect the goals of the project (Johnson & Onmweugbuzie, 2004). Given the exploratory nature of the ESI-CO, a mixed-methods design best fit the need to measure the success of the program and to guide future directions. In the variation of mixed-methods design that was selected, researchers conduct separate quantitative and qualitative "mini-studies," either concurrently or sequentially, within the context of a larger research study and integrate respective findings to address research questions (Johnson & Onmwuegbuzie, 2004). For the purposes of testing the applicability of ESI-CO, data collection began with quantitative methods, which were followed by qualitative assessment of families' experiences in the program. During the quantitative phase of the project, weekly changes in caregiver behavior were measured through the multiple baseline protocol in addition to pre-post-and follow-up data collected before and after each phase of the intervention. Qualitative data were collected through interviews conducted at the conclusion of each family's involvement in the project. Though analyzed separately, quantitative and qualitative findings were interpreted together to provide the most comprehensive review of the outcome of the project.

Participants

Twenty-seven families were referred to the project, 13 of whom did not meet eligibility requirements. Of the 17 eligible families, 13 participated in the initial assessment. All of these children received ASD diagnoses and all 13 families agreed to participate in the study. Four families discontinued participation during the baseline phase. For three of those families, reasons cited for discontinuation were time constraints. In the fourth family, the child was accepted into another treatment program. Of the remaining nine families, four have completed the project, two are in the follow-up phase, and two are in treatment (Figure 1). It was decided that one family should withdraw during the treatment phase because it became apparent English was not their predominantly spoken language in the home. None of the ESI-CO staff members were proficient in the family's predominantly spoken language, nor were translated questionnaires available. Thus, it was not possible to continue data collection. The family discontinued participation in the research, but arrangements were made for treatment services to continue through a different agency. Participant attrition was calculated using the full sample of the 13 families who participated in an initial assessment and agreed to take part in the intervention. 13 families started the project, four discontinued during baseline, one left during treatment, so a total of eight families continued participation, yielding an attrition rate of 38%.

Figure 3. Participant recruitment, enrollment, and retention

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┌─────────────────────┐
│ 27 families referred │
│ and screened for     │─────────────┐
│ eligibility          │             │    ┌──────────────────────────────────┐
└─────────────────────┘             │    │ 13 families excluded:             │
           │                        └───▶│ • 5 exceeded education requirement │
           ▼                             │ • 1 exceeded income                │
┌─────────────────────┐                  │ • 4 exceeded income & education    │
│ 14 families scheduled│                  │ • 1 child exceeded age             │
│ for initial assessment│                 │ • 2 not interested in participating│
└─────────────────────┘                  └──────────────────────────────────┘
           │
           │                             ┌──────────────────────────────────┐
           │                             │ 1 family excluded:                │
           ├────────────────────────────▶│ • Did not attend initial assessment.│
           ▼                             │   Attempts to contact failed.     │
┌─────────────────────┐                  └──────────────────────────────────┘
│ 13 families entered  │
│ Baseline             │
└─────────────────────┘                  ┌──────────────────────────────────┐
           │                             │ 4 families discontinued:          │
           ├────────────────────────────▶│ • 3 due to time constraints       │
           ▼                             │ • 1 accepted into another intervention│
┌─────────────────────┐                  │   program                         │
│ 9 families entered   │                  └──────────────────────────────────┘
│ Treatment            │
└─────────────────────┘                  ┌──────────────────────────────────┐
           │                             │ 1 family discontinued:            │
           ├────────────────────────────▶│ • Withdrawn from study            │
           ▼                             └──────────────────────────────────┘
┌─────────────────────┐
│ Current Status:      │
│ • 4 families completed│
│ • 2 in follow-up     │
│ • 2 in Treatment     │
└─────────────────────┘
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Within the eight families who continued participating, all caregivers were the

biological mothers of the affected child. Family incomes ranged from less than $10,000

to $35,000 and all families except for one received some form of public assistance (i.e.

Medicaid, Food Stamps, Supplemental Security Income). Six caregivers reported living

in suburban/city regions and two reported living in small town/rural regions. All families

lived in Southeast Michigan. Child participants were all male and ranged from age 24

months to 40 months at the initial assessment. All children received a diagnosis of ASD

at the initial assessment, and four of the eight children were assessed as having cognitive

skills within the range of intellectual disability. Table 4 provides a full summary of

caregiver and child characteristics for families who completed the intervention and for

those who discontinued participation (data from the withdrawn family are not included).

Table 4. Participant characteristics

	Completers		Non-Completers	
Caregiver Characteristics	**Mean (SD)**	**Range**	**Mean (SD)**	**Range**
Age (years)	31.38 (4.75)	21 – 36	39.7 (19.34)	28 – 62
Ethnicity				
African American	4		1	
Caucasian	4		3	
Marital status				
Unmarried	3		0	
Unmarried, Co-living	3		3	
Married	2		1	
Education				
Some High School	0		1	
High School Graduate	3		3	
Some College	5		1	
Family income (yearly)	$18,300 (10,000)	< $10,000 – 35,000	$23,200 (1,100)	<$10,000 – 32,000
Number of children in family	2.38 (1.41)	1 – 5	3.25 (1.71)	1 – 5
Child Characteristics				
Age (months)	28.38 (5.21)	24 – 40	29.75 (4.9)	23 – 34
Ethnicity				
African American	3		1	
Caucasian	3		3	
Multiracial	2		0	
Verbal IQ	40.12 (16.10)	27 – 71	53.5 (12.12)	38 – 61
Nonverbal IQ	70.13 (13.91)	50 – 96	58.0 (11.22)	43 – 74
Adaptive Behavior Composite	75.38 (8.73)	64 – 85	73.75 (10.14)	64 – 89

Intervention Procedures

Referral and Initial Evaluation Phase: Referrals were received through local

health clinics, school districts, and Early On, a Part C Michigan state agency providing

early intervention services for infants and toddlers exhibiting developmental delay or

disability. Additional referrals were received from the First Words project, an ongoing

research project at the University of Michigan Autism and Communication Disorders

Center (UMACC) examining early indicators of ASD. Eligibility was determined at two

levels, family and child. At the family level, selection criteria included: 1) caregiver(s)

with no more than 2 years of college experience; 2) family income equal to or below two

times the federal poverty line; and 3) English as the predominantly-spoken language. At

the child level, selection criteria for participation included: 1) a diagnosis of ASD; 2)

between 18 and 42 months of age; and 3) adequate hearing, vision, and motor control to

make simple actions (giving, reaching).

Upon referral, families were administered an intake phone interview to assess

family level eligibility. If criteria were met, an initial diagnostic assessment with a

licensed clinician was scheduled.   Assessments were conducted at UMACC or in the

home if families were unable to travel. Assessments took place over two half-day

sessions of 3-4 hours and consisted of a parent interview and child observation and

testing, respectively. Additionally, all families participated in a feedback session in

which an ASD diagnosis was given, if appropriate, and discussed. Recommendations for

future intervention and support were made. At this time, the family was offered the

opportunity to participate in the intervention phase of ESI-CO.

Baseline and Treatment Phase: The study utilized a multiple baseline single-

subject design that took place in the family's home (refer back to Chapter 4 for a

description of the multiple baseline design). Caregiver and child dyads completed three

to four baseline observations over the duration of two to four weeks followed by bi-

weekly ESI-CO treatment for a total of 24 sessions. Families also participated in a total

of 12 fidelity observations videotaped by a research assistant blind to which activities were targeted and which were not. During treatment sessions, the interventionist also assisted each caregiver in applying for available resources available to children with ASD in the region.

Follow-up Phase: During the follow-up phase, interventionists no longer provided weekly home intervention sessions. Once per month for three months, the interventionist visited the family to provide consultation on the child's progress and the caregiver/child dyad participated in a videotaped fidelity observation. Between monthly visits, the interventionist communicated via telephone or email to help families enroll in local autism services and plan for their child's transition to Part B special education services. Additionally, interventionists encouraged the caregivers to continue using intervention strategies during everyday activities and routines.

Quantitative Measures

Weekly Measures.   The following measures were administered weekly during the treatment phase of the project.

Treatment attendance was measured by calculating the number of sessions completed per family, number of cancellations/no shows, and length of time to complete all 24 treatment sessions during the intervention phase.

Treatment adherence was measured through the ESI-CO Intervention Hours, a parent log used to document the number of hours during which caregivers implemented ESI-CO strategies in activities and routines outside of sessions with the interventionist. Caregivers were instructed to complete the log on a weekly basis during the treatment

phase. Hours reported were considered "engaged time" between caregiver and child and counted toward the amount of weekly intervention each child received.

The *Measure of Active Engagement and Transactional Supports* (Wetherby & Morgan, 2010) is a 20-item Likert scale rating of child engagement and caregiver support. Item scores range from 1 to 4, with a score of 1 representing inadequate application of the strategy and a score of 4 representing more than adequate application of the strategy. The present study utilized the 10 items pertaining to caregiver supports, referred to as the Transactional Support (TS) measure (Appendix A). The TS was scored from the 12 weekly caregiver fidelity videotapes by raters who were blind to targeted activities. Scores ranged from 10-40 (i.e. 25 – 100%), with higher scores or percentages indicating higher fidelity of caregiver implemented ESI-CO strategies. To be eligible to code, each rater was required to obtain reliability, defined as three consecutive codings with a percent agreement of 80% or above with consensus. Inter-rater reliability was estimated through independent codings of 10 randomly selected activities and was within the acceptable range (ICC = 0.70).

Pre-, Post, and Follow-up Measures. These measures were administered at the initial assessment, three months later upon completion of the treatment phase, and at the final assessment after the three monthly follow-up visits were completed. They included measures regarding family environment, caregiver characteristics, and child characteristics. All measures, with the exception of the Other Intervention Log which was developed specifically for the ESI Project, have well-established and documented psychometric properties, with high levels of inter-rater and test-retest reliability and validity.

Family Resource Scale (FRS; Lee & Dunst, 1987). This survey is completed by the caregivers and measures their perceived adequacy of physical and human resources available to the family. It consists of 30 items scored from 1 to 5 with scores of one indicating resource levels that are not at all adequate and scores of 5 indicating resource levels that are almost always adequate. Exploratory factor analysis has revealed six subscales, including Basic Needs, Housing/Utilities, Benefits, Social Needs/Self Care, Child Care, and Extra Resources (Brannan, Manteuffel, Holden, & Heflinger, 2006). Mean scores ranging from 1-5 are calculated for each subscale. An FRS total subscale is computed by summing the six mean subscale scores.

Family Support Scale (FSS; Dunst, Trivette & Hamby, 1994). This is a 36-item self-report measure designed to assess how often caregivers of children with disability utilize sources of social support and the degree to which they find those sources helpful in rearing their children. Modifications were made by Bromley, Hare and Davison (2004) to make the FSS more applicable to caregivers caring for children with ASD.

Family Impact Questionnaire-R (FIQ-R; Donenberg & Baker, 1993). This survey measures parents' perception of the impact of their child on the family's life relative to the impact "most" children his/her age have on their parents/family. Items are rated from zero to three, with scores of zero corresponding to no impact on the family and scores of three corresponding to high impact.

Autism Diagnostic Interview-Revised (ADI-R; LeCouteur, Lord, & Rutter, 2003) is a comprehensive, standardized parent interview designed to distinguish children with ASD from non-ASD and DD populations. The ADI-R covers developmental and behavioral aspects of autism. When appropriate, the toddler version of the ADI-R was

used. This measure was only administered during the initial assessment.

The *Autism Diagnostic Observation Schedule* (ADOS; Lord, Risi, Lambrecht, Cook, Leventhal, DiLavore, Pickles, & Rutter, 2000) is a semi-structured, standardized assessment of communication, social interaction, and play for children referred because of possible autism. The appropriate ADOS module is selected based on the child's age and language skills.

The *Mullen Scales of Early Learning* (MSEL: Mullen, 1995) is a standardized test that measures developmental level with separate scores for four cognitive scales— Visual Reception, Fine Motor, Receptive Language, and Expressive Language.   Scores from the MSEL can also be used to generate verbal, nonverbal, and full scale ratio IQ scores.

The *Vineland Adaptive Behavior Scales-II* (VABS; Survey Interview Form; Sparrow, Cicchetii, & Balla, 2004) yields a standard score in four domains— Communication, Daily Living, Social, and Motor, and an Adaptive Behavior Composite.

The *Other Intervention Log* is a parent report survey documenting the number of hours of other intervention received outside of ESI-CO. This form documents the hours in psychosocial or educational treatments and whether the child is receiving alternative treatments (e.g., diet, chelation).

Qualitative Measures

The *ESI-CO Exit Interview* is a semi-structured interview developed for this project to assess caregivers' perceptions of their experiences participating in the project (Appendix B). The interview consists of 20 questions designed to gain caregivers' evaluation of their overall experience in the project, as well as their opinions regarding each respective aspect of the project (i.e. treatment, follow-up, and clinic evaluations).

Quantitative Data Analyses

<u>Description of Environmental and Family Context</u>. Analyses were conducted using data from the four families who have completed all phases of the intervention. Similar to other studies with limited sample size (Lyon & Budd, 2010), descriptive rather than statistical analyses were used to address research questions. The Family Resource Scale, Family Support Scale (FSS), and Family Impact Questionnaire (FIQ) were used to describe the environmental and family context of each participating family. The FRS was also used to examine whether availability of resources was related to treatment attendance. We hypothesized that families with fewer resources or forms of social support would be more likely to discontinue participation in the project or have lower treatment attendance and adherence.

<u>Treatment attendance and adherence.</u> Descriptive analyses were also used to describe patterns of treatment attendance and adherence. We hypothesized that caregivers with fewer treatment session cancellations would show greater adherence to treatment recommendations, demonstrated by the number of hours reported engaging children in activities and routines outside of treatment sessions. The amount of reported time spent in each activity category was also examined to see if any patterns of engagement emerged.

<u>Caregiver change in Transactional Supports</u>. Visual analysis is the predominant method of data analysis in single-subject research literature (Kazdin, 2011; Brossart, Parker, Olson, & Mahadevan, 2006). The use of additional statistical procedures, such as calculations of effect size, is also recommended. Both methods were used to examine

trends in caregivers' mastery of treatment strategies within each targeted and non-targeted activity during baseline, treatment, and follow-up.

Graphs of weekly TS scores were generated for each activity. Visual analysis of each graph was conducted by examining changes in slope between baseline and treatment to determine the effect of treatment on caregiver transactional supports. Attention was paid as to whether there were differences in trends when comparing targeted activities versus activities that were held in baseline for the entirety of the treatment phase (i.e. non-targeted activities).

Effect sizes for each activity were calculated following methods outlined by Busk and Serlin (1992) in which the standardized mean difference between two variables is used to estimate the magnitude of a relationship. Effect sizes were interpreted following Cohen's (1992) guidelines (i.e. small = .20 or greater; medium = .50 or greater; and large = .80 or greater). Two series of effect size calculations were conducted:

Group activity analysis: We examined trends across activities and families by computing the average TS score across all treatment means and baseline means, respectively. To examine whether there was an overall effect of treatment, the difference between the mean of all baselines and mean of all targets was divided by the standard deviation of all baselines. We hypothesized that there would be an overall positive effect size, but of only small to moderate magnitude due to variation across all activities.

To examine whether caregivers' skills learned in targeted activities generalized to non-targeted activities, non-targeted activities were divided into two groups based on whether they were initiated during the first half of treatment or the second half of treatment. Separate effect sizes were calculated comparing targeted activities versus non-

targets (first half of treatment) and targeted activities versus non-targets (second half of treatment). We hypothesized that the effect size for targets versus non-targets (first half of treatment) would be larger than that of targets versus non-targets (second half of treatment), because skills acquired during targeted activities during the first half of treatment would begin to generalize to non-targeted activities during the second half of treatment.

Group activity follow-up analysis: The average TS scores for targeted and non-targeted activities collected during the follow-up phase were calculated by averaging all follow-up activities across families for targets and non-targets, respectively. Effect sizes were calculated by dividing the difference between follow-up and treatment means by the standard deviation of the treatment mean. We hypothesized that gains made in treatment would maintain during follow-up. Thus we expected that the magnitude of the effect size between activities during treatment and follow-up would be negligible. We also hypothesized that gains in TS scores would have higher levels of maintenance for targeted activities versus non-targeted activities, or rather, that caregivers would have lower follow-up TS scores for activities that were not targeted during treatment. This would be evidenced by negative effect sizes of greater magnitude for the non-targeted activities.

Relationship between TS scores, treatment attendance and adherence. Correlations were computed to examine the relationship between caregivers' acquisition of transactional supports and their levels of attendance and adherence. It was hypothesized that caregivers with higher levels of treatment session cancellations and

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fewer reported hours of time spent engaging children in treatment activities would be associated with lower TS scores.

Caregiver reported change in family context and enrollment in services. Scores from the FSS and FIQ were also compared across assessments (initial, post-treatment, and follow-up) to determine whether caregivers' reports changed over the duration of the intervention. We hypothesized that caregivers would report utilizing more forms of social support related to autism-specific services and that caregivers' perceptions of the impact their child had on the family would be affected positively, reflected by a decrease in reported perceptions of negative impact and an increase in positive impact.

Qualitative Data Analysis

A phenomenological approach was taken in conducting and analyzing the ESI-CO Exit Interviews. The shared experience, or phenomena, upon which the caregivers were asked to reflect was their experience participating in the ESI-CO project. Interviews were conducted during the third and final fidelity observation and took place in the families' homes. An ESI-CO staff member familiar with the family, but who was not their individual interventionist, conducted the interviews. Interventionists were not present. Interviews lasted from 10-30 minutes and were videotaped. Using the procedure outlined by Creswell (2007), each video was transcribed into a written document. Transcriptions were completed by one individual and reviewed by another to ensure accuracy. Five ESI-CO staff members read each transcript and identified significant statements (i.e. words, phrases, or sentences that have particular meaning or direct relevance to the phenomenon being studied, Creswell, 2007). Inter-rater reliability ranged from 47-91% (M = 68%). During a group discussion, significant statements were

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categorized into codes, which were then reduced to overarching themes. Disagreements in code and theme identification were discussed until consensus was achieved. Specific hypotheses for the qualitative analysis were not generated to eliminate the potential for bias during coding and thematic discovery.

Chapter 6. Results

Description of Families Included in the Analyses

Family 1 included Rosario (21 years), Joe (25 years), and their biological son, Bobby (29 months)[1]. Rosario identified as biracial (African American and Caucasian), Joe as Hispanic, Bobby as multiracial (African American, Caucasian, and Hispanic). Rosario and Joe both completed high school and had no college experience. She worked full-time as a coffee house shift supervisor and he was a factory production worker for an automobile company. Their family income was $12,000 per year and they received aid through Medicaid and Women, Infants, and Children (WIC). Rosario and Joe lived together but were unmarried. During the course of their involvement in ESI-CO, however, they became engaged. Bobby was their only child. Bobby had been identified as speech delayed by Early On, the Part C-funded early intervention program in the state of Michigan. At one point he was receiving four hours of weekly intervention services from Early On, but at the time of joining the ESI-CO project, Rosario reported Bobby was not receiving any other treatment. The family was referred to ESI-CO by both Early On and Bobby's developmental pediatrician. At the initial assessment, Bobby had no verbal language. He produced some vowel sounds, but was not yet babbling communicatively. His developmental level was measured in the intellectually impaired range.

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[1] All names have been changed

Family 2 included Angela (27 years) and her biological son, Marcus (3 years, 4 months). They identified as African American. Angela had three other children; Tre, Maurice, and Amaya, who were 10 years, 7 years, and 18 months, respectively. Marcus and Amaya were full biological siblings and Tre and Maurice were maternal half-siblings to Marcus and Amaya, and to each other. Maurice had a diagnosis of Attention Deficit/Hyperactivity Disorder. None of the children's biological fathers lived in the home. Angela had graduated from high school and had some college experience. She was currently unemployed and the family income was less than $10,000 per year. They received Medicaid and WIC services, in addition to Food Stamps. Marcus had not received any early intervention services nor had he attended preschool. The family was referred to the ESI-CO project by his developmental pediatrician. Angela reported that Marcus communicated using some single words and some sentences, but at the time of the first assessment, he did not speak. His developmental level was measured in the range of intellectual impairment.

Family 3 included Susan (36 years) and her biological son, Kyle (24 months). They identified as Caucasian. Susan had one additional child who was 18 years old and maternal half-sister to Kyle. Neither Kyle's nor his sister's father lived in the home. Susan had graduated from high school and was unemployed. The family income was less than $10,000 and they received aid through Medicaid, WIC, Supplemental Security Income (SSI), and Food Stamps. Kyle was identified with developmental delay through Early On when he was six months old. Since then, he received one hour of individual therapy and one hour of group therapy per week. Susan and Kyle were referred to ESI-CO through their participation in the First Words Project, a research study at UMACC

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focusing on the early identification of communication and autism spectrum disorders.

When Kyle was first assessed, he produced some vowel sounds, but was not using sounds

or words communicatively. His developmental level was measured in the intellectually

impaired range.

Family 4 included Linda (36 years), Daniel (36 years), and their biological son,

Tyler (2 years, 11 months). Linda identified as Caucasian; Daniel and Tyler identified as

Caucasian and Hispanic. Linda reported a history of bipolar disorder. She and Daniel

were unmarried, but lived together with Tyler, who was their only child. Linda had some

college experience, but Daniel had not yet obtained his high school diploma. She worked

in health care administration and Daniel was employed in home construction. Midway

through their involvement with ESI-CO, Linda went on medical leave to be able to have

more time to focus on gaining services for Tyler. The family earned $24,000 per year

and also received aid through Medicaid, WIC, and Food Stamps. Starting when he was

19 months old, Tyler received one hour per week of group therapy through Early On.

Linda contacted UMACC with concerns about John's development after seeing an

advertisement in a local parent magazine. She was referred to the ESI-CO project by the

UMACC early intervention project manager. During Tyler's initial assessment, he

produced several words. He was not yet combining words into sentences, but did use a

variety of gestures to communicate. His developmental level was measured in the

average range.

Quantitative Results

Description of Environmental and Family Context. The Family Resource Scale

(FRS) was used to provide a profile of each family's available resources based on

caregiver perception. It was also used to contextualize the average level of resources available within the ESI-CO sample compared to a previously published impoverished sample from the System of Care (SOC) Study (Brannan et al., 2006). Mean scores for the ESI-CO sample were lower than that of the SOC study on all subscales except one (Social Needs/Self Care), indicating that this group of families may have fewer available resources than families from other regions of the United States (Table 5). There was significant variability across subscales for all four families (Figure 4), though in general, Families 1 and 3 reported greater availability of resources than Families 2 and 4.

Table 5. Family Resource Scale mean subscale scores

FRS Subscales	ESI-CO Completers		ESI-CO Non-Completers		SOC Sample (Brannan et al., 2006)	
	Mean	*SD*	*Mean*	*SD*	*Mean*	*SD*
Total FRS score	17.98	2.41	23.86	4.93	21.90	4.32
Basic Needs	3.60	1.07	4.53	0.64	4.04	0.84
Housing & Utilities	4.17	0.97	4.61	0.54	4.44	0.68
Benefits	3.19	0.90	3.75	0.90	3.95	0.97
Social Needs/Self Care	3.38	1.20	3.29	1.16	3.31	0.89
Child Care	2.00	1.15	1.67	0.29	3.62	1.50
Extra Resources	1.65	0.94	2.33	1.50	2.59	1.09

The FRS was also used to compare the families who completed ESI-CO to those who discontinued participation. Data were available on three of the four non-completers (Family B did not complete any questionnaires at the initial assessment). Mean scores on the FRS subscales were either comparable, or slightly higher than those of the ESI-CO completers (Table 5 and Figure 5) except for childcare, which was not significantly different. It was hypothesized that families with fewer resources would be more likely to discontinue treatment. Discontinuation of the intervention project by the non-completers, however, did not seem related to differences in perceived availability of resources.

Figure 4. FRS subscales by family: Treatment Completers
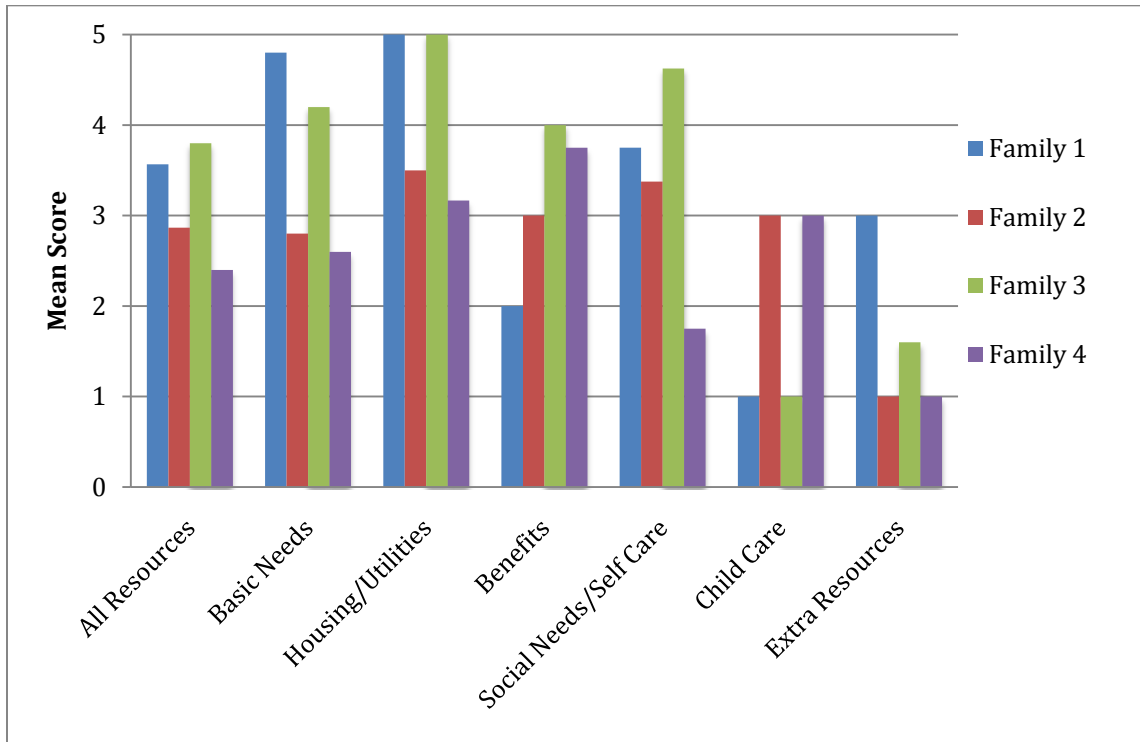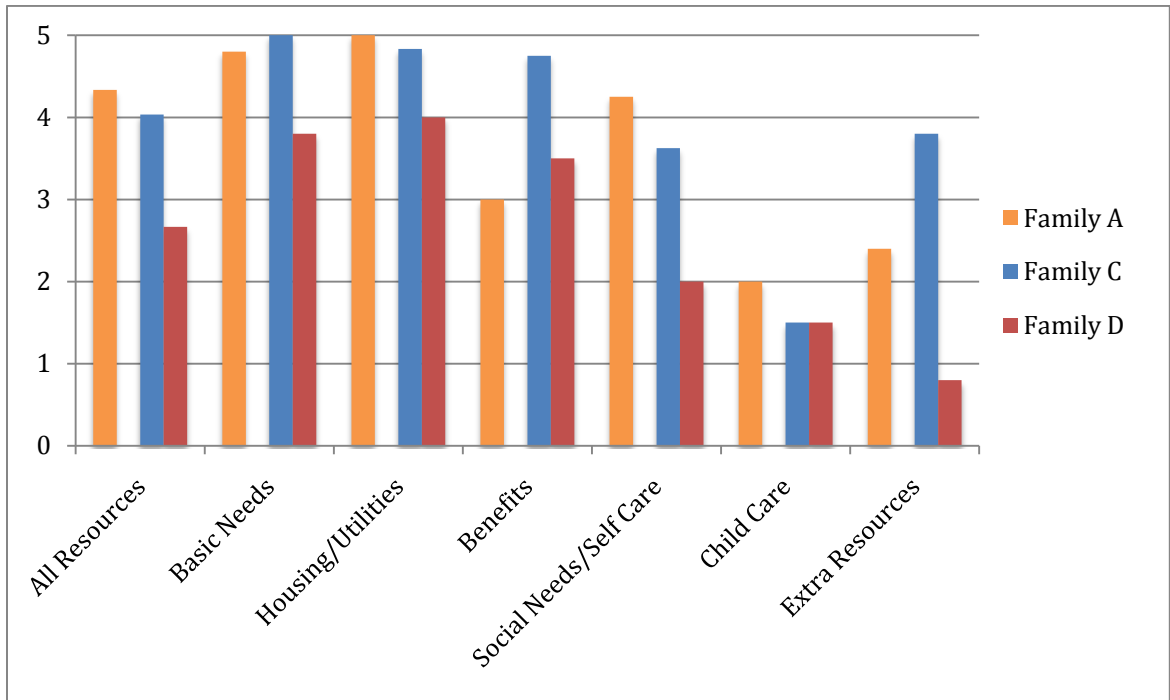

Figure 5. FRS subscales by family: Treatment non-completers

Caregivers' reports on the use and helpfulness of various forms of social supports were captured using the Family Support Scale (FSS) (Tables 6 and 7). All of the families were more likely to utilize support from family members than from friends, co-workers, group organizations or professionals (i.e. physicians or intervention programs). Families 3 and 4 were the only ones participating in an early intervention program, but they did not rate them as being a helpful source of support.

Table 6. Use of forms of social support reported at initial assessment

| Source of Support	Every Day	Once per Week	Once per Month	Very Rarely, or never
Parents	4*	1,2,3		
Partner's Parents	1		4	2
Relatives		3,4	1	2
Partner's Relatives			1	2,4
Partner	1,3,4	2		
Friends			3	1,2,4
Partner's Friends				1,2,4
Own Children	2,3			1,4
Co-Workers				1,2,4
Parents' Groups				1,2,4
Social groups/clubs				1,2,4
Religious Organizations				1,2,4
General Practitioner				1,2,4
Early Intervention Program		3,4		1,2
School				1,2,4
Professional Support				1,2,4
Statutory Services				1,2,4

* Numbers refer to individual families

Table 7. Helpfulness of forms of social support reported at initial assessment

Source of Support	Very helpful	Sometimes helpful	Not at all helpful	Not available
Parents	1,3,4	2		
Partner's Parents	1,4		2	
Relatives	1,3	4	2	
Partner's Relatives	1	4	2	
Partner	1,3	2,4		
Friends		3	1,2,4	
Partner's Friends			1,2,4	
Own Children	2	3		1,4
Co-Workers	1			2,4
Parent's Groups			4	1,2
Social groups/clubs				1,2,4
Religious Organizations				1,2,4
General Practitioner				1,2,4
Early Intervention Program				1,2,4
School				1,2,4
Professional Support	3			1,2,4
Statutory Services				1,2,4

The caregivers' perceptions of the impact their child had on family life were measured by the Family Impact Questionnaire (FIQ). Overall, caregivers rated their children as having moderate positive aspect (M = 1.5, SD = 0.55) and only some negative impact (M = 1.52, SD = 0.38) on their lives. Caregivers 1, 2, and 3 reported their child had greater positive impact than negative impact on family life (Figure 6). Caregiver 4, however, reported that her child had greater negative impact than positive impact.

Figure 6. Impact of child on family reported at initial assessment
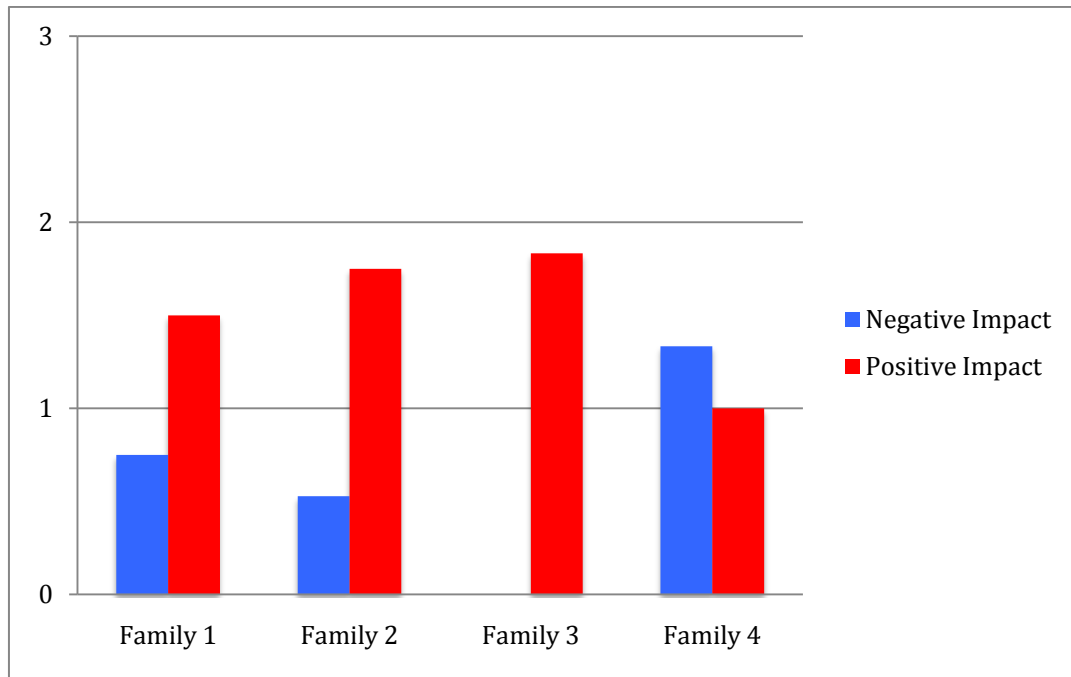
Treatment Attendance and Adherence. Each of the four families completed all 24 sessions during the treatment phase and three sessions during the follow-up phase. The length of time it took to complete the intervention, however, varied across families (Figure 7). During the treatment phase, variation in length of completion was due to the number of session cancellations (Figure 8). The reasons reported for cancelling treatment sessions were also varied, but the majority of cancelled sessions were due to reported child or caregiver illness (Figure 9). The length of the follow-up phase was affected by both interventionist and family schedules. The interventionist for Families 1 and 2 was working part-time for the ESI-CO project, thus scheduling was more difficult.

Figure 7. Length of time to complete ESI-CO project by family
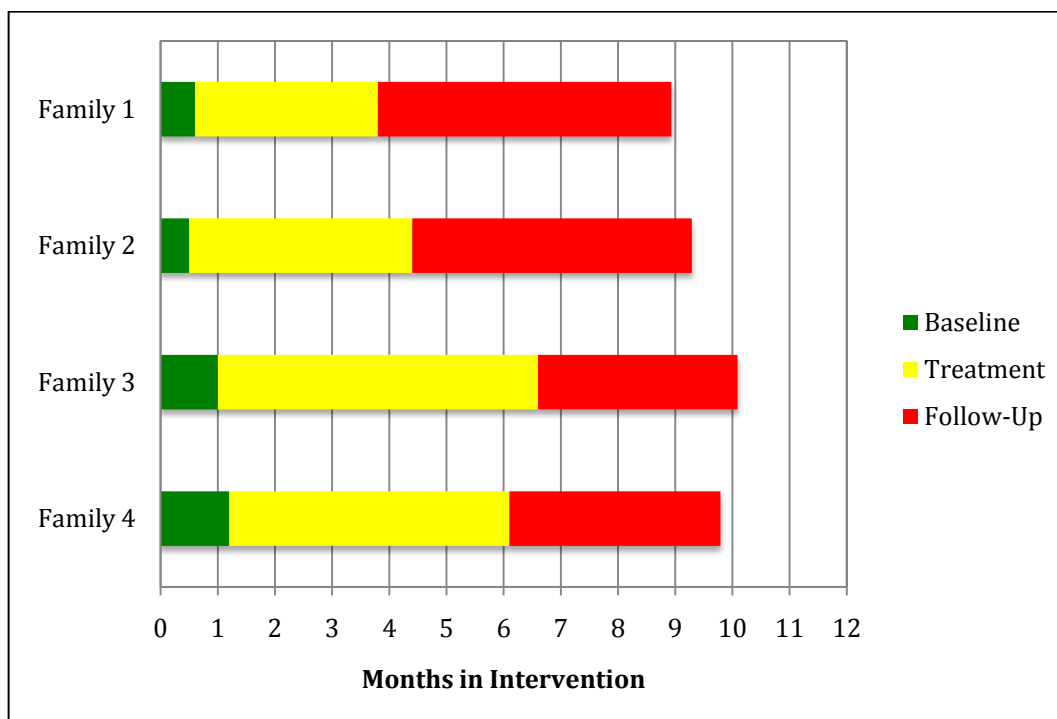
The amount of time caregivers spent engaged in the eight activities outside of treatment sessions also varied considerably. The average time spent per week ranged from 5.9 to 21.6 hours ($M = 13.7$, $SD = 5.6$; Figure 10). When examined by activity category, families spent the most time engaging their children in Play with Toys ($M = 4.63$ hours, $SD = 2.46$), followed by Caregiving ($M = 3.38$, $SD = 2.38$), Meals and Snacks ($M = 3.27$, $SD = 1.82$), Play with People ($M = 2.84$, $SD = 2.49$), Books ($M = 2.22$, $SD = 1.74$), and other activities outside of the specified eight activities ($M = 1.55$, $SD = 3.1$). Family chores were the least likely to have been included in reported activities ($M = 0.59$, $SD = 0.44$; Figure 11).

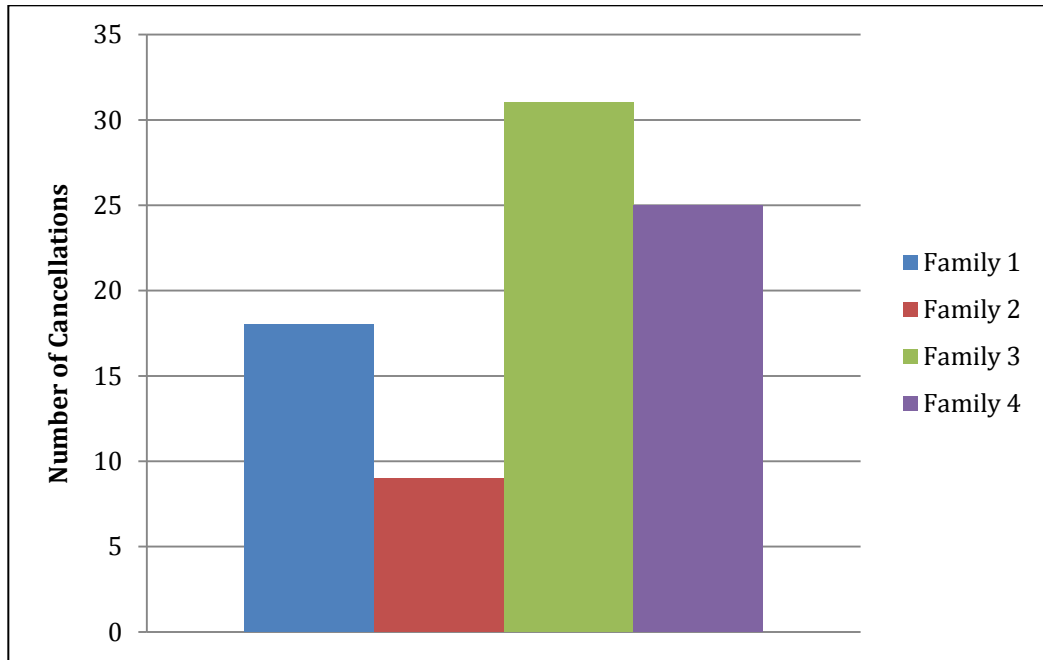**Figure 8. Number of cancellations during treatment phase by family**

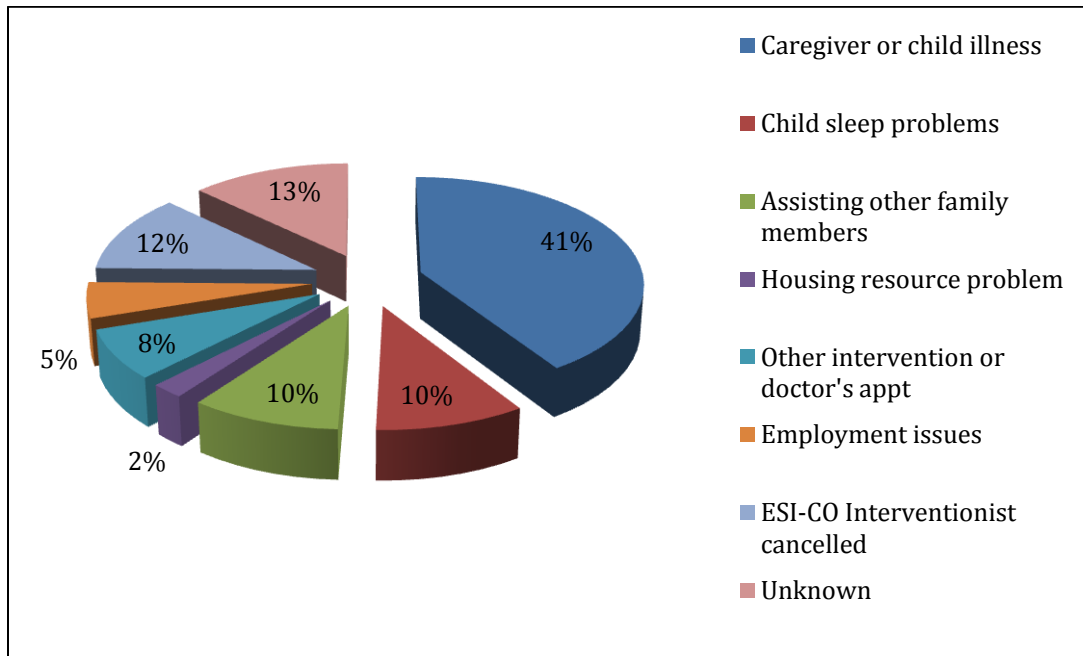**Figure 9. Reasons for cancellation reported by families**

Figure 10. Average weekly engaged time in intervention activities
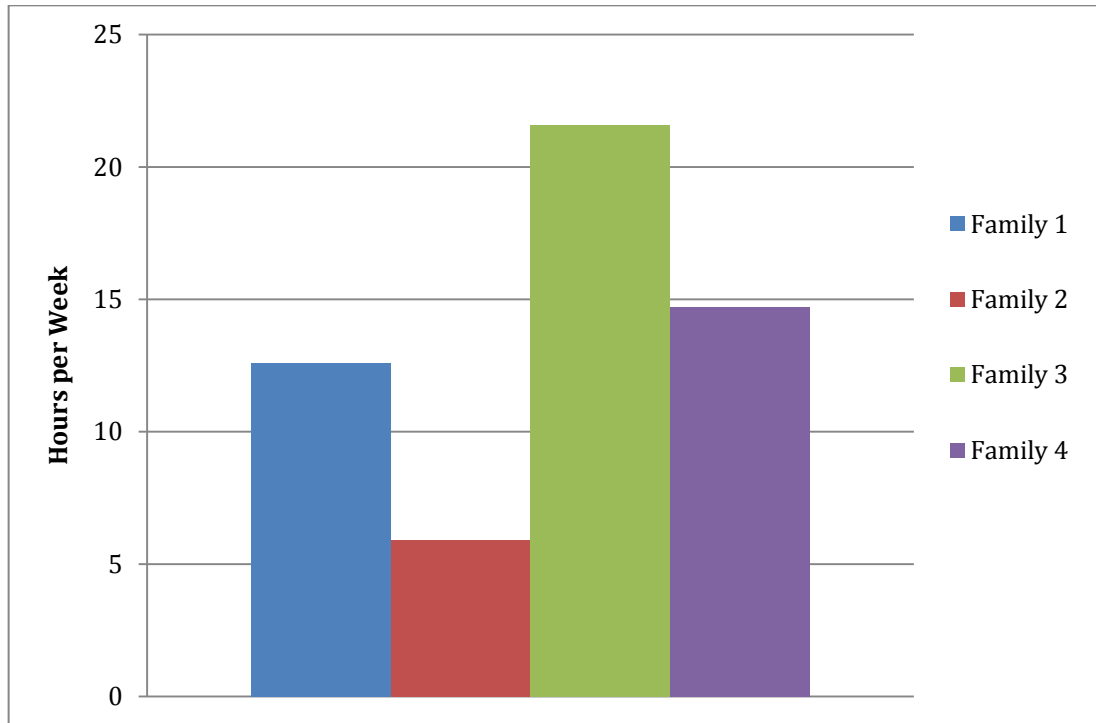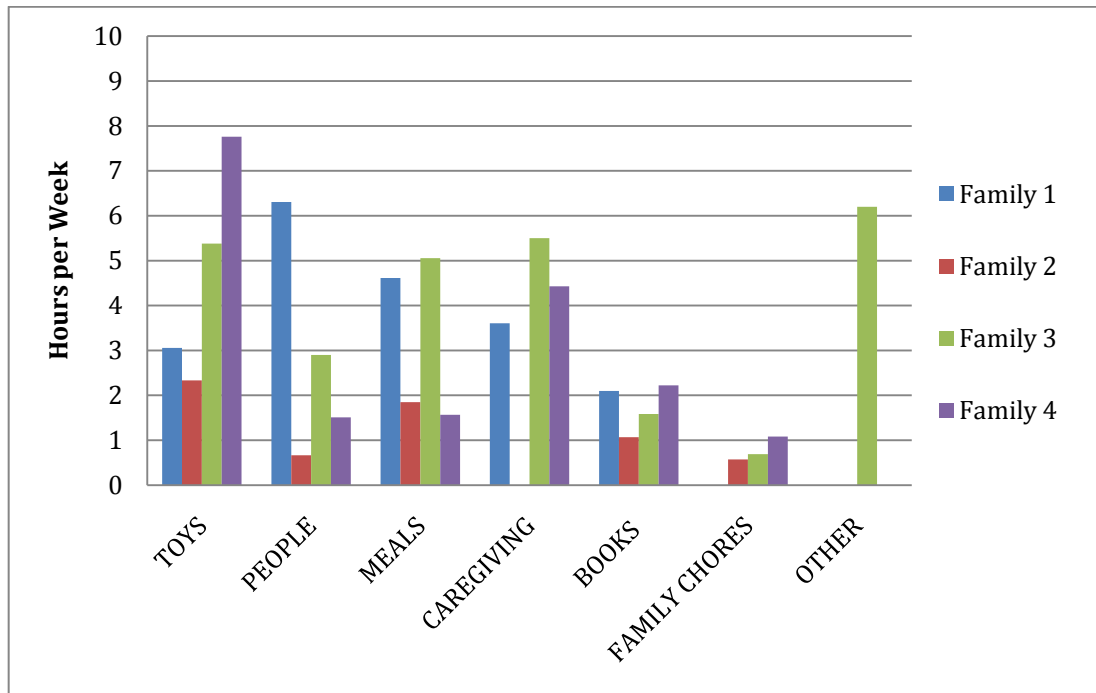

Figure 11. Average weekly engaged time by activity category

Caregiver change in Transactional Supports, Visual Analysis. A total of 48 graphs of activities were generated for all four families (Appendix C). Thirty-one of the graphs represented activities that were targeted during the treatment phase. The remaining 17 activities were implemented by the families, but were never targeted with the interventionist. Visual analysis revealed that out of the 31 targeted activities, 16 (52%) demonstrated positive treatment effects, 8 had no treatment effect (26%), and 7 had negative treatment effects (23%). For the 17 non-targeted activities, 13 had three or more time points; those with fewer observations were excluded from visual analysis. Of the 13 non-targeted activities with three points or more, 11 (85%) had positive slopes indicating improvement over time.

Caregiver change in Transactional Supports, Effect size analysis. Calculations of effect sizes yielded a clearer interpretation of the trends in TS scores. We hypothesized there would be an overall positive effect of treatment when the mean TS score of all targeted activities was compared to the mean TS score of all activities in baseline. This hypothesis was supported. TS scores for targeted activities (M = 67.06, SD = 15.16) were greater than TS scores for non-targeted activities (M = 61.46, SD = 15.21). The effect size of all targeted activities versus all non-targets was 0.36, indicating a small, but positive treatment effect. We also expected that as caregivers participated in the treatment phase, they would begin to generalize skills learned during targeted activities to non-targeted activities. This hypothesis was also supported. TS scores for non-targeted activities in the first half of the treatment phase (M = 59.25, SD = 13.74) were lower than TS scores for non-targeted activities in the second half of the treatment phase (M = 67.76, SD = 17.43). When comparing targeted activities to non-targeted activities during the

first half of treatment, the effect size was 0.57, indicating a medium treatment effect. During the second half of the treatment phase, however, the effect size of targeted activities versus non-targets was -0.04, indicating a negligible treatment effect. Together, these findings suggest that there were overall positive treatment effects and that skills that caregivers acquired during targeted activities generalized to non-targeted activities during the second half of the treatment phase. (See Table 8 for a summary of calculated effect sizes).

**Table 8. Effect sizes for Treatment and Follow-up phases**

Treatment Phase	Effect Size
Targeted activities vs. Non-targeted (All)	0.36
Targeted activities vs. Non-targeted (First half of treatment)	0.57
Targeted activities vs. Non-targeted (Second half of treatment)	-0.04

Follow-up Phase	Effect Size
Targeted activities (treatment phase) vs. All activities (Follow-up phase)	-0.12
Targeted activities (treatment phase) vs. Targeted activities (Follow-up phase)	-0.15
Non-targeted activities (treatment phase) vs. Non-targeted (Follow-up phase)	0.23

Effect size analyses were also conducted to examine our hypothesis that gains made during treatment would be maintained during follow-up. There was a slight reduction in total TS scores during the follow-up phase (M = 65.21, SD = 15.62). The effect size comparing the average follow-up score to the average treatment score, however, was -0.12, indicating that overall, gains made during the treatment phase were maintained during the follow-up phase. Thus, our hypothesis was supported. We also hypothesized that the follow-up score for targeted activities would be higher than the follow-up TS score for non-targeted activities. This hypothesis was not supported. Average follow-up TS scores for targeted activities (M = 64.77, SD = 14.53) were very similar to follow-up TS scores for non-targeted activities (M = 65.79, SD = 17.13). The effect size comparing targeted activities versus targeted follow-up activities was -0.15,

indicating maintenance of scores. The effect size comparing non-targeted activities to non-targeted follow-up activities, however, was 0.23. Caregivers actually continued to improve on non-targeted activities during the follow-up phase to the point in which their scores on targeted versus non-targeted follow-up activities were very similar. This supports the finding that caregivers skills learned in targeted activities generalized to non-targeted activities during treatment, but further, indicates that this generalization continued during follow-up.

Caregiver change in Transactional Supports by Family.   Though there were overall positive treatment effects in caregivers' acquisition of transactional supports, there was variation in each caregiver's TS scores and effect sizes (Figure 12 and Table 9).

Figure 12. Average TS scores by family
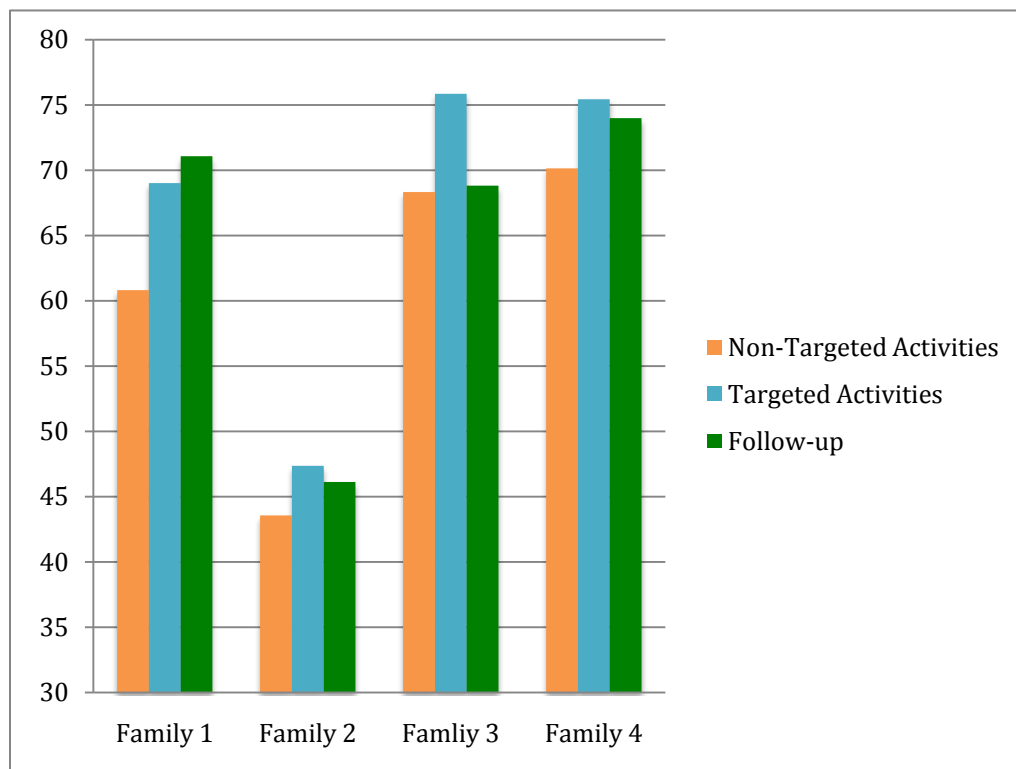
Family 1. During the treatment phase, the interventionist targeted seven different activities with Rosario and Bobby. Rosario worked on four additional activities (non-targets) without instruction from the interventionist. She mastered (i.e. met fidelity criteria of a TS score of 70 or above on three consecutive scorings) four targeted activities and no non-targeted activities. Her mean TS scores ranged from 64.34 to 75.00 for targeted activities (M = 69.02, SD = 8.94) and from 45.83 to 65.89 for non-targeted activities (M = 60.82, SD = 11.53). Her average follow-up score for targeted and non-targeted activities was 71.08 (SD = 9.85). Overall, Rosario demonstrated positive treatment effects (ES = 0.71) with generalization of strategies learned in non-targeted activities from the first half of treatment (ES = 0.97) to the second half (ES = -0.36) in the second half of the treatment phase with continued improvement in the follow-up phase (ES = 0.21).

Family 2. During the treatment phase, the interventionist targeted six different activities with Angela and Marcus. Angela worked on four additional non-targeted activities. During the course of the treatment phase, Angela did not master any targeted or non-targeted activities.   After approximately 10 treatment sessions, the interventionist made the decision to target different activities even though fidelity had not been met so that the family would experience some variation in activities targeted. Angela's mean TS scores ranged from 47.91 to 58.33 for targeted activities (M = 47.36, SD = 12.20) and from 30.00 to 50.90 for non-targeted activities (M = 43.56, SD = 11.67). Her average follow-up score for both targeted and non-targeted activities was 46.13 (SD = 11.69). Despite not having met fidelity on any activities, Angela did demonstrate overall positive treatment effects (ES = 0.32) with generalization of skills to non-targeted activities from

the first half of treatment (ES = .50) to the second half of treatment (ES = 0.002), with maintenance in the follow-up phase (ES = -0.10).

 Family 3. Eight different activities were targeted with Susan and Kyle during the treatment phase. She worked on four additional activities without interventionist instruction. Susan met fidelity on seven of the targeted activities and two of the non-targeted. Her mean TS scores ranged from 60 to 87.5 for targeted activities (M = 75.86, SD = 8.97) and from 42.5 to 82.5 for non-targeted activities (M = 68.33, SD = 10.49). Her average follow-up score for both targeted and non-targeted activities was 68.83 (SD = 12.05). Overall, Susan demonstrated positive treatment effects (ES = 0.72) with generalization and further improvement of strategies learned in non-targeted activities from the first half of treatment (ES = 1.09) to the second half (ES = 0.39). Her scores during follow-up decreased, yielding an effect size of -0.58.

 Family 4. During the treatment phase, 10 activities were targeted with Linda and Tyler and 5 activities were non-targeted. Linda mastered eight targeted activities and three non-targeted activities. Her mean TS scores ranged from 52.5 to 92.5 for targeted activities (M = 75.45, SD = 11.44) and from 45.00 to 92.5 for non-targeted activities (M = 70.15, SD = 12.33). Her average follow-up score for both targeted and non-targeted activities was 74.00 (SD = 12.58; ES = -0.12). Linda demonstrated small positive treatment effects (ES = 0.42), with significant generalization over the course of the treatment phase. Her scores in non-targeted activities increased greatly from the first half of treatment (ES = 0.95) to the second half (ES = -0.90) and were maintained during follow-up (ES = -0.12).

Table 9. Treatment effect sizes by family

	Targets vs. Non-targets (All)	Targets vs. Non-targets (1st half Tx)	Targets vs. Non-targets (2nd half Tx)	Treatment vs. Follow-up
Family 1	0.71	0.97	-0.36	0.21
Family 2	0.32	0.50	0.002	-0.10
Family 3	0.72	1.09	0.39	-0.58
Family 4	0.42	0.95	-0.90	-0.12

Relationship between TS scores, treatment attendance and adherence. Contrary to expectations, the number of session cancellations was positively correlated with the amount of engaged time (r(3)=.86, p<.05). The family with the most cancellations (Family 3), was the also the one in which the caregiver reported the highest number of hours of engaged time spent in activities outside of sessions. Conversely, the family with the least amount of cancellations (Family 2) reported the lowest amount of engaged time. As hypothesized, the relationship between engaged time and TS score was positively correlated, but not significant (r(3)=.88, p = .118). As the amount of engaged time increased, caregivers TS scores tended to be higher.

Caregiver reported change in family context. Caregivers demonstrated changes in their perception of the impact of their child on family life. During the course of the intervention, perceived negative impact decreased for each caregiver, with the exception of Caregiver 3, who reported her child had no negative impact at both the initial and follow-up appointments (Figure 13). Overall, negative impact decreased across each assessment (Initial: M = 0.65, SD = 0.55; Post-Treatment: M = 0.54, SD = 0.51; Follow-up: M = 0.50, SD = 0.49). The effect sizes between the initial assessment and post-treatment and the initial assessment and follow-up were -0.20 and -0.27, respectively.

Perceived positive impact increased for each family, with the exception of Caregiver 2, who reported a decrease in positive impact (Figure 14). The mean level of positive impact increased across each assessment (Initial: $M = 1.52$, $SD = 0.38$; Post-Treatment: $M = 1.60$, $SD = 0.59$; Follow-up: $M = 1.79$, $SD = 0.48$) with an effect size of 0.21 between the initial assessment and post-treatment and 0.71 between the initial assessment and follow-up.

Figure 13. Perceived negative impact over time
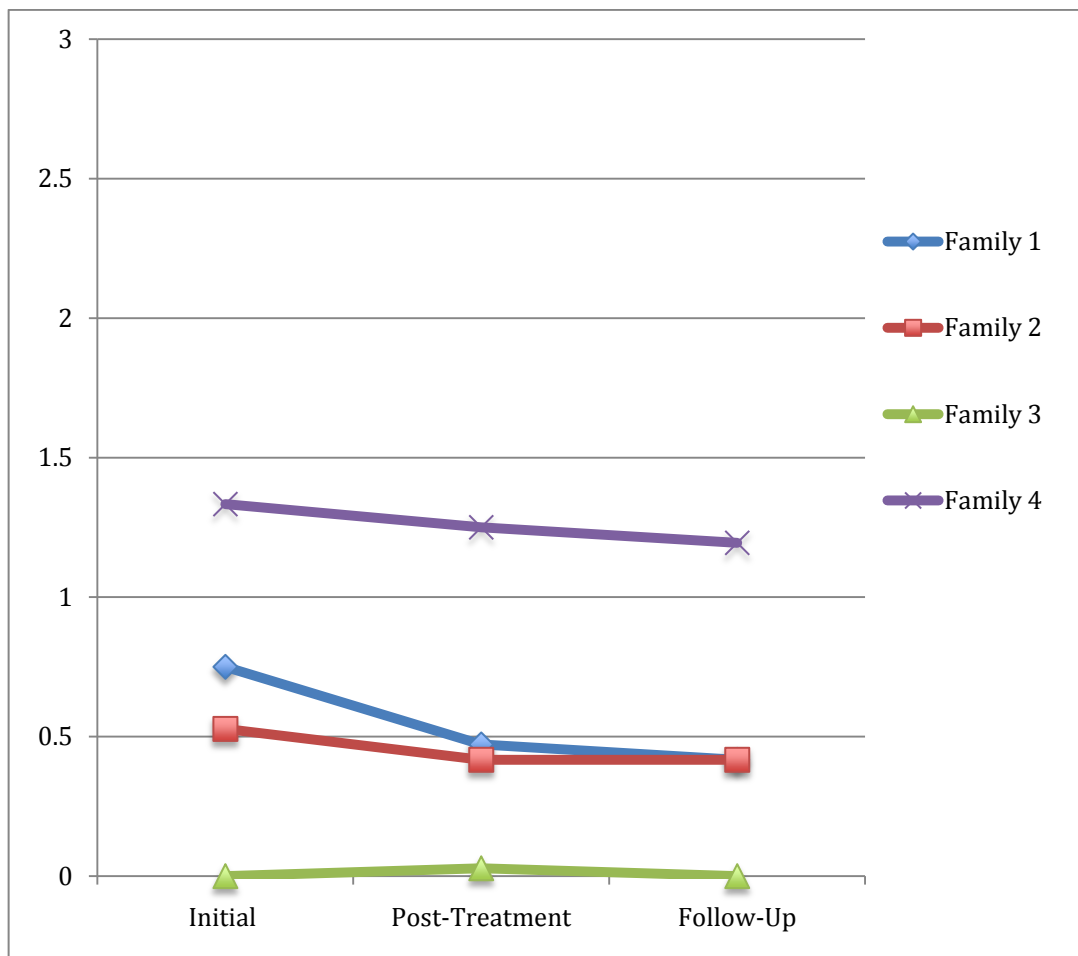
Figure 14. Perceived positive impact over time
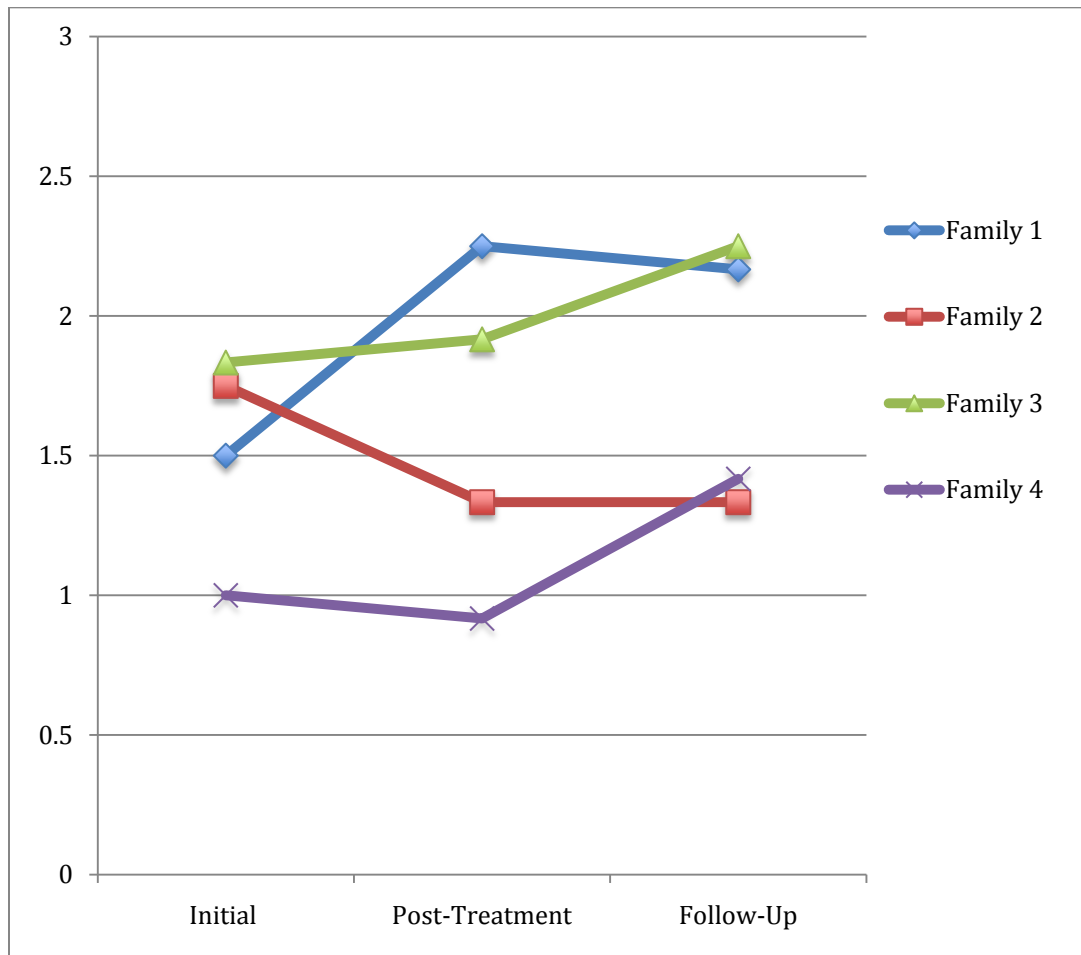
Caregivers' responses on the Family Support Scale at the follow-up appointment were reflective of changes in the type and amount of utilized supports (Tables 10 and 11). All four families reported utilizing a professional form of support, including an early intervention or school program. Furthermore, all four families rated support from these sources as being helpful. The changes in forms of support reported were expected, as establishing these connections was a component of the ESI-CO intervention. During the course of each family's involvement in the project, each family was enrolled in at least three new forms of support resources (Table 12).

Table 10. Use of forms of social support reported at follow-up assessment

Source of Support	Every Day	Once per Week	Once per Month	Very Rarely, or never
Parents	1,3,4			2
Partner's Parents	1,4	3		2
Relatives	1	3	4	2
Partner's Relatives	1			2,3,4
Partner	1,4			2,3
Friends	3	1	4	2
Partner's Friends		1	4	2,3
Own Children				1,2,4
Co-Workers		1		2,3,4
Parent's Groups			1	2,3,4
Social groups/clubs				1,2,3,4
Religious Organizations			3	1,2,4
General Practitioner			1,2,3	4
Early Intervention Program	1	4		2
School	1,2,3	4		
Professional Support			1,2	3,4
Statutory Services				

Table 11. Helpfulness of forms of social support reported at follow-up assessment

Source of Support	Very helpful	Sometimes helpful	Not at all helpful	Not available
Parents	1,3,4		2	
Partner's Parents	1,3,4		2	
Relatives	1,3	4	2	
Partner's Relatives	1		2,4	3
Partner	1		2,4	3
Friends	3		1,2,4	
Partner's Friends			1,2,4	3
Own Children	3	2		1,4
Co-Workers		1,2,4		3
Parent's Groups			1,2,4	3
Social groups/clubs			2	1,4
Religious Organizations			2	1,4
General Practitioner			2	1,4
Early Intervention Program		2	1	4
School	1			4
Professional Support	1,3	2,4		
Statutory Services	2,3	4		1

Table 12. Resources added during participation in ESI-CO
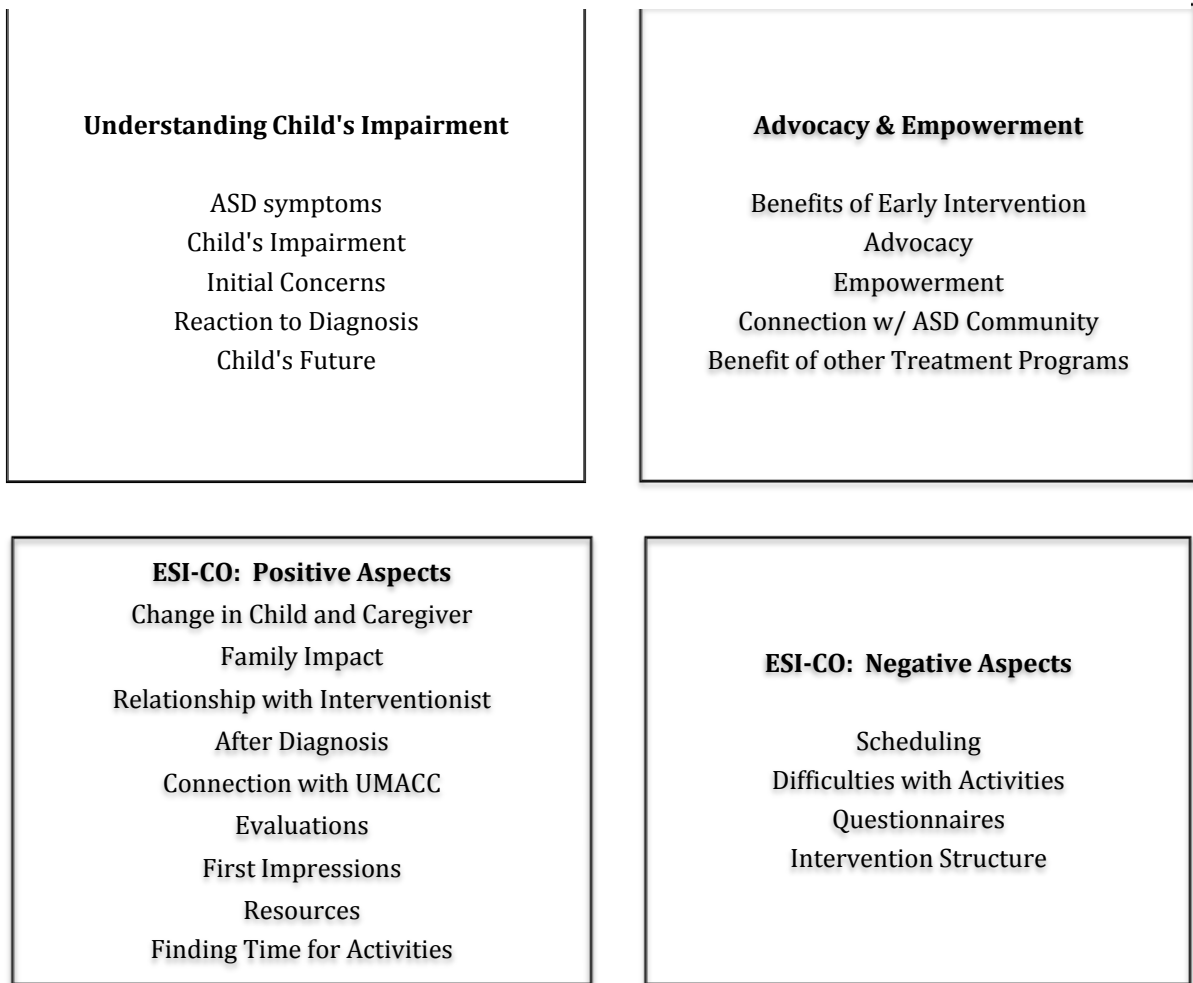
Family 1	Family 2	Family 3	Family 4
• Enrolled in special education • Supplemental Security Income • Michigan Family Support Subsidy • Participation in monthly parent support group	• Enrolled in special education • Michigan Family Support Subsidy • Supplemental Security Income	• Enrolled in special education • Referral to feeding specialist • Michigan Family Support Subsidy	• Increase in number of hours special education services received • Supplemental Security Income • Referral to behavioral aide

Qualitative Results

ESI-CO Exit Interview. All four caregivers participated in the exit interview.

Each interview took place in their homes, before the last parent fidelity meeting. Three

of the interviews (Susan, Angela, and Linda) were conducted by a research assistant who

had worked on the project since its beginning. She had videotaped each of the families

on a semi-regular basis. The other interview (Rosario) was completed by an ESI-CO

interventionist. She had conducted one treatment session with Rosario and Bobby when

their interventionist was out of town and had videotaped them several times.

The length of the interviews ranged from 10 to 25 minutes. Overall, each

caregiver described a positive experience with ESI-CO. A total of 23 codes were

identified and categorized into four themes: Understanding Child's Impairment,

Advocacy and Empowerment, ESI-CO Negative Aspects, and ESI-CO: Positive Aspects

(Figure 15).

Figure 15. ESI-CO Exit Interview themes and codes

Understanding Child's Impairment ASD symptoms Child's Impairment Initial Concerns Reaction to Diagnosis Child's Future	**Advocacy & Empowerment** Benefits of Early Intervention Advocacy Empowerment Connection w/ ASD Community Benefit of other Treatment Programs
ESI-CO: Positive Aspects Change in Child and Caregiver Family Impact Relationship with Interventionist After Diagnosis Connection with UMACC Evaluations First Impressions Resources Finding Time for Activities	**ESI-CO: Negative Aspects** Scheduling Difficulties with Activities Questionnaires Intervention Structure

Understanding Child's Impairment. A strong theme that emerged was an understanding of the children's impairment that included acknowledging features of ASD (i.e. insistence on routine, decreased social engagement, etc.) When describing Marcus at the beginning of treatment, Angela commented, "Yeah, he would shut me out. Or anybody for that matter." Rosario described recognizing Bobby's insistence on routine:

> He wasn't down on a schedule, now he is. I wake up in the morning, I take dad to work,
> you know. I get breakfast, like we, every day we have McDonalds before school and
> after school, because if we don't, like, he will have a bad day. And like, last week we
> tried not to get him fries after school and it was just terrible. He cried and he cried and
> it's like, you know, like they say, its part of the routine. He's used to get fries every day
> so that's what he looks for… (Rosario)

Several caregivers commented on how their perspectives of their child had changed. For example, moving from thinking of the child as one who acts out or is deliberately disruptive to one who requires more time and patience to be able to understand his environment. "Instead of being like, oh, he's a brat, being like, oh no, he just needs extra time…" Understanding language level was also something several caregivers commented on. For Linda, whose child's language increased dramatically during the intervention, a key understanding was adjusting her language to his level. Even though she knew he could understand most of what was said to him, to increase his expressive language, it was important for her to adjust hers.

> She taught me like when we first started he was only saying a couple words. And a lot of times he understood what we would say but to get him to try to she taught me, ya know, start off with like two words, ya know? Instead of saying a whole sentence to him like "Tyler, go get the ball" "get ball," ya know?

For Angela, a theme of treatment was learning the heterogeneity of the autism spectrum. Marcus had a female cousin who also had ASD, yet Angela often commented how he differed from her. Once he started preschool, she noted that he was one of the only children who could talk. Understanding the "different forms that it comes in" seemed central to her formulation of goals and expectations for Marcus. Even though she acknowledged his "delay," she made a conscious decision to not treat him differently from his other siblings.

> I try to be normal with him-- pretty much how I do everything with him, uh-huh. I think --I think that's why even he does so well. I don't teach him anything like he's slow. Sometimes you just have to thoroughly explain to him to not get lost. (Angela)

The evaluations also contributed to caregivers' understanding of their child. For Rosario, this meant understanding the extent to which Bobby's cognitive skills were impaired.

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Very helpful because it broke down, like, where his cognitive level was. You know where he is, you know, as a three year old compared to, you know, other three-year olds. It's funny to see, you know, he may be three, but his brain is at like 15 months. And that's crazy to think, you know? Okay my child is three but how can his brain be that far behind? And it's just crazy how you guys put that into perspective for us…

Advocacy and Empowerment. Linda and Rosario described taking ownership in getting their children help while they were young and in making decisions about what was important to focus on in their child's treatment.

Well yeah and got him even more help and the more help that I got him the more I think he came along. And I read that it's better if you find out and get your child help when they're young because they can actually they may have signs of it at all time but they can be live to be productive normal people. (Linda)

For the most part we did, but then there were some days where, certain areas, that's what we worked on, like puzzles, or books. We were like, he's getting everything else, let's focus on these two things because, he's still not getting them. But most days we did everything, except for those days when you know, we wanted to focus on the puzzles or the books, which were his two main issues. (Rosario)

Rosario, in particular, developed a strong sense of autism advocacy, becoming committed to spreading knowledge and awareness.

Oh, definitely, I mean I try to like get awareness out as much as I can cause I know what it is, I know more about it you know. Plus having a kid on the spectrum, you know, it helps me when I see a kid in the store who I would have normally thought, oh that kid's a brat, you know, that mom can't control it. When I see the signs of autism, or special needs I can honestly be like, okay that mom may need some help or whatever. So it's made me aware and I am always talking about it at work and explaining what it is you know. And I carry around that 100 days, you know that first 100 days that you guys gave us when you first came? Because like people will ask me questions and I'm like okay, hold on let me make sure I'm giving you the right information because you know, people don't want to get the wrong knowledge, like, you know. I'm just helping get awareness out now and before I'm like, I wouldn't even know, you know, what it was. Now I'm like, "oh did you know?" And they're like "shut up, Rosario" and I'm like, you know, but, I want to get awareness out there.

The desire to educate others about autism was instilled in her fiancé as well:

Dad was in denial before and now dad's like "my son has autism you know, don't stare, if you have any questions ask me". He's more patient too and more understanding because before he was like "why do parents look at us", you know, and now he's kind of feeling a little bit okay, you know, "if you want to stare I can tell you my son has autism".

ESI-CO: Negative Aspects. Two subthemes seemed to fit within the theme of

negative aspects: Difficulties with the structure of the intervention and difficulties

engaging the children. When describing how she felt about having ESI-CO team

members visit three times per week (twice for treatment, once for taping a parent fidelity)

Angela commented, "Um, [it was a] little tedious at first but that's fine." Linda

acknowledged difficulty scheduling around her work schedule, saying "If I was not

working at all it probably would have been a lot easier, ya know…there were times when

you guys had to come out really late." For all of the families, cancellations due to illness

were common. As Angela said, "Between those and a toothache or somethin'—

somethin' got in the way."

The format of home intervention had its advantages and disadvantages. Susan

appreciated having treatment in her home, saying "Yeah I liked just knowing that you can

have someone in your home to help you. In your setting not…in a building or wherever

but. It's more in your home." Rosario, who spoke very positively about home

intervention, admitted that initially, she worried about feeling judged.

> I think the first couple of times it was kind of scary cause you're like "wait, what does
> this person think of me," you know, "are they going to judge me," you know?

In comparison to the follow-up phase in which the interventionist only visited once per

month, however, Rosario preferred the weekly visits.

> The once a month or twice a month, you know, she'd come we'd be like, "man I forgot
> what I was going to ask her." You just had so much to like, to give her that we had half
> the session just spent talking when you know we were supposed to be working with
> Bobby but yeah, I think I liked the two times a week more.

Each caregiver was asked to complete a plethora of questionnaires throughout the

intervention. Caregivers were explicitly asked how they felt about this requirement.

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Though they were all in agreement that the questionnaires were time consuming, there was recognition of their purpose.

> They were long. I didn't mind doing 'em but they were long. It was just long and I knew why I had to do it. Um and I knew why it was so long. I mean if anyone saw the questionnaire they would understand that it is complex but it's for a good cause…(Linda)

For Rosario, completing long questionnaires was part of being a parent of a child with special needs and she seemed somewhat resigned to their necessity.

> I think it's just something you have to do. Like, it's not any more than going to a doctor's office. I didn't have a problem with it, I mean…with my son having autism spectrum disorder, there's tons of paperwork to fill out, like weekly, so, it's just like something you do.

Beyond the structure of the intervention, the caregivers often commented on how aspects of their child's impairment or behavior impeded progress during activities. For Linda, whose child was able to engage in flexible symbolic play, it was difficult to limit him to the prescribed activities. "[It was] challenging to get him to actually do the uh ones that he's supposed to be doing for the tapings. You know what I'm saying?" Tyler was also experiencing significant difficulties sleeping through the night during the course of the intervention, resulting in crankiness or extreme tiredness when she tried to engage him. For Susan, she perceived his repetitive interests as challenging, telling the interviewer, "It's hard to get him to sit for that long and do blocks. Besides, he likes to line them up and play different."

ESI-CO: Positive Aspects. For all of the caregivers, participation in ESI-CO provided benefits of knowing what steps to take after receiving a diagnosis, positively changing their behaviors as caregivers, and seeing change in their children. For Susan, it was meaningful to receive a diagnosis and to figure out "where to go from there and establishing schools and everything that he needs." For Rosario, being involved in the

intervention provided concrete steps to take during a time when she felt unsure of how to

proceed.

> As a parent with a son on the aut-, you know, on the spectrum, I didn't know where to start, where to begin, and like, I came to you guys, and like you guys, told us, this is what you do from here on out…

For Linda, receiving Tyler's diagnosis was the end of a period of having concerns about

her son's development, but not receiving any concrete answers.

> It didn't bother me to drive all the way out there to find out what I did. Um and like I said if –if I wouldn't have done it, he might not be here –I mean where he is today.   You know what I mean? Because I may still be here sitting going "Oh my God what is wrong with my son?"

All of the caregivers noted changes in their child's behavior and ability, from

increased communication ("he's got a lot more eye contact, a lot more communication,

like verbally and non") to ease in adjusting to unexpected situations ("He's become—

he's more like with the transitions and going into things). Angela and Rosario described

change in their children across multiple domains:

> He talks--talks a lot more. More open as far as uh he used to just sit there. Now he's more of a runner. He runs around a whole lot. A lot! He's always in something. Way more curious. Uh huh way more curious as far as him uh I think um probably because he's communicates with us more too. So he's not so cautious about like you know like how he used to act. (Angela)

> I think before he was out of control, like we didn't know how to do anything with him other than like, pretty much yell at him and be like, hot-tempered with him and now we're like "okay Bobby let's go outside" and we can reach out our hand and he knows, like, "let's go." It's just helped *so* much, it's just changed, like before he couldn't eat with a spoon, now he eats yogurt, mac n' cheese, he can feed himself, like the things he can do now from last summer, like, I never thought he would get the puzzle and now all the sudden…aw, man, he does puzzles all day, at school, at home, he can read, like he can flip the pages of the book, you know things that he wasn't doing before, he would try it and then get frustrated, and now he's not freakin' out so much. It's really, really great. (Rosario)

For Linda, the change in her son was not just a result of ESI-CO, but also the

other services she obtained for Tyler. As she told the interviewer, "Tyler's come a long

way. And not just because of you guys but now I got him more therapy but he's come a

long way." For Rosario, receiving assistance enrolling Bobby in the Special Education

Program played a significant role in his improvement:

> And school, I think has helped a lot too. That was really good for Themba to help push getting Bobby in at the school cause like now he's going to go to school like, all summer...Oh definitely, cause like we were so worried, like, what's he going to do over the summer, but he's going to be in the extended school year program…

Each caregiver also noted changes in themselves and their families. Linda and

Rosario commented on increases in their patience and understanding, while Angela

commented on a shift in the family's confidence in approaching Marcus:

> I approach him more. Actually all of us do now. Cause we didn't know how to talk with him-- nobody knew how to talk to him at all.

Susan, in particular, embraced altering her behavior to encourage Kyle to communicate:

> Um I more or less give him the opportunity to tell me something before I just jump to it. I'm more relaxed and laid back whereas everyone else is rushed and trying to get it for him. I let him tell me kind of instead of just getting it. I have a lot more information now and I have a lot more skills whereas I didn't have any --I mean not as much as I do now.

Overall, each caregiver described positive changes in themselves, their children,

and their families.

Chapter 7: Discussion

Parent-mediated models of intervention for young children with ASD are gaining traction in the field, but few have focused on the implementation of such programs in families who are underserved (i.e. families with low incomes, limited education, or ethnic minority backgrounds). While some studies examining the efficacy of parent-mediated models have included changes in the parents' behavior as primary outcome measures (Carter et al., 2011; McConachie et al., 2005; Green et al., 2010), most have focused on changes in the child (Schertz & Odom, 2007; Kasari et al., 2010). Few, if any, have specifically focused on the environmental context of each family, particularly the effectiveness of early intervention programs in families with limited resources (low income and limited education). This dissertation presented the development and implementation of an early intervention program for families with limited resources. The focus was on two main factors: the effectiveness of the program in promoting positive change in caregivers and families of children with ASD and the effectiveness of the program in recruiting and retaining families in the intervention protocol.

Effectiveness of the ESI-CO program in promoting positive change.

A goal of the ESI-CO project was to promote positive change in participating families by 1) teaching caregivers strategies in which to facilitate their child's social and communicative development and encouraging them to embed those strategies into every day routines and activities, 2) increase caregivers' understanding of ASD; and 3)

assisting families to identify and enroll in any autism resources for which they were eligible.

Caregivers' Acquisition and Application of Transactional Supports. In ESI-CO, interventionists instructed caregivers how to use specific techniques referred to as transactional supports (e.g. establishing predictable routines, modeling appropriate language, pausing to create opportunities for communication) to increase their child's social engagement and communication. Caregivers selected eight activities to work with their child, but only received interventionist instruction on four of the activities at a time. A multiple baseline procedure was utilized to compare the effect of the interventionists' instruction on the caregivers' acquisition and application of the techniques in targeted activities versus activities in which no instruction was provided (non-targeted activities). Caregivers were observed each week engaging their child in activities and were rated on the degree to which they utilized transactional supports. Results showed that caregivers demonstrated greater use of transactional supports during targeted activities than non-targeted activities. However, as predicted, the difference between caregivers' behavior in targeted and non-targeted activities decreased as treatment progressed. During the second half of the treatment phase, caregivers demonstrated higher application of transactional supports in non-targeted activities as well as targeted activities, indicating that skills learned with the interventionist generalized to activities in which the interventionist had provided no instruction. Furthermore, the use of transactional supports extended beyond the treatment phase and into the follow-up phase. Caregivers' use of transactional supports during the follow-up phase were maintained up to three months after the completion of treatment. Overall, these findings demonstrate that the

intervention was effective in teaching caregivers new strategies for promoting their child's social and communicative skills. The small sample prevents us from going beyond description of these results to statements about statistical significance, but the magnitudes of effect sizes for changes in caregivers' behavior were consistent with those reported in other parent-mediated interventions that have demonstrated success in teaching parents to facilitate interactions with their children (Carter et al., 2011; McConachie, et al., 2005; Green et al., 2010).

For parent-mediated models to be effective, caregivers must go beyond the acquisition of facilitative strategies and also embed them into every day activities and routines with their children. The caregivers in the ESI-CO project not only demonstrated the ability to learn transactional supports, but also reported incorporating them into their daily lives. Treatment adherence, as measured by the number of hours caregivers reported engaging their child in routines and activities each week (i.e. engaged time), was approximately 14 hours across all families. Prior to intervention, none of the caregivers reported their child receiving more than five hours per week of autism intervention. Thus, the receipt of 14 hours of parent-mediated intervention per week was a significant increase.

Examining the reported hours of engaged time by activity category, caregivers spent the greatest amount of time engaging their child in Play with Toys and spent the least amount of time engaged in Family Chores. The rationale for including Family Chores as potential activities in which caregivers can facilitate social communication is that these are activities that occur regularly in a family's daily life. Based on the report of the caregivers in ESI-CO, however, incorporating their children into daily chores was not

preferred. Involving children in all domains of daily life may be harder for families than expected. Particularly in activities in which having a child "help" prevents them from being completed efficiently.

It was hypothesized that greater caregiver adherence (i.e. greater amounts of engaged time in activities) would be related to greater acquisition of transactional supports across activities. Though not significantly related statistically, adherence and acquisition of transactional supports were positively correlated. The caregivers with greater adherence (Susan, Family 3 and Linda, Family 4) received the highest average TS scores across activities. Rosario (Family 1), who received the third highest TS score reported spending fewer hours of engaged time than Susan and Linda, but still twice as many as Angela (Family 2). Angela's TS scores never reached fidelity. These results may suggest that time spent "practicing" embedding transactional supports into daily routines and activities with one's child increases mastery of such skills.   There are many factors, however, that may affect a caregivers' level of adherence to treatment strategies, including employment status and schedule, psychological well-being, number of other children in the family, and the degree to which the caregiver thinks the strategies are helpful (Ingoldsby, 2010; Nock & Ferriter, 2005). With a larger sample, the degree to which these factors may have influenced caregiver's mastery of transactional supports within activities of the ESI-CO project may be examined.

Caregivers' Understanding of ASD: Perception of Child. The degree to which caregivers view how caring for a child with ASD affects their family has received attention in the field (Bishop et al., 2007; Carr & Lord, under review; Barker, Hartley, Seltzer, Floyd, Greenberg, & Orsmond, 2011), particularly regarding the overall

construct of caregiver well-being. Caregivers of children with ASD often report lower

levels of well-being than caregivers of children with other disabilities (Abbeduto, Seltzer,

Shattuck, Krauss, Orsmond, & Murphy, 2004). Thus it is important to examine whether

different constructs of well-being are affected by intervention. In the present study,

caregivers' perception of the child's negative and positive impact on the family was

measured at each assessment. Perceived negative impact decreased during the treatment

for each caregiver, with the exception of Susan, who reported that Kyle had no negative

impact on domains of family life at both the initial and follow-up assessment. Perceived

positive impact increased for each caregiver, except for Angela, who reported a decrease

in the positive impact Marcus had on her family. Overall, the average level of negative

impact decreased across caregivers while the average level of reported positive impact

increased. A larger sample would be required to determine statistically if these changes

in impact were significant. The magnitudes of effect size corresponding to the decrease

in negative impact was small, suggesting that for these families, the change was not

meaningful. The magnitude of effect size of the increasing trend in positive impact,

however, was large, suggesting clinical significance (Hill, Bloom, Black, & Lipsey,

2008). This converges with the qualitative results, in which each caregiver reported

improvements in their child's behavior and level of impairment as a result of the

intervention.

  <u>Identification of and Enrollment in Autism Resources.</u> During the treatment and

follow-up phases, interventionists assisted families to identify and enroll in any

appropriate autism resources for which they were eligible. Support provided was

informational (i.e. informing families of the programs that were available), logistical (i.e.

placing phone calls and sending emails to providers who were difficult to reach, helping to complete applications, photocopying reports), and collaborative (i.e. serving as the liaison between providers and caregivers, attending Individual Education Plan meetings). As a result of support provided by the interventionists, each family was enrolled in at least three additional programs from what they reported at the initial assessment. For two families, this resulted in an increase in the number of hours of Part C-funded intervention. For the other two families, this resulted in enrollment in Part B-funded Special Education preschool classrooms. Additionally, all families were assisted in applying to Social Security Disability Insurance and the Michigan Family Support Subsidy, a program providing financial assistance to families of children with severe developmental disabilities. In addition to the tangible addition of these services, the assistance interventionists provided also gave caregivers a sense of support and advocacy. As one caregiver commented as she expressed frustration over communication difficulties with a local service providing ASD services, "I knew you guys [UMACC] had my back. You're my people!"

Participation in ESI-CO project also represented an increase in intervention services from what families reported receiving prior to the onset of treatment. Through ESI-CO, interventionists provided more intense, and autism-specific care than what is typically available through Part C-funded agencies. In the state of Michigan, Early On providers are limited to identifying children as developmentally delayed or language delayed and cannot provide a diagnosis of ASD. While this is for the protection of families who are in need of expert guidance, it leaves families in a state of decreased understanding of how their child is affected by the disorder or what specifically they

should do to intervene. For several of the ESI-CO caregivers, receiving an official ASD

diagnosis at the UMACC clinic and "knowing what steps to take" after the diagnosis,

were valued aspects of the intervention program. The ESI-CO interventionists were also

able to serve as liaisons between the Part C and B agencies and caregivers, helping

families to navigate a system that can be very confusing.

Other aspects of the ESI-CO model that caregivers noted as benefits of the

program were the home visit format and the experience of working individually with an

interventionist. Though some of the caregivers reported initially feeling anxious or

uncomfortable having ESI-CO staff in their home, home visits became a valued

component. For some parents, the benefit was practical, as it precluded the necessity of

making travel arrangements and limited travel expenses. For other parents, the benefit

was personal, in that they perceived their child to benefit from the experience of having

visitors at home and the relationship between caregiver and interventionists developed to

the point of feeling as if the interventionist were "one of the family." Caregivers also

mentioned the benefit of learning skills and new activities in which to engage their child.

Effectiveness of the ESI-CO Project in Recruiting and Retaining Participants.

The ESI-CO project was successful in enrolling eight families into the

intervention. The sample recruited was notably different from those traditionally

included in the autism literature. Most intervention studies include highly selected

samples of families, with the majority of the families from white, upper middle class

background with higher education levels (Lord, et al., 2005). In ESI-CO, the majority of

the caregivers were high school graduates with no more than several college credits.

Family incomes were close to the federal poverty line.

Specific strategies to increase participant retention and decrease attrition were implemented over the course of the intervention. Our attrition rate of 38% was higher than what is commonly reported in autism intervention literature (Carter et al., 2011; Dawson et al., 2010; Green et al., 2010; Kasari et al., 2010) but lower than what has been reported in non-autism specific interventions serving low-income populations (Fox & Holt, 2009; Lyon & Budd, 2010). We hypothesized that families would be more likely to discontinue participation during the baseline phase of the project before they began intervention. As expected, all families who discontinued (with the exception of the family withdrawn by us during the treatment phase) left prior to or during baseline. These families did not differ from the families who continued to participate in their access to resources before treatment, age, education level, or income so we cannot infer that differences in family characteristics contributed to their decision to discontinue. The family who left prior to the first baseline visit reported her child had been accepted into an alternative intensive therapy program. The remaining three families discontinued after one or two baseline visits. We hypothesize that the experience of having to wait two to four weeks for the onset of treatment negatively impacted these families' likelihood to initiate and complete intervention. Upon agreeing to participate, the families may have anticipated immediate support and intervention, but experienced disappointment after treatment was delayed. Alternatively, the experience of being videotaped without receiving any instruction of feedback may also have been a negative experience. Both of these possibilities have implications for research and community-based interventions. Research projects requiring longer baselines or participation in a control condition may result in higher rates of attrition from families in need of immediate assistance.

Similarly, community-based programs in which treatment waitlists are a necessity may lose families who are in great need of care. In populations in which health services are underutilized, such as families who are economically disadvantaged (Mandell, Ittenback, Levy, & Pinto-Martin, 2007), it may be especially important to implement treatment as soon as possible to avoid losing families less likely to seek out services again in the future.

With the design and the small sample size of the present study, it is not possible to determine causality in whether the low attrition rate is the result of our implementation of strategies to increase intervention participation. However, a discussion of the possible role of such strategies in contributing to our high retention is warranted. One of the strengths of our project was the presence of a strong referral system. The ESI-CO project benefitted from having a relationship with a developmental pediatrician whose clinic was located in a region with higher percentages of families with low-income and limited education. She was also well-informed about ASD and had a team committed to helping patients access autism-specific services. The developmental pediatrician also coordinated with local Early On coordinators to inform them of the availability of ESI-CO. As a result, eight of the 14 families scheduled for an initial assessment were joint referrals from the developmental pediatrician and local Early On coordinator. The collaboration with these professionals also extended beyond the referral process. For several of the families, continued communication between ESI-CO interventionists, Early On, and the pediatrician facilitated greater coordination of care which resulted in more efficient enrollment in autism resources such as the special education program.

Referrals from the developmental pediatrician also resulted in children being identified at risk for ASD at young ages. In recognition that children from underserved populations are often not diagnosed with ASD until school-age (Mandell, Listerud, Levy, & Pinto-Martin, 2002), we had expanded our age eligibility up to four years old, which is significantly higher than most early intervention programs. Despite this expansion, the average age of children referred was 29 months.

The effectiveness of our referral system highlights the importance of strong collaborations between general health clinics and those specializing in ASD. The provision of autism diagnostic and intervention services for young children is best undertaken by clinicians who are specifically trained in ASD (Carr & Lord, 2009), but these individuals are not always available at primary care clinics where families from underserved populations are most likely to first access the health care system. Non-subspecialist physicians are not often trained, nor do they have the time, to conduct the comprehensive diagnostic evaluations typically provided through specialized autism clinics. The administration of autism-specific screening tools by physicians during regularly scheduled health care maintenance visits physical check-ups is promoted by the American Academy of Pediatrics (Boyd et al., 2010) and can flag children who are at-risk for a diagnosis of ASD. Collaborations between physicians and clinics specializing in ASD can result in children being identified at-risk through their primary care physicians, and then quickly referred for in-depth comprehensive evaluations by individuals with expertise in diagnosing and treating ASD.   This system worked well for many of the ESI-CO families, in which referrals from primary care physicians to a developmental pediatrician resulted in them being sent to UMACC for in-depth evaluation and

intervention participation.   In many clinics, however, children are not regularly referred for further assessment at autism clinics. Future studies addressing factors that increase a physician's likelihood of referring children on for follow-up assessments and treatment would be helpful.

Though not specifically mentioned by the caregivers, there were other aspects of the project design that from the interventionists' perspectives, were integral to participant retention. The implementation of a liberal cancellation policy enabled interventionists to continue seeing families after numerous schedule changes. Treatment session cancellations occurred frequently, but it was the interventionists' opinion that the high rate of cancellations was in response to legitimate family stressors, rather than a reflection of not wanting to participate. Interventionists also did not require that caregivers engage their child for 25 hours per week, as is required of the ESI project. This was realistic for the caregivers, who completed an average of 14 hours of engaged time per week. It was also less stressful for the interventionists, who did not feel pressured to cajole or chastise their families for not meeting weekly goals.

The shortening of proposed treatment duration from nine months to three months also seemed to ease the pressure on participating families. Though they were appreciative of the weekly treatment sessions, several caregivers indicated looking forward to a schedule that was less demanding to maintain. The provision of bi-weekly treatment sessions over the course of three months is similar in frequency and duration to what has been implemented in several other parent-mediated interventions (Carter et al., 2011; Kasari et al., 2010; Schertz & Odom, 2007), but questions remain regarding ideal dissemination schedule. Our results demonstrate that caregivers acquired and began to

generalize strategies learned halfway through the treatment phase, after approximately 14 treatment sessions. In some respects, this may support an argument for even shorter duration of treatment, but we feel 24 sessions over three months should be the minimum frequency and duration. Overall, caregivers demonstrated quick acquisition of skills, but most did not reach levels of fidelity across activities (i.e. TS score of 70% or above) until after the first 14 sessions. For caregivers who never achieved mastery on particular activities, greater magnitude of skills acquisition may have occurred with longer treatment duration. It is also important to note that regardless of whether a caregiver meets fidelity, goals and objectives for activities change and become more complex over time as the child develops skills and flexibility and caregivers benefit from the instruction of the interventionist in identifying new directions for each activity. In the ESI-CO project, the interventionists would have welcomed more time to work with each caregiver to be able to target a broader depth of objectives. From the caregiver's perspective, however, it seems that 24 bi-weekly treatment sessions spanned an appropriate and feasible amount of time.

Limitations of intervention.

Despite the effectiveness of the ESI-CO intervention model in recruiting and retaining families from an underserved population, there were limitations to the research design and intervention protocol. All of the families were able to participate in the 24 scheduled treatment sessions, but the time it took them to do so was much longer than anticipated. In what was designed to be a seven-month study, the length of time to complete the project ranged from 9 to 10 months. The liberal cancellation policy helped to keep families involved, but such a policy may not be sustainable for research projects

or agencies with limited time or financial resources. It is also unknown whether caregivers' progress in the program was impeded by the frequency of cancellations. With fewer interruptions in treatment delivery, they may have progressed more quickly, or in greater magnitude.

As mentioned above, the ESI-CO caregiver with the highest number of cancellations demonstrated the greatest treatment adherence, while the caregiver with the lowest number of cancellations demonstrated the least. The contrast between these two families speaks to the importance of redefining our constructs of treatment engagement and attendance. To assume that lack of attendance is a proxy for lower commitment to treatment goals may be a disservice to families who are dedicated to participating, but limited by daily stressors. In doing so, agency policies dictating that clients are not allowed to continue if sessions are cancelled frequently may be inadvertently withholding treatment from those who want it the most. Conversely, it may be detrimental to view *lack* of cancellation as a proxy for treatment engagement. Families who adhere to treatment schedules despite being less invested in the treatment model may actually feel disempowered to request that treatment stop. The use of record logs to chart what families are doing at home between treatment sessions may serve as a better method for measure family commitment and adherence to a treatment program.

While certain aspects of the research and intervention design were structured to increase methodological rigor, there were times when the research structure interfered with the clinical judgment of the interventionists.   Perhaps the greatest way in which the research protocol conflicted with clinical practice was in the application of the multiple baseline design. The multiple baseline format was chosen over randomized controlled or

single subject research designs due to lack of sufficient funds to sustain two treatment conditions and the desire to prevent families from having to wait for the onset of treatment services. Despite this, the multiple baseline design still required that families spend two to four weeks participating in baseline observations before treatment begun. As mentioned above, the delay in treatment onset may have contributed to participant attrition during the baseline phase.

Shifting baselines by activity afforded the opportunity to measure experimental causality but it was also confusing for interventionists to implement and maintain. Furthermore, requiring families to participate in eight weekly activities during video observations was reported as trying for caregivers who found it difficult to sustain their child's engagement for the required hour or more. The format of having targeted and non-targeted activities also limited the interventionists to providing instruction only in those activities that were targeted. When caregivers had questions that were relevant to non-targeted activities, interventionists were limited in their responses. This created an environment in which the interventionists felt they could not offer guidance in the activities in which the child and caregiver required the most assistance.

Mastery of targeted activities in the ESI-CO project was determined by caregivers' scores on the Measure of Transactional Supports (TS). This measure was created by the developers of the ESI model to detect change in caregivers' use of facilitative strategies relevant to the core objectives of ESI and its psychometric properties have not yet been well-established. Inter-rater reliability on the TS for the present study was not high, but within an acceptable range. Item analyses to determine which TS items best capture caregiver change and result in optimal consistency among

90

raters will be important to conduct to provide further validation of the TS as outcome measure.

The exploratory nature of the ESI-CO project prompted researchers to disseminate a large number of research questionnaires and interviews to provide as much information as possible about a population that receives little recognition in the research field. The multitude of questionnaires, however, was difficult for caregivers to maintain and resulted in a significant amount of missing data. The ESI-CO project would have benefitted from finding a balance between addressing multiple research questions and reducing research requirements to ensure that the experience was not overburdening for participating caregivers. Providing caregivers with incentives for completing questionnaires may have also been a useful strategy for increasing rates of questionnaire completion. Moving forward, the continued collection of qualitative data will inform the development of more specific research questions and streamline the number of quantitative measures included.

Future Directions of ESI-CO.

Despite some of the disadvantages of the design and methods of the ESI-CO intervention model, the present study yields promising preliminary results in the ability of the model to promote positive change in families from underserved populations. To aid in the goal of continuing to study the effectiveness of early intervention programs in families from this population, the most important next step in the research paradigm is to recruit a larger participant sample. Doing so will afford more options for experimental design and more opportunities to examine predictors of positive change. It will also

enable us to examine statistically how environmental and family contexts contribute to treatment outcome.

An additional next step of the ESI-CO project will be the investigation of an unexamined topic in the present study: child outcome. Some parent-mediated models of autism intervention have demonstrated improvement in children's skill level and reduction of autism symptoms (Kasari et al., 2010; Schertz & Odom, 2007), but others have failed to produce significant change (Green et al., 2010) or have found differential outcomes based on the child's level of impairment (Carter et al., 2011). While it is meaningful that in the present study, parents and caregivers demonstrated the accumulation of facilitative strategies and reported positive change in their children, the success of our intervention model is contingent upon its ability to promote positive change within the affected child. Important questions to address will be the direct effect of the intervention on children's social engagement and communication, but also the mediating and moderating factors of caregivers, families, and environmental context, and individual differences across children.

With the inclusion of family and environmental context in the study of autism intervention it is also imperative to take into account other family members who may play a role in the affected child's development. Though ESI-CO was open to having additional caregivers involved in the treatment, research protocol still required one parent to be identified as the primary caregiver. The role of other family members is often overlooked in the literature of family process models (Barnett, 2008). In populations in which "traditional" family structures are not the norm, we must focus not only on

mothers, but also fathers, father figures, siblings, extended family, and extended kinship networks.

Future directions in autism intervention research should also include a broader conceptualization of the concept of "underserved." In the present study, 13 families were screened ineligible for participation, six of which met one eligibility requirement, but not the other (i.e. met criteria for income, but exceeded education cutoff). It is important to recognize that while these additional families did not meet our specific eligibility criteria, they may have had limited access to diagnostic and treatment resources for ASD.

In the broader autism field, particularly in the research by Mandell and colleagues, underserved families have been defined as those of racial and ethnic minority background (Mandell, Wiggins, Carpenter, Daniels, DiGuiseppi, Durkin, et al., 2009). Intersections between culture, race, ethnicity and the experiences of families of children on the autism spectrum are becoming increasingly researched in the autism field (Blacher and McIntyre, 2006; Carr & Lord, under review; Magaña & Smith, 2006; Mandell & Novak, 2005) and should not be overlooked in the research domain of intervention. There is a great need for the field to identify what characterizes the families least likely to receive diagnostic and intervention services—whether it consists of socioeconomic status, culture, race and ethnic background, or most likely, interactions between all of these constructs—and to determine what definition of "underserved" would best ensure these families are represented in the research.

Conclusions.

Our understanding of ASD has increased exponentially since the introductory papers of Kanner (1943) and Asperger (1944). From their first observations, autism was

conceptualized as only affecting white, affluent families with high levels of education. In past decades, epidemiological research has led the field in calling to our attention that the disorder affects families across cultural, ethnic, demographic, and socioeconomic levels (CDC, 2009; Kogan, et al., 2007). At this time, it is imperative that the field comes full circle and recognizes that not everyone has equal access to autism education, diagnosis, and intervention services.

The purpose of this dissertation was to serve as the first step in a research program exploring intervention methods promoting positive child and family outcomes within an underserved population. Though results for the ESI-CO project are preliminary, this study demonstrates that with funding, effort, and understanding, families who have traditionally been underrepresented in autism intervention research can have a voice and contribute to the development and implementation of autism interventions benefitting families of all backgrounds.

APPENDICES

Appendix A: Measure of Transactional Supports
(Used and adapted with permission from Wetherby and Morgan, 2010)

1. **Within each activity is the caregiver….*Promoting child participation and a productive role for the child?***
   Determine whether the caregiver arranges materials and positions self to promote child participation in a shared activity, provides an active, productive, and appropriate role that is clear to the child, and assists child in maintaining a role throughout activity.

1	2	3	4
Rarely provides role			Provides role most of the time

2. **Within each activity is the caregiver…*Providing support to make the activity predictable?***
   Determine whether the caregiver provides support to help the child understand the next step within the activity. This can include setting up a predictable sequence of events or an activity structure that helps the child understand the next step. This can be done with a combination of verbal, nonverbal, and other visual supports.

1	2	3	4
Predictable rarely			Predictable most of the time

3. **Within each activity is the caregiver…*Creating a balance of turns?***
   Is the interaction reciprocal or is the caregiver dominating the conversation or activity?

1	2	3	4
Balanced rarely			Balanced most of the time

4. **Within each activity is the caregiver…*Promoting child initiations?***
   Does the caregiver consistently provide opportunities for the child to initiate by waiting, offering choices, asking simple yes/no questions, waiting expectantly, and providing opportunities for the child to 'fill in the blank' etc.?

1	2	3	4
Promotes initiations rarely or not at all			Promotes initiations at least 2 times/minute

5. **Within each activity is the caregiver…*Following the child's attentional focus?***
   Determine whether the caregiver talks about what the child is paying attention to or actively participating in. This does not include redirecting or requiring the child to shift attention.

1	2	3	4

Rarely follows focus   Consistently follows
                                                              focus

6. Within each activity is the caregiver…*Providing an appropriate level of prompting?*

When physical or verbal prompting is provided, ensure that it is the minimal needed and not prolonged or intrusive.

1	2	3	4
prompting is intrusive OR Caregiver rarely provides prompts			Level of prompting is appropriate

7. Within each activity is the caregiver…*Providing nonverbal and verbal models?*

Determine whether the caregiver models appropriate sounds or words using child perspective language. In addition, does the caregiver model gestures, functional actions, and/or play for the child?

1	2	3	4
Provides models rarely or not at all			Provides models at least 2 times/minute

8. Within each activity is the caregiver…*Supporting the child's comprehension?*

Determine whether the caregiver poses questions or commands that are appropriate to the child's level of understanding by securing the child's attention and making use of contextual cues and gestures to support the child's comprehension skills.

1	2	3	4
Supports comprehension rarely or not at all			Supports comprehension at least 2 times/minute

9. Within each activity is the caregiver…*Displaying appropriate expectations and demands?*

If the child is upset or frustrated, does the caregiver lower expectation and help them become more regulated? If the child is well-regulated, does the caregiver raise expectations and push for more?

1	2	3	4
Adjusts demands rarely			Adjusts demands most of the time

10. Within each activity, is the caregiver….supporting extended reciprocal interaction by offering developmental support or additional motivation as needed?

For example, the parent is able to motivate the child to remain engaged for an extended number of turns in a variety of different ways: expanding the play to include more sophisticated scenarios or novel concepts; modeling a turn with exaggerated intonation or "silliness", or adding music or a jingle to the activity. In newer or more challenging activities the caregiver is also able to offer the necessary developmental support to keep the child participating through an additional turn and/or clean up of the activity.

1	2	3	4
Elaborates rarely			Elaborates activity most of the time

Appendix B. ESI-CO Exit Interview

Instructions: Make sure to ask each question verbatim. If necessary, ask follow-up probes. You don't have to take notes, but *make sure the camera is recording and that the caregivers' face is visible.*

Thanks for visiting with me today. Now that you and [child's name] are done with the project, we wanted to ask you some questions about your experience. Your answers will help us learn how to help other families in the future.

I'm going to start with some general questions.

1. Why did you become involved in the ESI-CO project?

2. What was it like for you to participate in ESI-CO?

Now lets talk about the time when [insert interventionist's name] came to your house twice a week for sessions…

3. What was it like to have [interventionist's name] come to your house to work with you and (child)?

4. What was it like doing activities with [child's name]?

    o Were there certain types of activities that you liked to do more than others? Or that [child's name] liked to do more than others?

    o What activities were the hardest to do?

    o Were you able to work on the activities every day? (***If no)*** Why not?

5. What did you like about having [interventionist name] come to your house twice a week?

6. What was hard about having [interventionist name] come to your house twice a week?

7. What was it like being videotaped with [your child] once a week?

8. How did you feel about filling out the questionnaires?

Now I'll ask you some questions about the three monthly visits, after [interventionist's name] stopped coming by twice a week…

9. How did you feel when the weekly visits ended?

10. What was it like having [interventionist's name] only visit you once a month? How about the monthly videotaping sessions?

    o   Overall, what did you like about the monthly visits?

    o   What was difficult about the monthly visits?
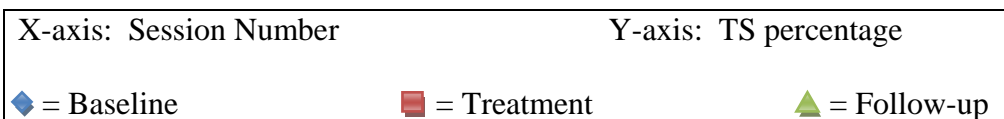
I have a few questions about coming to UMACC for the evaluations…

11. What was it like having [child's name] evaluated at UMACC?

    o   Did you find it helpful to have the evaluations?

    o   Was there anything that you learned about [child's name] from the evaluations?

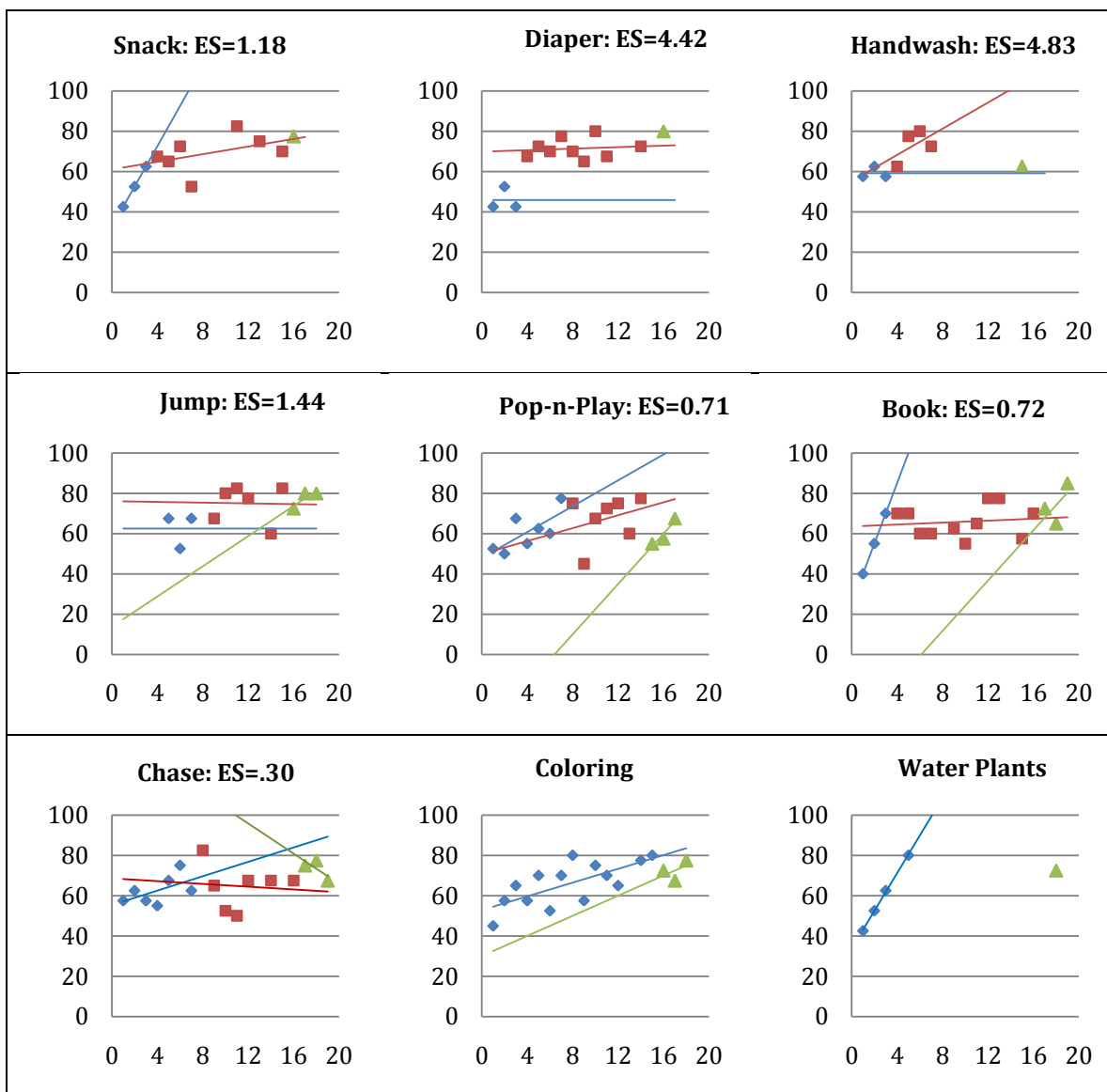*Now I just have a few more questions about your overall experience with ESI-CO…*

12. What did you like the most about being in ESI-CO?

13. What was the most difficult?

14. Is there anything you would have liked to have been different about ESI-CO?

15. How have you changed as a result of doing ESI-CO?

    o   If you had to pick one thing that is different about you now from when you started working with [interventionist's name], what would it be?

    o   Did this experience change the way you think about [child's name]?

    o   Did this experience change the way you think about autism?

16. Do you think [your child] changed as a result of doing ESI-CO? If so, how?

    o   Is there anything you hoped would change about [child's name] that didn't change?

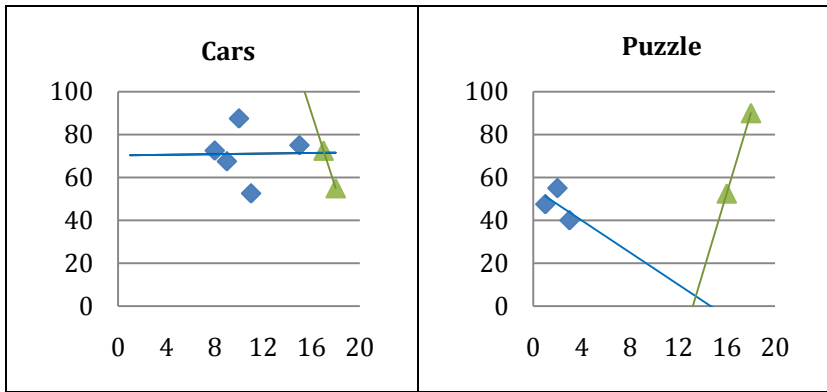17. What are your goals for [child's name] in the future?

18. What would you want other parents to know about what it's like to have a child on the autism spectrum?

19. What would you tell other parents who might become involved in a project like ESI-CO?

20. Is there anything I haven't asked you that you feel is important for us to know?
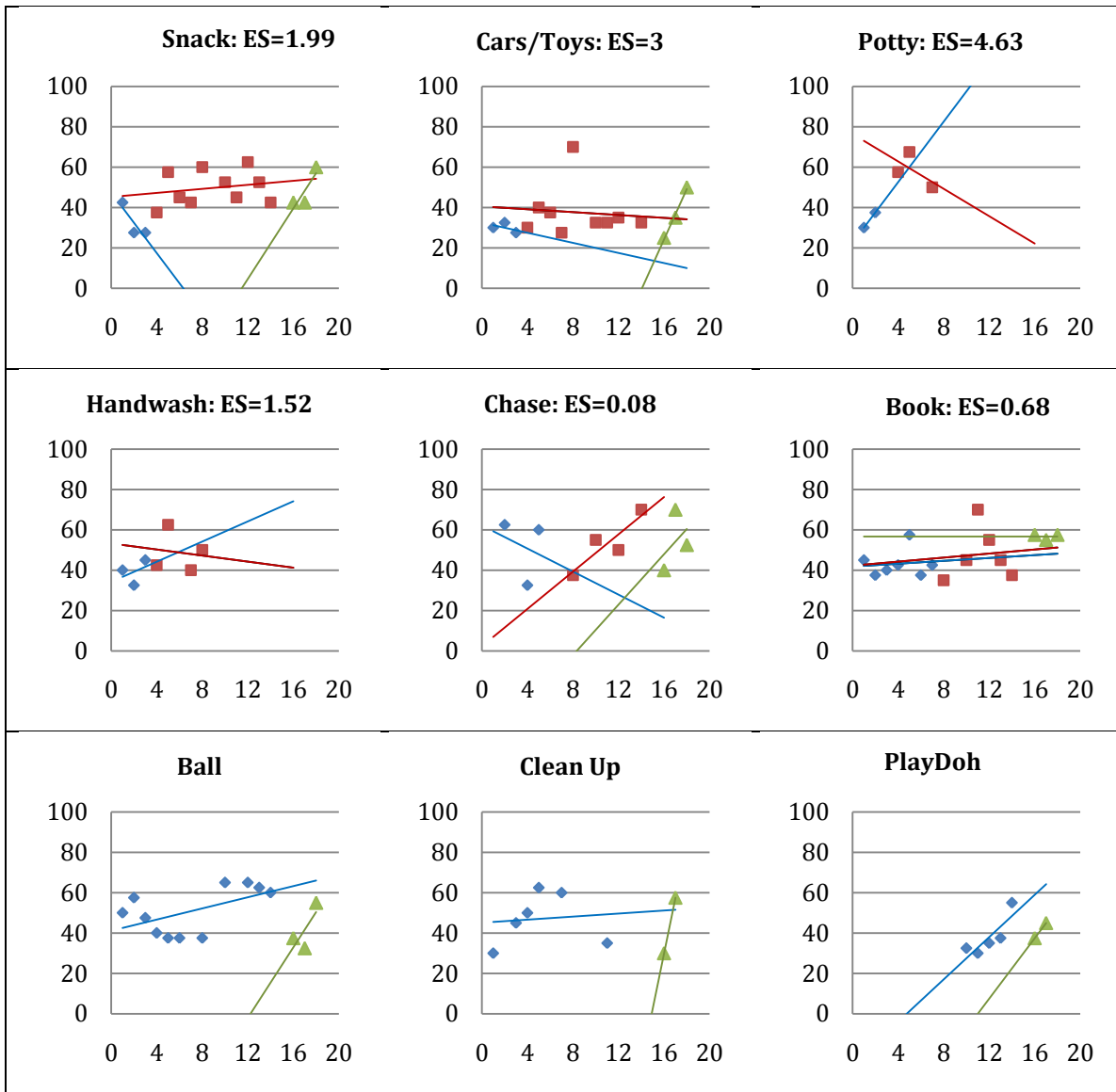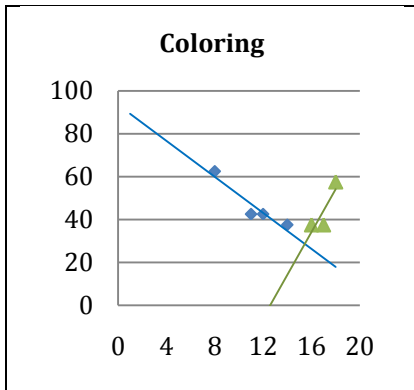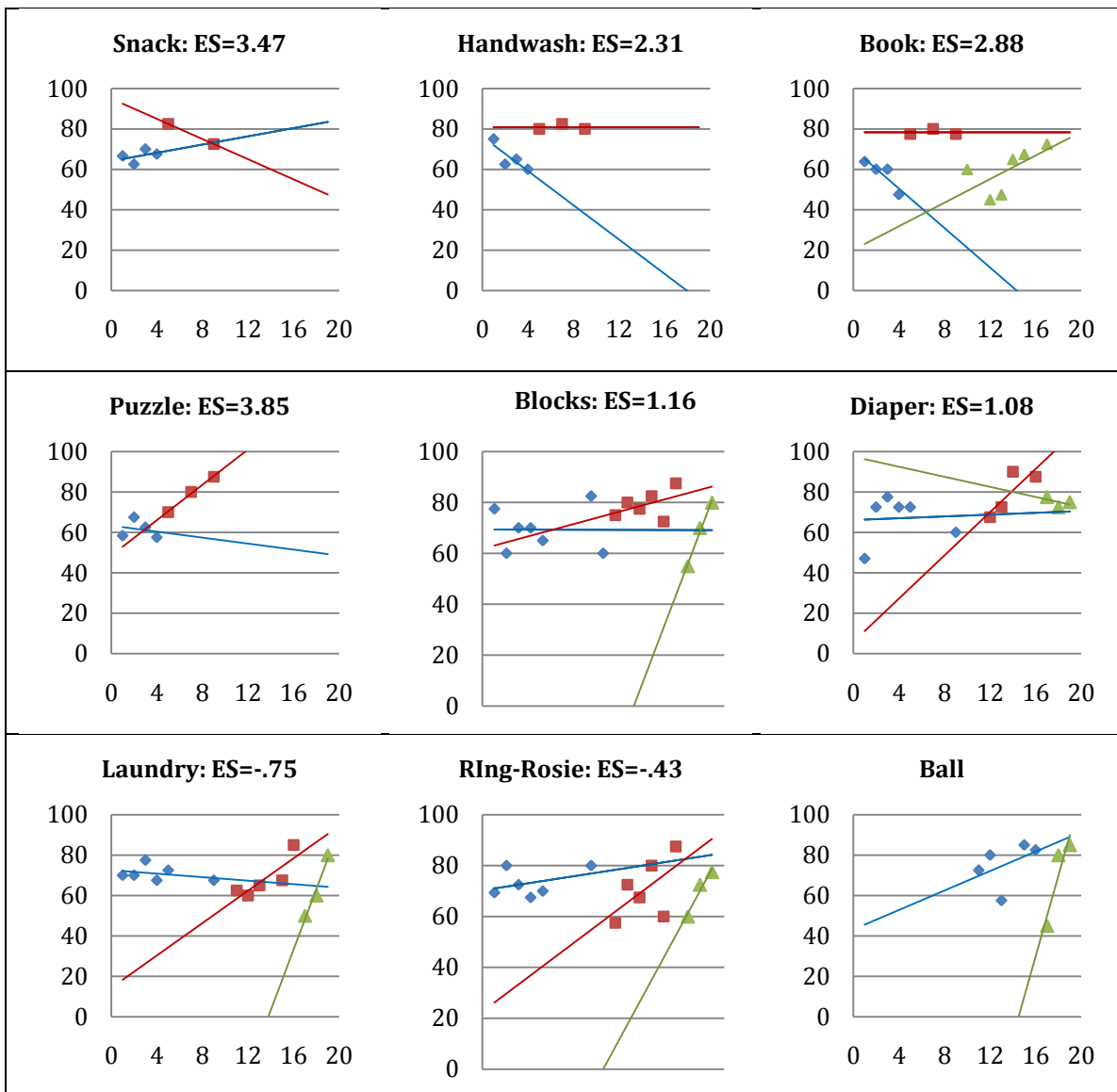
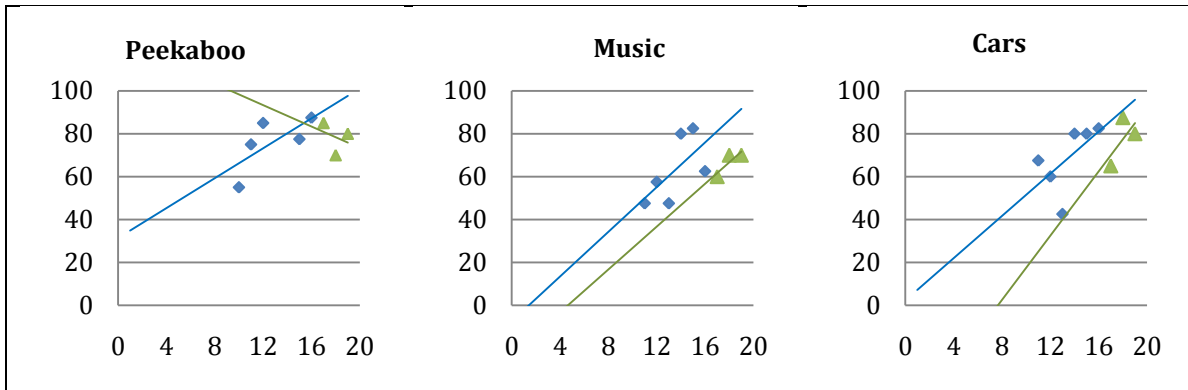# Appendix C. TS Scores by Family

X-axis: Session Number	Y-axis: TS percentage
◆ = Baseline	■ = Treatment ▲ = Follow-up

Family 1

Snack: ES=1.18

Diaper: ES=4.42

Handwash: ES=4.83

Jump: ES=1.44

Pop-n-Play: ES=0.71

Book: ES=0.72

Chase: ES=.30

Coloring

Water Plants

Cars | Puzzle

Family 2

Snack: ES=1.99 | Cars/Toys: ES=3 | Potty: ES=4.63

Handwash: ES=1.52 | Chase: ES=0.08 | Book: ES=0.68

Ball | Clean Up | PlayDoh

Coloring

Family 3

Snack: ES=3.47

Handwash: ES=2.31

Book: ES=2.88

Puzzle: ES=3.85

Blocks: ES=1.16

Diaper: ES=1.08

Laundry: ES=-.75

RIng-Rosie: ES=-.43

Ball

Peekaboo

Music

Cars

Family 4

Snack: ES = 0.92

Ball: ES = 1.30

Dishes: ES=1.56

Handwash: ES=0.65

Book: ES=2.78

Diaper: ES=1.18

Blocks: ES=1.45

Cars: ES=-4.24

Brush Teeth: ES=-.34

Hide&Seek: ES=-.70

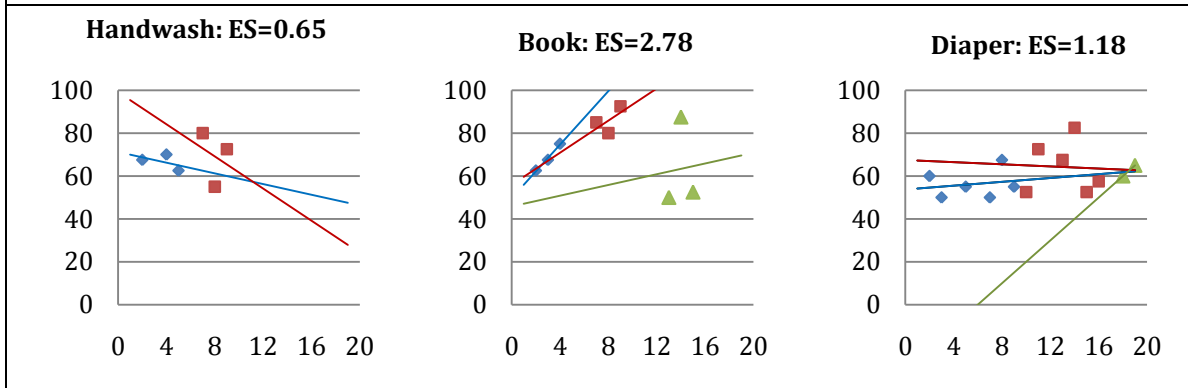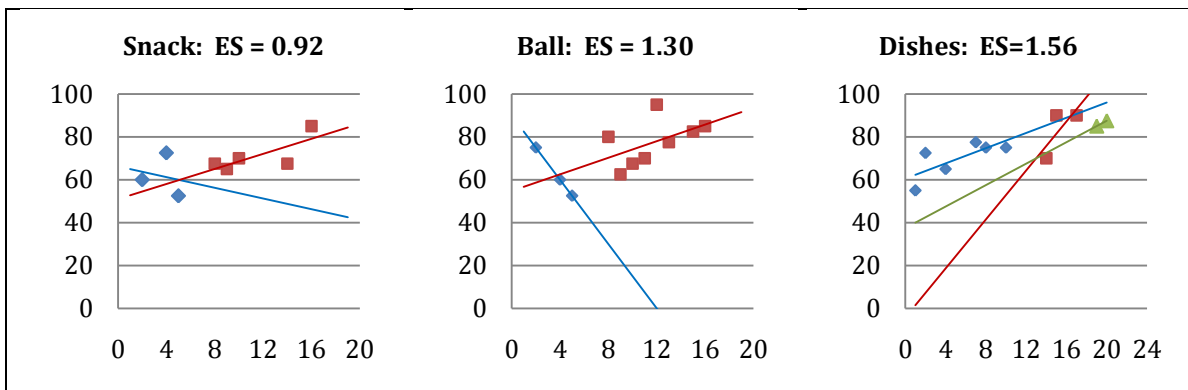**Bubbles**

Hockey

Coloring

Peekaboo

Feed the Cat
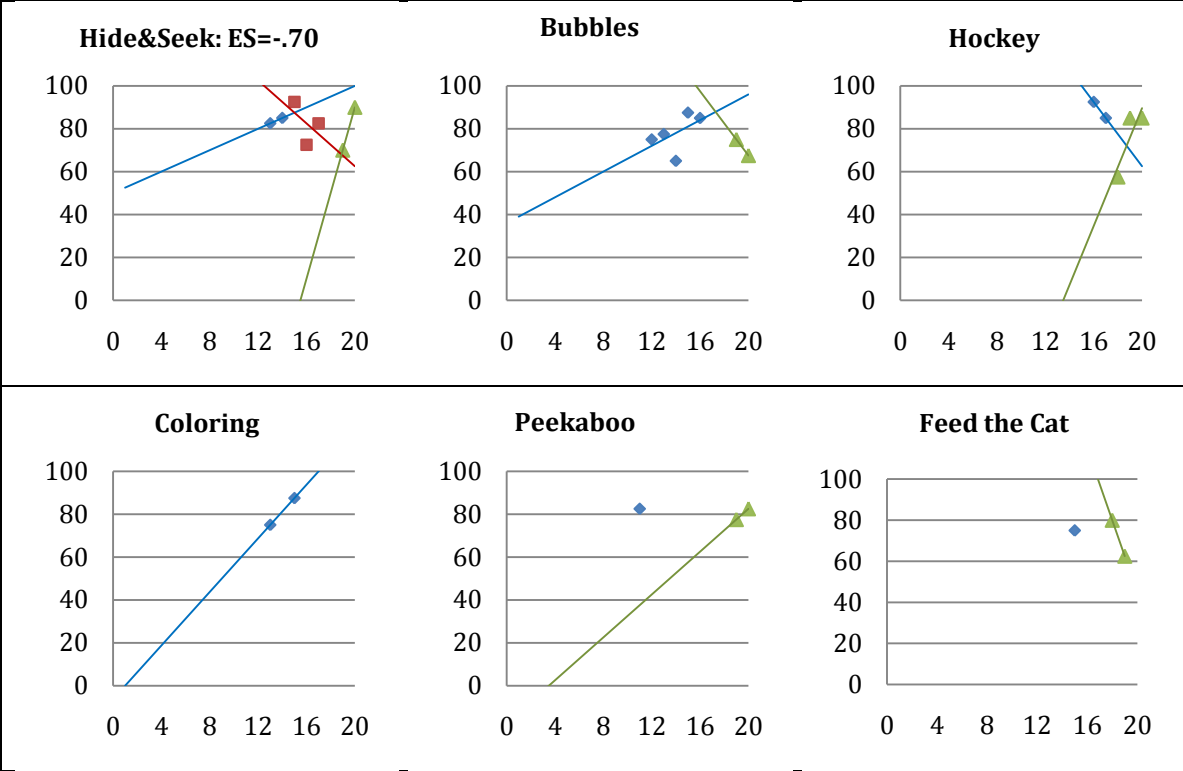
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Chapter 1: Introduction

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Chapter 2: Strategies for Decreasing Barriers in Service to Intervention Programs

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