



## Interventions for children with Fetal Alcohol Spectrum Disorders (FASDS): Overview of findings for five innovative research projects

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## Research in Developmental Disabilities



# Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects<sup>☆</sup>

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### ABSTRACT

It is well established that prenatal exposure to alcohol causes damage to the developing fetus, resulting in a spectrum of disorders known as fetal alcohol spectrum disorders (FASDs). Although our understanding of the deficits and disturbances associated with FASDs is far from complete, there are consistent findings indicating these are serious, lifelong disabilities—especially when these disabilities result from central nervous system damage. Until recently, information and strategies for interventions specific to individuals with FASDs have been gleaned from interventions used with people with other disabilities and from the practical wisdom gained by parents and clinicians through trial and error or shared through informal networks. Although informative to a limited degree, such interventions have been implemented without being evaluated systematically or scientifically. The purpose of this article is to provide a brief overview of a general intervention framework developed for individuals with FASDs and the methods and general findings of five specific intervention research studies conducted

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within this framework. The studies evaluated five different interventions in five diverse locations in the United States, with different segments of the FASD population. Nonetheless, all participants showed improvement in the target behaviors or skills, with four studies achieving statistical significance in treatment outcomes. Important lessons emerged from these five interventions that may explain success: including parent education or training, teaching children specific skills they would usually learn by observation or abstraction, and integration into existing systems of treatment. A major implication of these research studies for families dealing with FASDs is that there are now interventions available that can address their children's needs and that can be presented as scientifically validated and efficacious to intervention agents such as schools, social services, and mental health providers. In the field of FASD research and clinical service, a common theme reported by families has been that clinicians and professionals have been reluctant to diagnose their children because there were no known effective treatments. Results of these five studies dispel that concern by demonstrating several interventions that have been shown to improve the lives of individuals with FASDs and their families.

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It is well established that prenatal exposure to alcohol can damage a developing fetus, resulting in a spectrum of disorders known as fetal alcohol spectrum disorders (FASDs; Jones, Smith, Ulleland, & Streissguth, 1973; Warren et al., 2004). Affected individuals can experience a wide range of negative life long effects, including structural malformations, learning disabilities (including mental retardation), or complex and persistent psychosocial problems. The full spectrum includes diagnoses of fetal alcohol syndrome (FAS), partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD) (Bertrand et al., 2004; Stratton, Howe, & Battaglia, 1996).

Despite ongoing efforts to prevent alcohol-exposed pregnancies, infants continue to be born with FASDs (Hymbaugh et al., 2002; May & Gossage, 2001; May et al., 2006). FASDs are not as rare as generally thought and studies of particularly vulnerable populations have yielded prevalence estimates that exceed those of other, more widely recognized developmental disabilities. Studies in the United States have reported prevalence rates for the full FAS case definition, ranging from 0.2 to 1.5 cases per 1000 births across various populations (Astley, Stachowiak, Clarren, & Clausen, 2002; Bertrand et al., 2004; May & Gossage, 2001). Prevalence estimates for the entire spectrum range from 3 to 10 times the prevalence of full FAS (Stratton et al., 1996) resulting in thousands of children born affected by prenatal alcohol exposure each year.

As is true for all children with developmental disabilities, access to interventions, especially early interventions, is a protective factor that improves the long-term developmental outlook for those with an FASD (Streissguth, Barr, Kogan, & Bookstein, 1996). Thus, interventions for individuals affected by prenatal alcohol exposure are an important educational and public health need. Despite the troubling number of children with FASDs, information and strategies for interventions specific to this population have been gleaned from interventions used with other disabilities without adaptation and from the practical wisdom gained by parents and clinicians through trial and error or informal networks. In 2001, in response to the Healthy Children Act of 2000, the Centers for Disease Control and Prevention (CDC) provided federal funding to develop systematic, specific, and scientifically evaluated interventions appropriate for children with FASDs and their families. Awards were made to five grantees to develop interventions. All five interventions specifically addressed the neurodevelopmental needs of children with FASDs. The purpose of this article is to provide a brief overview of the

general framework and procedures for these intervention projects and their central findings. More in-depth descriptions of the methodology and results for each intervention study are addressed in publications elsewhere (Chasnoff et al., submitted for publication; Kable, Coles, & Taddeo, 2007; O'Connor et al., 2006; Olson et al., in preparation).

### **1. Intervention framework**

All of the interventions were designed to improve the developmental outcomes of individuals with FASDs, reduce secondary conditions, and improve the lives of families affected by FASDs. Although our understanding of the deficits and disturbances associated with FASDs is far from complete, individuals exposed to alcohol during fetal development can show evidence of central nervous system (CNS) dysfunction resulting from structural brain damage (Ma et al., 2005; Spadoni, McGee, Fryer, & Riley, 2007). These CNS disabilities can range from subtle to serious, with affected individuals presenting variable combinations of deficits in memory, information processing, academic skills, social skills (including pragmatic language and social communication skills), attention, motor skills, and executive functioning, as well as significant behavioral and mental health issues (Bertrand et al., 2004; Kable & Coles, 2004; O'Connor et al., 2002; Streissguth et al., 1996). Learning and life skills affected by prenatal exposure vary greatly among individuals, depending on the amount of alcohol exposure, the timing and pattern of exposure, and the affected individual's current environmental history (Streissguth, 1997). As a result, the intervention appropriate for an individual with an FASD and his or her family vary according to these factors.

Grantees were requested to incorporate three common components in their intervention trials: (a) interventions targeting a specific area of deficit or risk among the study population (rather than entering into a single, collaborative intervention to be implemented by all sites), (b) provide children in both treatment and control groups with multidisciplinary assessments that guided referrals for standard care as indicated (e.g., speech therapy), and (c) incorporate specific instruction and training for parents and caregivers regarding basic information about FASDs, advocacy skills, and caregiver support. Across sites, specific interventions focused on math skills, behavioral regulation, peer relations and social communication, executive functioning, compliance, learning readiness, and challenging behaviors of clinical concern.

### **2. Human subjects approval**

All studies were approved by the CDC Institutional Review Board (IRB) and by the individual IRBs from each research site. For children under state guardianship, the IRB of the applicable state Department of Children and Family Services reviewed and approved the research. Informed consent was obtained from the parent(s) or legal guardian(s), and assent was obtained from children at appropriate ages for each intervention.

### **3. Diagnosis of participants across intervention sites**

Participants for all interventions were recruited from established FASDs and genetics clinics. Every child received a multidisciplinary evaluation by trained clinicians to assess for the presence of the diagnostic features of an FASD. Children with any of the diagnoses within the spectrum were eligible. Two of the study sites (University of California at Los Angeles and University of Washington) used the *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code* (Astley, 2004). This system uses a 4-digit diagnostic code reflecting the magnitude of expression of four key diagnostic features of fetal alcohol syndrome (1) growth deficiency; (2) the FAS facial phenotype, including short palpebral fissures, flat philtrum, and thin upper lip; (3) CNS dysfunction; and (4) gestational alcohol exposure.

Two sites (Children's Research Triangle and University of Oklahoma Health Sciences Center) used a modified system adapted from the IOM (Stratton et al., 1996) and incorporated aspects of the 4-digit diagnostic code to assess severity of features. One site (Marcus Institute) used Pedscore, a weighted pediatric dysmorphia checklist (Fernhoff, Smith, & Falek, 1980) that has been demonstrated to

**Table 1**  
Baseline participant characteristics for each intervention research site.

Characteristic	Intervention research site				
	University of California at Los Angeles (N = 100)	Marcus Institute (N = 61)	Children's Research Triangle (N = 78)	University of Oklahoma Health Sciences Center (N = 58)	University of Washington (N = 52)
Ethnicity (%)					
White, non-Hispanic	54.0	57.4	37.2	39.1	50.0
Black or African American	17.0	38.4	42.3	23.9	25.9
Child sex: males (%)	51.0	60.7	67.9	60.0	51.9
Child age in years (M, SD)	8.59 (1.56)	6.38 (2.00)	8.73 (1.55)	4.70 (1.4)	8.06 (2.07)
Child composite IQ on K-Bit (M, SD)	97.24 (14.83)	81.08 (13.4)	89.79 (16.11)	87.90 (11.20)	94.3 (12.50)
Primary caregiver education (years)	16.28 (0.26)	12.84 (1.4)	14.41 (2.51)	13.90 (2.73)	14.47 (2.26)
Living with biological mother (%)	21.0	1.7	NA	1.1	13.4
Fetal alcohol syndrome (%) <sup>a</sup>	12.0	6.6	14.1	4.6	7.7

<sup>a</sup> FAS diagnosis based on criteria from *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*, 2004

accurately reflect common features associated with the diagnosis of an FASD. The Pedscore is the sum of the 30 weighted items on a standard pediatric dysmorphia checklist used to identify alcohol-related dysmorphic features. This checklist is a modification of the usual “genetics” checklist, upon which characteristics associated with the disorder are listed and weighted based on their saliency for the diagnosis (e.g., hypoplastic philtrum is a “3” on a 0–3 scale). The total dysmorphia score obtained is the sum of the 30 weighted items. Pedscores greater than 10 are assumed to indicate a clinically significant degree of alcohol-related dysmorphology. This score is then used with other criteria to diagnose children according to the IOM system (Stratton et al., 1996).

To provide consistency for comparison across sites, all sites re-categorized their participants according to the 2004 guidelines published by the National Taskforce on Fetal Alcohol Syndrome and Fetal Alcohol Effects (NTFASFAE), presented in Table 1. These guidelines address only the full FAS diagnosis. A diagnosis of FAS is applied if: (a) a child demonstrates all three cardinal facial dysmorphic features (small palpebral fissures, smooth philtrum, and thin vermilion border); (b) has prenatal or postnatal growth below the 10th percentile for height or weight; and (c) demonstrates structural, neurological or functional CNS deficits (Bertrand et al., 2004). A confirmed history of prenatal alcohol exposure is a qualifier of the diagnosis, but not a prerequisite according these guidelines.

#### 4. Study 1. Project bruin buddies: a social skills training program to improve peer friendships for children with fetal alcohol spectrum disorders (University of California at Los Angeles)

This study was designed to examine the effect of parent-assisted children's friendship training (CFT) (Frankel & Myatt, 2003) compared with the effect of delayed treatment control (DTC) on the social skills of children with a history of prenatal alcohol exposure, and to examine the maintenance of social skills gained over a 3-month period.

Research suggests that children with FASDs exhibit considerable social impairment. Problems understanding social cues, indiscriminant social behavior, and difficulty communicating in social contexts have been reported among this population (Streissguth, 1997). Both caregivers and teachers have rated children with prenatal exposure to alcohol as having poorer social skills than unexposed children, even after controlling for differences in cognitive functioning (Roebuck, Mattson, & Riley, 1999; Whaley, O'Connor, & Gunderson, 2001). Furthermore, studies of adolescents and adults with FASDs have indicated that social skills deficits continue into adulthood (Carmichael-Olson, Feldman, Streissguth, Sampson, & Bookstein, 1998). Given the high percentage of individuals with prenatal exposure to alcohol, who have significant social problems as they grow older, it is important to intervene early to promote adequate social problem solving and competence.

The procedure used in this study and all its social skills components were based on the developmental psychology literature pertaining to children's friendships, had been validated empirically, and had been successfully implemented for children 6–12 years of age in multiple clinical contexts and with children having a variety of developmental and psychiatric disorders (Frankel, 2005; Frankel & Myatt, 2003). The procedure included parents as facilitators of their children's social skill performance, which has proven to be a highly successful component of social skills training (Frankel, 2005; Ladd, Profilet, & Hart, 1992). The procedure was modified with specific treatment adaptations to account for the neurocognitive deficits common among children with FASDs. Modifications made primarily involved augmentation in how the treatment was delivered, rather than changes in the content or components of the intervention, thus, preserving the basic integrity of the treatment. Skills taught included: (a) social network formation with the aid of the, (b) informational interchange with peers leading to a common-ground activity, (c) entry into a group of children already in play, (d) in-home play dates, and (e) conflict avoidance and negotiation. Skills were taught didactically through instruction on simple rules of social behavior; modeling, rehearsal, and performance feedback during treatment sessions; rehearsal at home; homework assignments; and coaching by parents during play between children.

#### 4.1. Method

##### 4.1.1. Participants

A total of 183 children 6–12 years of age were assessed for eligibility in the study. Of that number, 83 were excluded for not meeting inclusion criteria ( $N = 63$ ) or failing to keep evaluation appointment ( $N = 20$ ). Of the remaining 100 children, 96 completed the study with 4 families failing to complete the study (2 during intervention and 2 during the delayed treatment waiting period). Sample participants had to have had measurable social skills deficits ( $\geq -1$  standard deviation below the mean) on the socialization domain of the Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984), and a verbal IQ of  $\geq 70$  on the Kaufman Brief Intelligence Test (K-BIT; Kaufman & Kaufman, 1990). Sample characteristics are presented in Table 1.

##### 4.1.2. Measures and procedures

A two-group CFT or DTC longitudinal design was used. Each consecutive set of 14–16 eligible children formed a cohort. The children within a cohort were assigned, in alternating sequence, to one of the two study conditions (7–8 children in each condition), with an attempt to equate groups on sex and ethnicity. The CFT group received 12 sessions, 90 min in length, delivered over the course of 12 weeks. Parents attended separate concurrent sessions in which they received education on the issues related to FASDs and were instructed on key social skills being taught to their children. On completion of the 12-week intervention, participants in the CFT condition were administered a post-treatment assessment. Children in the DTC condition, for whom treatment had been delayed, then received the CFT. After completing treatment, the DTC participants were then assessed. At the same time, the CFT group completed a 3-month follow-up assessment.

Children and parents were assessed prior to CFT or DTC training, 12 weeks later, and then again at 3 month's follow-up. Children's understanding of the rules of social behavior was measured using the Test of Social Skills Knowledge (TSSK; Frankel, 1994), which is a 17-item forced-choice, criterion-based measure. This measure and similar measures have been used successfully in evaluating treatment gains in other studies of social skills training (Frankel & Myatt, 2003; Piffner & McBurnett, 1997). Scores range from 0 to 17, with a higher score reflecting higher social skills knowledge.

Social skill performance was evaluated with the Social Skills Rating System Parent Form (SSRS-P) (Gresham & Elliott, 1990). The SSRS-P is comprised of two scales: Social Skills and Problem Behaviors, presented as standard scores ( $M = 100$ ;  $SD = 15$ ). The Social Skills scale measures cooperation, assertion, responsibility, and self-control. Lower scores represent poorer social functioning. The Problem Behaviors scale measures internalizing, externalizing, and hyperactivity. Higher scores represent greater problem behaviors. The SSRS-P has high criterion-related validity, correlating significantly with other established measures of child social and problem behaviors.

The Test of Parent Knowledge of FASDs, a project-developed questionnaire in a true/false, forced-choice format, was used to assess parental knowledge about the neurodevelopmental effects associated with prenatal alcohol exposure and of parent advocacy opportunities.

Following treatment, parents were queried regarding their satisfaction with the intervention using the Parent Satisfaction Questionnaire, a project-developed measure consisting of questions rated on a Likert scale with values ranging from negative to neutral to positive.

#### 4.2. Results

Chi-square and independent *t*-tests revealed no statistically significant differences at baseline between the CFT and DTC conditions on demographic variables. To examine the effect of social skills training on children with FASDs, a two-condition (CFT, DTC) ANCOVA design was used. Analyses were conducted on the scores derived from the TSSK completed by the children and on the scores on the SSRS-P completed by the parents. The post-treatment score was the dependent variable and the baseline score was used as a covariate to control for initial levels. After controlling for covariates, children in the CFT group showed statistically significant improvement in their knowledge of appropriate social behavior compared with children in the DTC group (prior to their receipt of the social skills training,  $p < .0001$ ). According to parent report, similar results also were obtained in increasing actual social skills ( $p < .03$ ) and in decreasing problem behaviors ( $p < .05$ ). To examine the maintenance of social skills over a 3-month period following treatment, data from children in the CFT condition were analyzed using two-tailed pairwise *t*-tests. The DTC group received treatment during this time period so they could not be used as a comparison group. Change scores on the TSSK and the SSRS-P from baseline to 3 month's follow-up constituted the dependent variables. Results indicated that children's social skills knowledge, improvement in social skills, and decrease in problem behaviors were maintained over the 3-month follow-up period. Importantly, social skills improved significantly from post-treatment to 3 month's follow-up ( $p < .002$ ), suggesting that children were continuing to benefit from the intervention targeting social skills performance. Similar gains were reported for the children in the DTC group following treatment with CFT.

Results from questionnaires on parent knowledge about prenatal alcohol exposure and parent satisfaction revealed that, following treatment, parents in both groups reported more knowledge about their children's conditions and a high level of satisfaction with the intervention. More than 85% of parents reported that the approach to treating their children's social skills problems was appropriate and 89.2% said they would recommend the training to a friend or relative. Regarding the information that they learned in the sessions, 92.5% of parents reported that the information was useful to them.

#### 4.3. Discussion and conclusions

This study was the first systematic evaluation of a treatment for improving the social functioning of children with FASDs. As such, it represents a promising intervention for these children, who experience multiple failures in social interaction leading to poor peer choices and, for some, juvenile delinquency (Schonfels, Mattson, & Riley (2005)). However, the treatment was performed in a highly controlled university setting. Thus, the next step in determining its effectiveness would be to test the treatment among children enrolling in more typical community-based programs. Given the high rates of mental health problems among children with FASDs (Streissguth et al., 1996; Streissguth & O'Malley, 2000), these children are likely to be seen for treatment in such community settings. Providing increased access to interventions that have been demonstrated empirically to be efficacious with this population is a critical step toward reducing some of the devastating secondary disabilities faced by children with FASDs and in helping their families facilitate change.

### 5. Study 2. Georgia-sociocognitive habilitation using the math interactive learning experience (MILE) program (Marcus Institute)

This project was developed to evaluate the effect of a sociocognitive habilitation program designed to improve the behavioral and mathematical functioning of alcohol-affected children. Deficits in



mathematical functioning have been reported consistently among alcohol-affected individuals (Coles et al., 1991; Goldschmidt, Richardson, Stoffer, Geva, & Day, 1996; Howell, Lynch, Platzman, Smith, & Coles, 2006; Jacobson et al., 2003; Mattson, Riley, Gramling, Delis, & Jones, 1998; Streissguth et al., 1996) and have been demonstrated throughout the lifespan of these individuals (Kopera-Frye, Dehaene, & Streissguth, 1996). Poor myelination, particularly in areas affecting the cross-hemispheric transfer of information (Ma et al., 2005; Wozniak et al., 2006) and altered development and functioning of parietal regions of the brain that are involved in the visual-spatial processing of information (Dehaene, 1997; Geary, 1993) have been posited as potential reasons for the relative deficit in mathematics skills seen among alcohol-affected children.

A psychoeducational program for alcohol-affected children that provided learning strategies to compensate for core alcohol-related neurodevelopmental deficits was developed to facilitate mathematics learning. The program included intensive, short-term individual instruction of each child, as well as training for the child's caregivers and teachers. The goal was to provide a consistent method of instruction of mathematical concepts across therapeutic, home, and school environments. Most clinically referred children have problematic medical and caregiving histories, as well as socioeconomic problems and behavior problems that must be taken into account in designing intervention studies (Kalberg & Buckley, 2007; Kable & Coles, 2004). Therefore, support – which included caregiver education, case management services, and psychiatric consultations, as needed – also was incorporated to allow the child to achieve *readiness to learn*.

Program developers hypothesized that the learning readiness components of the intervention program would increase parental knowledge, would be viewed as helpful, and would result in improved parental perception of behavior. It also was hypothesized that children randomly assigned to a targeted habilitative program to facilitate their mathematical development would demonstrate greater maturation in mathematics skills compared with children who received standard psychoeducational services.

## 5.1. Method

### 5.1.1. Participants

Children 3–10 years of age who had a clinical diagnosis of FAS or pFAS were recruited from the Atlanta metropolitan area. Participants were required to have been with their current caregiver for at least 6 months prior to enrollment and to be projected to remain with that same caregiver for the next 6 months. Participants were excluded if their cognitive functioning was in the moderately intellectually deficient range or below, or if they had other serious mental health problems that might have interfered with their ability to benefit from academic instruction. Children who had a dual diagnosis of an FASD and attention deficit disorder were not excluded from participation. A total of 87 participants consented and were enrolled in the study, but only 61 completed study requirements for randomization. Of these, 56 completed post-testing. The mathematics group had two participants drop out and the psychoeducational only group had three families who failed to return for post-testing. Sample characteristics are presented in Table 1.

### 5.1.2. Measures and procedures

**5.1.2.1. Readiness to learn.** To establish readiness to learn among participants, case management and psychiatric consultation were provided as needed. Caregivers of participants also were required to attend two training workshops. The first workshop educated parents about FAS and provided information about special education and methods for advocating for their children. The second provided training in how to build positive behavioral regulation skills among children. Parents were given informational manuals elaborating workshop content to use as a reference.

**5.1.2.2. Mathematics intervention overview.** After caregivers completed the workshops, participants were randomly assigned to either the mathematics intervention group or a standard psychoeducational treatment only contrast group. All participants received the standard psychoeducational treatment consisting of a comprehensive neurodevelopmental evaluation, assistance with educational placement,

and development of an individualized educational plan within the context of their home school. In addition to the standard psychoeducational services, those in the mathematics intervention group received 6 weeks of tutoring services. Caregivers in the mathematics intervention group also received instruction in supporting mathematics learning at home and weekly home assignments to complement the individualized tutoring sessions. The staff special educator also met with the participant child's teacher to discuss the alcohol-related neurodevelopmental problems the participant had and the individualized educational goals for the program.

The mathematics instructional component of this program was called the math interactive learning experience (MILE). The program incorporated an active learning approach to instruction that was adapted from the "plan-do-review" methodology developed by the High-Scope Perry Preschool Project and was found to have positive long-term consequences on academic achievement and educational attainment (Luster & McAdoo, 1996; Weikart & Schweinhart, 1992) among high-risk children and to be beneficial in cognitive rehabilitation programs for children with acquired brain damage (Ylvisaker et al., 2007).

Children and caregivers in the mathematics intervention group were evaluated prior to participating in the group workshops and within 4 weeks of completing the tutoring program. To control for time between assessments, a participant child from the standard psychoeducational only group was assessed in the same week as a participant child from the mathematics intervention group. Children were evaluated by a psychologist or psychology trainee who was blind to group status.

*5.1.2.3. Satisfaction.* Following the workshops, caregiver satisfaction for both groups was assessed using Likert scale responses to questions regarding their experiences with the specific treatment components and interactions with staff members.

*5.1.2.4. Treatment and FAS knowledge.* Caregiver knowledge was assessed for both groups also. Assessed areas included the neurodevelopmental compromises associated with prenatal exposure to alcohol, the specific challenges to learning presented by these difficulties, and behavioral regulation principles. Questionnaires used multiple choice formats.

*5.1.2.5. Behavioral outcomes.* To measure caregiver experience of children's behavior, the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001a, 2001b) was administered at pre-test and post-test to caregivers in both groups.

*5.1.2.6. Academic outcomes.* All children were administered the *Test of Early Mathematical Ability*, 2nd edition (TEMA-2; Ginsburg & Baroody, 1990) and selected mathematics-related subtests from the *Bracken Early Concept Scales-Revised* (Bracken, 1998). For children 5 years of age or older, the *Key Math-R/NU* (Connolly, 2001) also was administered. For children younger than 5 years of age, developmental testing of premathematics concepts was done using items from the *Bayley Scales of Infant Development*, 2nd edition (Bayley, 1993). Finally, the quality of number writing was assessed by rating the child's number writing for order, orientation, neatness, consistency, and general recognizability using an instrument developed as part of this study (Coles, Kable, Dent, & Lee, 2004).

## 5.2. Results

Analyses were conducted of the 56 participants who completed post-testing using a two-condition ( $N = 29$  mathematics intervention;  $N = 27$  psychoeducation only) MANOVA design. Caregiver satisfaction with workshops was very high, with over 90% of caregivers in both study groups agreeing that trainers were knowledgeable and materials were easy to understand and helpful. Pre-test and post-test score differences revealed significant gains in knowledge of FASDs, advocacy topics ( $p < .05$ ), and behavioral regulation ( $p < .000$ ). At post-testing, caregivers also reported fewer problem behaviors on the CBCL ( $p < .000$ ).

Because of the passage of time and the fact that students in both groups were receiving mathematics instruction in school, it was predicted that both groups of children would demonstrate gains in mathematics knowledge, but significantly higher gains would be observed for children in the

group receiving direct mathematics instruction. This prediction was confirmed: 58.6% of those in the mathematics treatment group demonstrated a gain of over one standard deviation on any of the four mathematics outcome measures used, while only 23.1% of those in the psychoeducation only group did so ( $p < .008$ ).

### 5.3. Discussion and conclusions

Study results suggested that parent-training components of the program were well received and were associated with reports of improved behavior at post-testing. Although it was possible that these findings might have been temporary or the result of experimenter or participant expectation, they did suggest that educational interventions might be helpful for caregivers and might lead to positive behavioral changes for children. Additional research is needed to further assess the clinical efficacy of the parent training components of this intervention. This study used only a pre-test/post-test design and not a control group with random assignment to evaluate the effect of the workshop, as was done to evaluate the mathematics intervention component.

The results of the mathematics intervention component suggested that a targeted psychoeducational program that addresses the alcohol-related neurodevelopmental difficulties might help to remediate deficits associated with prenatal alcohol exposure. Although the program was relatively short in duration, participants in the mathematics treatment group were more likely to have made a clinically significant gain than were participants assigned to the standard psychoeducational intervention group, providing evidence that effective teaching methods can improve learning for alcohol-affected children.

## 6. Study 3. Neurocognitive habilitation for children with fetal alcohol spectrum disorders (Children's Research Triangle)

The specific aim of this study was to develop and evaluate a program of neurocognitive habilitation for children who had been in foster care or who had been adopted, and who had a diagnosis of FAS or ARND. In 1998, the *U.S. General Accounting Office* (1998) reported that 74% of children in foster care in Illinois had at least one parent who was required to undergo drug or alcohol treatment as part of the case plan for family reunification. In about half the cases, alcohol was used alone or in combination with illegal drugs such as cocaine or heroin, and almost all of the children had been prenatally exposed. The pervasiveness of alcohol involvement in these cases indicated that children in foster care were a group of children at very high risk of an FASD. Even children who eventually were adopted, still had foster care as part of their developmental history (Astley et al., 2002; Streissguth et al., 1996). Unfortunately, the very factors that protect children with FASDs from developing secondary disabilities are the ones that children in the child welfare system frequently lack, such as being raised in a stable, nurturing home; being diagnosed before 6 years of age; having no sexual or physical abuse history; not changing households every few years; not living in a poor quality home; and receiving early intervention services (Streissguth et al., 1996). Thus, children with FASDs and their families need interventions tailored to their foster care experiences, and which can provide skills that mitigate negative experiences as well as counteract any lack of protective factors.

The neurocognitive habilitation program was developed to be a systematic intervention strategy for children in the child welfare system that had a diagnosis of FAS or ARND. The program provided education and support to enhance the families' capabilities to care for the children, and focuses on improving the children's executive functioning, a central deficit for children with FASDs (Mattson et al., 1998; Rasmussen, 2005). The intervention strategies developed for the program focused on the concept that children would be best equipped to improve their executive functioning deficits if they were better able to self-regulate. The program curriculum combined self-regulation techniques and strategies with tools for improving executive functioning skill sets: memory, cause and effect reasoning, sequencing, planning, and problem solving.

Many of the concepts for improving self-regulation that were used in the neurocognitive habilitation program curriculum were adapted from the *Alert Program*® (Williams & Shellenberger, 1996). The *Alert Program*® uses the metaphor of a car engine to describe the concept of self-regulation. Children are told that their brains are like a car's engine and can make their bodies run in high-, low-, or just-right gear. The

program is broken down into three stages: teaching children engine speed identification skills, offering children a variety of strategies to change their engine speeds to desired speed states, and learning to monitor sensorimotor input to regulate their state of arousal.

## 6.1. Method

### 6.1.1. Participants

A total of 78 foster and adopted children, 6–11 years 11 months of age, who had a confirmed history of prenatal alcohol exposure were recruited to participate in the study. Consents for participation were signed by the foster or adoptive parent(s) and, as appropriate, the Office of the Guardian of the Illinois Department of Children and Family Services (DCFS). Four children, all assigned to the treatment group, were eliminated from the sample because they and their parents did not participate in at least 4 of the 12 treatment sessions and did not follow through for exit and follow-up evaluations. These four children (three males, 1 female) did not differ from other children enrolled in the study or from other children assigned to the treatment group.

The Behavior Rating Inventory of Executive Function (BRIEF; Gioia, Isquith, Guy, & Kenworthy, 2000) is a questionnaire that assesses executive function behaviors in home and school environments. The BRIEF's internal consistency and test–retest reliability have been demonstrated to be adequate, while convergent and discriminant validity have been demonstrated with other measures of inattention, impulsivity, learning skill, and emotional and behavioral functioning.

The Roberts Apperception Test for Children (RATC) (McArthur & Roberts, 1982) is designed for children and adolescents 6–15 years of age to assess their perceptions of common interpersonal situations. Children's responses are scored on standardized scales measuring adaptive and maladaptive functioning (eight adaptive scales and five clinical scales) and providing *t* scores. The RATC scoring system has shown adequate interrater agreement and split-half reliability estimates have shown reasonable consistency. The validity of the RATC has been demonstrated in multiple ways (McArthur & Roberts, 1982.).

### 6.1.2. Measures and procedures

A total of 90 children and their families qualified for the study and were invited to participate; 12 declined because of geographical issues. From the 78 children who were enrolled in the study, 2 cohorts were developed via random table assignment after initial intake and a general treatment plan had been completed. The children in the intervention group ( $N = 40$ ) received a full evaluation at Children's Research Triangle and participated in a course of 12 weekly 75-min neurocognitive habilitation group therapy sessions based on the *Alert Program*® (Williams & Shellenberger, 1996), while their parent(s) concurrently participated in a parent education group. The intervention lasted for 12 weekly sessions.

Control group children ( $N = 38$ ) received a full evaluation at Children's Research Triangle, but were referred for services such as occupational therapy, physical therapy, or speech and language therapy through existing community- and school-based agencies, the community standard for service access and delivery at the time of the study. In contrast to children in the intervention group, children and their families in the control group did not participate in neurocognitive habilitation group therapy.

Children were enrolled in cohorts and, as much as possible, the intervention children were divided by chronological and developmental levels, with an optimal group size of five children. Licensed clinical psychologists and post-doctoral fellows under the direct supervision of a licensed psychologist conducted the assessments. Therapy services were provided by licensed clinical psychologists, licensed clinical social workers, and pre- and post-doctoral students under the direct supervision of a licensed psychologist. Outcome measures (BRIEF and RATC) were administered during the post-intervention period (following the approximately 12 weeks of intervention services) and after a comparable delay for children in the control group.

## 6.2. Results

Of the 40 families in the intervention group who began treatment, 4 were not able to complete the intervention or post-testing. None of the families in the control group were lost to follow-up. Because

the research design was a repeated measures design, a double multivariate analysis of variance approach to the data analysis—which is an extension of profile analysis—was used. The multiple subscales of a measure are considered a profile and three major questions must be addressed about this profile: (a) *Do different groups have parallel profiles* (parallelism question)? (b) *Does one group, on average, score higher on the combined subscales than another* (levels question)? and (c) *Are all the subscales the same at each time point of measurement* (flatness question)? In each analysis, all three of these questions were tested.

#### 6.2.1. Brief

The multivariate omnibus test of significance that tested the effect of the treatment over time on the BRIEF was statistically significant ( $p = .006$ ). Because the BRIEF has eight subtests, we conducted follow-up tests (Roy–Bargmann stepdown  $F$ -tests) to try to understand exactly how the treatment and control groups differed. There were no differences between the groups on any single subtest that were pronounced enough to reach statistical significance. These results suggest that the significant effect seen between the groups would be best understood as a combination of the subtests. That is, no single subtest independently would account for more of the variance between groups than any other subtest.

#### 6.2.2. RATC

The multivariate omnibus test of significance that tested the effect of the treatment over time on the RATC adaptive scales was statistically significant ( $p = .012$ ). There are eight adaptive scales, so again we conducted follow-up tests. One subtest did have a substantial difference that reached significance ( $p < .01$ ): the Resolution 1 scale was the subscale that differentiated between the treatment and control groups. It appeared that children in the control group tended to narrate stories with more ease and identify unrealistic solutions to problems.

### 6.3. Discussion and conclusions

The results of this study suggested that children who participated in the neurocognitive habilitation program demonstrated significant improvement in executive functioning skills compared with the children in the control group. Because the treatment approach focused on the concept that children's self-regulatory problems contribute to executive functioning difficulties, the result suggested that the self-regulatory strategies and techniques taught to the children were beneficial from the parents' perspective; children appeared to learn the regulatory strategies and techniques taught in group and, as a result, parents saw improvements in the children's executive functioning skills.

The children in the treatment group at outcome also differed from those in the control group in their response to a projective storytelling test on the RATC: children in the treatment group told fewer stories that had unrealistic solutions to problems. This result might seem less intuitive than the first because the treatment approach clearly did not address directly storytelling or developing realistic solutions to stories specifically. However, one plausible explanation for this result would be related to the content of the groups. One component of the therapy focused on sequencing skills and cause-and-effect thinking. Thus, it was possible that the children internalized these concepts, as demonstrated through projective stories that had fewer unrealistic endings.

The results of this study suggested that the neurocognitive habilitation program is a promising approach to help foster and adopted children with FASDs improve their self-regulation and executive functioning skills. Further refinement of this curriculum and further investigation is needed to establish the treatment efficacy of this program.

## 7. Study 4. Parent–child interaction therapy: application of an evidence-based treatment to reduce behavior problems among children with fetal alcohol spectrum disorders (University of Oklahoma Health Sciences Center)

The aim of the study was to evaluate two group-based interventions for children with FASDs that would reduce (a) behavior problems among children with FASDs and (b) decrease parenting stress

among caregivers. One treatment used a group adaptation of an evidenced-based behavioral parent training treatment, Parent-Child Interaction Therapy (PCIT) (Eyberg & Boggs, 1998) that provided both parents and children with a live, coached practice of behavioral parenting skills. The other was a parent-only Parenting Support and Management (PSM) program that comprised components from other effective behavioral programs (Barkley, 1997; Webster-Stratton, 2001).

Behavior difficulties are significant secondary disabilities among very young children with prenatal exposure to alcohol and other substances (Streissguth et al., 1996). According to research, caregivers' perceptions of children with prenatal exposure to alcohol and other drugs are more negative than those of children without exposure due to ongoing behavior problems that do not respond to traditional parenting (Griffith, Azuma, & Chasnoff, 1994; Paley, O'Connor, Frankel, & Marquardt, 2006). Furthermore, both biological and foster mothers of children with prenatal substance exposure have reported higher levels of parenting stress than have caregivers of children without prenatal exposure (Griffith et al., 1994). The difficult behaviors often seen among the children with FASDs together with the caregivers' negative perceptions and stress often have a detrimental impact on the child's development. Effective intervention programs to address the behavior problems of very young children with an FASD, and the distress experienced by caregivers, are essential for the overall well-being of the children and their caregivers (Bertrand et al., 2004; Streissguth et al., 1996).

Behavioral parent training is considered the single most effective method for ameliorating significant externalizing behavior problems among children in general (Brestan & Eyberg, 1998; Brinkmeyer & Eyberg, 2003). PCIT is an empirically supported intervention consisting of behavioral parent training to effect significant behavior change by the child. PCIT seeks to enhance the parent-child relationship, increase appropriate social skills, reduce inappropriate behaviors, and institute a positive discipline program (Eyberg & Boggs, 1998). PCIT is a short-term intervention, typically lasting 12–16 sessions. Decreases in conduct problems and noncompliant behaviors, as well as improvements in a child's self-esteem, have been found for those who complete PCIT (Eisenstadt, Eyberg, McNeil, Newcomb, & Funderburk, 1993). Although PCIT focuses on the parent-child relationship, research has found generalization of the positive effects to daycare, preschool, and elementary school settings (McNeil, Eyberg, Eisenstadt, Newcomb, & Funderburk, 1991).

A caveat is that behavioral parent training programs such as PCIT presume that disruptive childhood behavior originates in parent-child interaction patterns that inadvertently condition and reinforce disruptive behavior and create a negative parent-child relationship. However, the origin of the behavior problems for children with FASD are most likely rooted in the brain damage caused by prenatal exposure to alcohol. Thus the general PCIT intervention needs to be adapted to accommodate specific parenting skills that work within the learning and behavior skills of the child with an FASD who has brain damage.

## 7.1. Methods

### 7.1.1. Participants

A total of 58 children 3–7 years of age with an FASD and their caregivers were recruited for participation in this study. The FASD diagnosis was made by a clinical geneticist using a modified IOM criterion after a clinical dysmorphia and CNS evaluation. Children participating had to have cognitive functioning at  $\geq 30$  months as measured by the *Bayley Scales of Infant Development*-second edition (Bayley, 1993) or the *Wechsler Preschool and Primary Scales of Intelligence*-third edition (WPPSI-III; Wechsler, 2002). Caregivers had to have an IQ of  $\geq 65$  on the K-BIT (Kaufman & Kaufman, 1990) to obtain reasonable comprehension of self-report measures. Sample characteristics are presented in Table 1. Of the 58 children recruited for the study, 46 entered treatment and were randomized.

### 7.1.2. Measures and procedures

The project used a randomized two-group longitudinal design. A blocked randomization pattern was used to ensure that both intervention conditions had equivalent proportions of biological versus nonbiological parents and equivalent proportions of male and female children. Following a comprehensive developmental and genetics evaluation to ascertain that FASD inclusion criteria were met, all families received a basic education/advocacy service prior to the parenting intervention.

Participant in both treatment and comparison conditions received 14 weeks of the assigned intervention (PCIT or PSM), with each weekly session lasting 90 min. Measures of child disruptive behavior problems and parenting stress were collected at each weekly treatment visit. A larger test-battery of measures was collected at baseline, mid-treatment, and treatment completion.

The PCIT intervention caregivers and children both were seen for treatment. Families were seen with their children for all but 2 of the 14 weekly sessions. Those two sessions focused on behavior education in general to orient families to the concept of behavior changes. In the remaining sessions, skills taught to the caregivers were practiced in session with their child with in vivo coaching via a one-way mirror and listening device placed in the parent's ear (bug-in-the-ear). Parent-child interactions were scored (coded) prior to treatment in order to assess areas most in need of intervention, as well as to establish a baseline of parent-child interaction pattern. At each of the sessions, an assessment of skills was obtained to focus the session in a family-specific manner. Families were provided feedback after each session regarding their progress in acquiring targeted skills and homework between sessions. They moved through the intervention based on skill acquisition.

The comparison program for this study also had a group format for parents only, intended to represent a plausibly beneficial but less costly and intensive intervention that could be easier to implement in community settings. It incorporated elements and approaches adapted from other supported behavioral programs shown to reduce behavior problems among children (Barkley, 1997; Webster-Stratton, 2001). The components included psychoeducation about development among children with an FASD, then moved families from awareness through acceptance and then to action, including ideas such as behavioral contracts and star charts. Discussions of implementation, challenges, and problem solving were part of each session with the group participants.

Prior to beginning the intervention, all parents completed a series of questionnaires. These included the *Parenting Stress Index third edition-Short Form* (PSI; Abidin, 1995), the *Eyberg Child Behavior Inventory* (ECBI; Eyberg & Pincus, 1999), and the CBCL. All of these measures have strong psychometric properties. An observation of parent-child interactions was completed and rated using the *Dyadic Parent-Child Interaction Coding System-II* (DPICS-II; Eyberg & Robinson, 2002) (presented elsewhere). The PSI and ECBI were completed each week. The ECBI shows good treatment sensitivity, such that any change is due to intervention rather than passage of time. All measures were administered again at the completion of treatment and at follow-up appointments.

## 7.2. Results

Approximately half (46%) of families in the study completed the entire 14-week treatment program (50% for PCIT, 42% for PSM). In general, an attrition rate of 50–75% has been reported for children referred for treatment associated with externalizing behavior problems (Brinkmeyer & Eyberg, 2003), so the observed rates were well within that range. Group differences in attrition were examined using a simple nonparametric survival analysis. This approach allows examination of dropout events and hazard rates across time. Group differences did not approach statistical significance and the survival and hazard functions visually appeared quite similar. Qualitative surveys of reasons for dropout were examined and, most often, dropout was reported to have little to do with the intervention and more to do with life circumstances (e.g., military deployment, serious illness, surgery, death in the family, removal of child from home, and job conflicts). The average number of sessions completed was 9.14 for the PCIT group and 8.92 for the PSM group.

Weekly PSI and ECBI measures were analyzed using growth models. Models for each of the two ECBI scale scores (Intensity and Problem scales) and the overall PSI score were executed. Each model treated intercepts and slopes as random effects and included tests for group differences in intercepts and slopes. Significant time (session) effects were observed for the PSI ( $p < .05$ ), the ECBI Intensity score ( $p < .001$ ) and the ECBI Problem score ( $p < .001$ ). All effects were in the direction of significant reductions in scores across time. Group comparisons of time slopes (i.e., improvement rates) did not reach statistical significance for any of the three tests, although there was a nonsignificant trend favoring PCIT for the PSI ( $p = .14$ ).

To estimate prescores and postscores from the growth models, estimated marginal means were generated for the pretime and posttime points. For children in the PCIT group, the mean EBCI pre-test standard score was 65, with a mean standard score of 58 post-test. For the PSM group on this measure, the mean pre-test standard score was 63, with a mean standard score of 57 post-test. Mean ECBI scores were in the clinically significant for both groups at baseline. At post-treatment, mean scores for both groups had dropped below clinical cutoffs. Examining variance components of the growth model suggested that there was very little case-to-case variation in rates of improvement across sessions.

For parents in the PCIT group, the mean PSI pre-test standard score was 97, with a mean standard score of 84 post-test. For the PSM group parents, on the PSI, the mean pre-test standard score was 88, with a mean standard score of 85 post-test.

### 7.3. Discussion and conclusions

Improvement over time was noted across outcome measures and across intervention conditions. No statistically significant differences in improvement between the two randomized intervention conditions were observed. Significant overall improvement in parent distress over time was noted across participants, and there were nonsignificant trends for group PCIT to yield somewhat greater rates of improvement. Child behavior problems also improved over time for both groups at rates that did not differ. Because the study did not include a placebo or no-treatment condition, spontaneous improvement, regression toward the mean or measurement artifact cannot be ruled out as explanations for improvement over time. Nonetheless, it is more likely that the improvements were to some extent the result of the interventions rather than simply the passage of time. As the measure of behavior problems, the ECBI has been found to be stable over timeframes comparable with those in this study, with change usually noted only in response to effective intervention (Eyberg & Pincus, 1999). Furthermore, research related to children with FASDs who have behavior difficulties in the significant range (as these children presented), generally do not show decreases in problems with time (Streissguth et al., 1996).

This study also found promise for reduction in behavior problems using a simple and easily implemented parent-only support and education intervention—PSM. This format might prove more cost effective in working with families with children with FASDs, given that it would require less effort and cost to deploy. Parents in both intervention programs were satisfied with treatment. All PCIT parents reported feeling positive about the program, and indicated that they would recommend it to a friend or relative. All parents enrolled in the PSM group also reported feeling positive about the program, and 80% indicated that they would recommend PSM to a friend or relative. In terms of behavioral change, 100% of PCIT parents felt that their presenting problems had improved, while 70% of PSM parents reported improvement. All parents felt neutral or confident that their child could manage future behavior problems using the skills from their respective programs. No significant differences in mean overall satisfaction were seen between groups.

In sum, the study generally supported both intervention models as viable alternatives for caregivers of children with FASDs, which was encouraging. Clear improvement can be observed using even brief behavioral interventions, using different types and intensities of behavioral interventions, even within the context of limited intervention dose and retention. This was particularly encouraging given that behavior problems among children with FASDs are generally viewed as strongly neurologically involved and not simply the product of parent–child interaction patterns.

A few limitations and corresponding directions for future research should be considered. First, the study sample was small and precluded examining potentially important case factors that might have suggested a differential benefit for one intervention model over the other. For example, it is possible that group differences might have existed depending on the initial level of a child's disruptive behavior or the parent's distress. Second, not all potentially important outcomes were examined. For example, it would have been important to learn whether the improvements noted on parent-report measures would translate to school or other environments. The nonsignificant trend favoring PCIT for reducing parent stress needs to be examined in a study with greater statistical power (i.e., having a larger sample size).



## 8. Study 5. Families moving forward: a behavioral consultation intervention to improve outcomes for families raising children with fetal alcohol spectrum disorders (University of Washington)

The overall goal of this study was to evaluate an intervention designed to improve caregiver self-efficacy, meet family needs, and reduce child problem behaviors. The specific aims of the study were: (a) to create a feasible, specialized behavioral consultation intervention – the Families Moving Forward (FMF) Program – for caregivers raising children with FASDs, based in part on positive behavior support techniques, and (b) to assess the efficacy of the FMF intervention, when compared with the community standard of care, using a randomized control trial design.

Most children with FASDs are identified in elementary school—a pivotal time when neurodevelopmental deficits and problematic, often disruptive behavior commonly emerge among children with prenatal alcohol exposure. What can be called “challenging behavior” is an important issue for this child population. In clinical data for 861 school-aged children referred to an FASD diagnostic clinic network in Washington State, a striking 82% showed a variety of behavior and learning problems. Parents raising children with FASDs often are highly stressed by these children (Paley et al., 2006) and these families have many unmet intervention and resource needs (Olson, Brooks, Davis, & Astley, 2004). Clinical experience and wisdom in the field suggest these parents struggle to attain positive parenting attitudes, find and use effective parenting skills, acquire needed specialized knowledge, and make effective linkages to appropriate school and community resources (Olson, Jirikowic, Kartin, & Astley, 2007).

Developmental systems literature and natural history research on individuals with FASDs has identified a cluster of factors describing a nurturing, appropriately structured, stable caregiving environment in childhood as an important protective influence for positive outcome (Streissguth et al., 2004). Translation of these concepts into tailored, useful, family-focused, scientifically validated parenting and behavior management intervention methods for use by clinicians is an important next step. Interventions are needed especially for use with caregivers raising children with FASDs who in the preschool and school years already show challenging behaviors of clinical concern, with inevitable signs of family and school disruption. Parenting intervention methods must be flexible enough to apply to the very diverse group of birth, foster, kinship, and adoptive families who raise children with FASDs. Intervention methods must also respond to the often complex psychosocial histories and circumstances of these children.

The FMF model was designed to modify specific parenting attitudes and parenting responses toward their child's problem behaviors. Through changed caregiving, the ultimate aim of FMF services was to reduce clinically concerning child problem behavior and improve other outcomes during the school years. The newly developed FMF model of behavioral consultation integrated several empirically supported child management and parent training techniques—and the clinical wisdom of “what works” in the field of FASDs (Kalberg & Buckley, 2007; Kleinfeld & Westcott, 1993; Streissguth, 1997). Most centrally, clinicians using the FMF intervention teach caregivers the skills involved in a “parent-friendly” positive behavior support approach to dealing with challenging child behaviors (called “brainstorming”). Developed in 2002, this approach is based on social learning theory and is congruent with evolving literatures on developmental disabilities and traumatic brain injury (e.g., Hieneman, Childs, & Sergay, 2006; Koegel, Koegel, & Dunlap, 1996; Lucyshyn, Dunlap, & Albin, 2002; O'Neill et al., 1997; Schoenbrodt, 2001; Ylvisaker et al., 2007). The FMF model simplifies and organizes the positive behavior support approach to make it systematic and usable for parents and clinicians. In the FMF intervention model, there is a strong emphasis on helping parents to learn and use antecedent-based behavior strategies, as well as on how to create and advocate for “accommodations” (modifications of the physical or caregiving environment) for their child. Clinicians using the FMF intervention assist caregivers in altering cognitions and attitudes, most centrally “reframing” their understanding of the behavior of the child with FASDs as affected by neurodevelopmental disabilities rather than as willful disobedience. The FMF intervention is hypothesized to improve parenting self-efficacy; meet family needs; reduce child-related stress; lead to other beneficial changes in parenting knowledge and behavior; and, ultimately, reduce “challenging” child disruptive behavior.

## 8.1. Methods

### 8.1.1. Participants

A sample of 52 children 5–11 years of age and their caregivers were enrolled from the Washington State FAS Diagnostic and Prevention Network (FAS DPN) of diagnostic clinics. Child participants all had measurable externalizing or attention problems, or both, of clinical concern at enrollment using an age-appropriate version of the CBCL (Achenbach and Rescorla, 2001b). All had evidence of variable but clear neuropsychological impairment and marked adaptive function problems seen in comprehensive test results across multiple developmental domains, yet were high-functioning enough to show a verbal IQ of  $\geq 70$  (and a group mean score well within the average range) on the K-BIT. There were other inclusion and exclusion criteria (e.g., living within driving distance of the University of Washington and no history of head injuries.). This sample was carefully selected to focus on children with FASDs who had demonstrated significant challenging behaviors at a young age, and were those most likely to show later costly secondary disabilities. See Table 1 for sample demographics.

### 8.1.2. Measures and procedures

A study was conducted using a stratified, randomized block design to assign families to either the FMF intervention group or to the community standard of care group, balanced on race or ethnicity, child sex, and birth or non-birth parent family structure. The community standard of care group received any of a range of services currently available in Washington State, which is a relatively well-served geographic area. This was a conservative intent-to-treat study design, so all participants enrolled in treatment were included in the analysis regardless of treatment dose received. Analyses revealed groups (each with  $N = 26$ ) were well-matched on these variables, and on child age, alcohol-related diagnosis at enrollment, cumulative postnatal risk, and caregiver education.

The FMF intervention is a feasible, low-intensity, sustained model of supportive behavioral consultation lasting 9–11 months, with at least 16 every-other-week sessions typically lasting 90 min each. Services are carried out by mental health providers who receive affordable, specialized training to carry out the intervention. Limited and focused consultation with school staff and, when appropriate, community providers are available. This is an “added value” intervention, so FMF participation does not preclude families or children from receiving medication or other community services. In fact, interventionists also try to link families to needed resources in the community. The FMF intervention is manualized into a “flow” of sessions, but is also individualized for different families. There is a curriculum of easily readable, brief written materials to select from and use in sessions easily obtainable from the FMF training office. Checklists, now computerized, completed by providers after each session allow efficient monitoring of intervention fidelity. Interventionists have access to a supervisor, resource information from an FASD family advocacy group, and, if needed, brief expert consultation from a psychologist or occupational therapist, or both. In this initial efficacy trial, FMF services were provided in families' homes, but the intervention model was developed to be flexible enough for use in a variety of clinical settings.

The FMF intervention was newly developed, so some outcome measures were created for the study; and multiple aspects of sample characteristics, treatment process, and treatment outcome were examined. Primary outcomes discussed here include change from baseline to follow-up on: (a) parenting attitudes of efficacy and child-related stress as measured by the Parenting Sense of Competence (PSOC) Efficacy Scale score (Johnston & Mash, 1989); (b) stress levels as measured by the PSI Child Domain score (Abidin, 1995); and (c) caregiver ratings of child disruptive behavior immediately post-intervention as assessed by the ECBI Problem score (Eyberg & Pincus, 1999). Also discussed here are group differences at follow-up on: (a) perceived family needs met (a measure developed for this study assessing satisfaction with support received from child- and family-focused services) (family needs met, average of applicable needs met); (b) self-reported rating of change in parental self-care across the intervention period (a measure developed for the study); and (c) caregiver ratings of satisfaction with provider skill in caring for children with special health care needs using the Multidimensional Assessment of Parental Satisfaction (MAPS) score (Ireys & Perry, 1999). Results reported here were gathered immediately post-treatment, unless otherwise noted (e.g., PSI). The PSOC, ECBI, PSI, and MAPS all have very adequate psychometric properties.

## 8.2. Results

One hundred percent of children and 96% of caregivers completed baseline and follow-up assessments across both study groups. Of the 26 families enrolled in an intervention, 96% completed the full 9–11-month treatment (with one of the families completing a simplified intervention retaining all basic features of the model). Analyses were based on all 52 children (FMF group,  $N = 26$ ; community standard group,  $N = 26$ ).

Compared with caregivers in the community standard of care group, from baseline to follow-up, caregivers participating in the FMF intervention showed a significantly improved sense of parenting self-efficacy immediately post-treatment. A greater percentage of caregivers parents in the FMF intervention group reported engaging in more self-care behaviors than parents in the community comparison group (72% versus 44%, respectively;  $p < .05$ ). No group differences emerged for change in child-related parenting stress, which was not surprising given the ongoing, marked executive functioning, other language and learning deficits or low adaptive function of these children.

A highly significant group difference ( $p < .01$ ) revealed that the FMF intervention group reported their family needs were met more often than did the comparison families. In addition, provider satisfaction was significantly higher among those in the intervention group. On average, parents receiving the intervention also reported FMF services as highly acceptable (mean of 6.51 overall on averaged 7-point scales, where 7 is the highest score), and that they had received “just the right amount” of services for their child and themselves. Intervention was delivered with good fidelity.

Findings of perceived child behavior change were also observed. Caregivers receiving FMF services reported immediately after treatment that their children with FASDs showed a significantly decreased number of challenging disruptive behavior problems. On the ECBI, a parent report measure, children in the FMF intervention group achieved a mean standard score of 66.88 at pre-test, clearly in the clinical range. At post-test, these children showed a mean standard score of 60.54—a score just above the cutoff between the borderline clinical range and what is considered within normal limits. Among those in the community comparison group, scores at baseline and follow-up indicated clinical concern about child behavior, with the mean ECBI pre-test standard score at 64.38 and the mean post-test standard score at 63.20. The group difference was statistically significant ( $p < .05$ ). Child behavior change over time, correlates of positive outcome, and group differences in parenting knowledge and behavior change will be discussed in future publications.

## 8.3. Discussion and conclusions

Children with FASDs and clinically concerning behavior problems, especially disruptive behavior and attention problems, place a heavy burden on caregivers at home and at school, and often come to the attention of mental health providers (Fryer, McGee, Matt, Riley, & Mattson, 2007; O'Connor et al., 2002; Streissguth & O'Malley, 2000). Preschool and school-aged children already struggling with clinically concerning behaviors are likely at highest risk for secondary disabilities in daily function later in life, which will require services that increase societal costs. The FMF model appears to provide a feasible, satisfying intervention with promising efficacy tailored to this high-priority group of children with FASDs and their caregivers. Data from this controlled study so far indicate a positive effect on parenting attitudes and headway on reducing child disruptive behaviors. More efficacy research is needed. Now under way in programmatic research is a project designed to streamline and transition the FMF training program and intervention from its use in a university setting to use by providers in a community setting. The current research will further assess FMF intervention feasibility and efficacy, examine program costs, ensure the FMF training program and intervention model are affordable, and make this scientifically validated intervention more widely available to families in need.

## 9. General discussion

Until now, information and strategies for interventions specific to individuals with FASDs have been gleaned from work with children having other disabilities (without appropriate adaptation) and

the practical wisdom gained by parents and clinicians through trial and error. Although informative to a limited degree, such evolving treatments have been implemented without systematic or scientific evaluation. The five interventions presented here are the first specifically designed and adapted for children with an FASD that have been scientifically tested.

These five diverse interventions uncovered basic ingredients that seem important to their success with individuals who have an FASD. Importantly, parent education or training was built into the general framework guiding all the studies. In two (Washington and Oklahoma) studies direct parent training was the primary intervention being assessed. In all studies, parents or caregivers showed improved knowledge about FASDs and applicable parenting issues. Also important was that a primary technique utilized was explicit instruction of the children (California, Georgia, and Illinois). That is, children with an FASD demonstrate a good capacity to learn new skills yet, because of underlying neurological impairment, must do so through explicit instruction rather than through observation and a process of abstracting rules, skills, and knowledge from ongoing situations as do children who are developing typically. Even those interventions focused on parent training included some amount of information on the efficacy of explicit instruction when working with their child with an FASD.

These five studies represent the wide range of possible treatments for children with cognitive, behavioral, or social problems resulting from prenatal alcohol exposure. It is essential to use programmatic research to develop multiple interventions that address the wide range of potential deficits associated with the FASD population. This approach to developing appropriate interventions is important because, as a group, children with FASDs are very heterogeneous in the nature and severity of their problems. The services needed for individuals with FASDs and their families vary according to differing neurological insults, the age or level of maturation of the child, the health or functioning of the family (see [Streissguth, 1997](#); [Streissguth et al., 1996](#)), and the overall environment in which the child is living.

Another vital finding across the five reported interventions was that the individualized and targeted interventions specific to deficits among children with an FASD can be implemented within a framework of current community services typically available. Each project worked with already available resources such as special education, therapy services, or counseling to integrate value-added interventions specific to individuals with FASDs. As a result, these scientifically validated intervention projects moved the field forward within a community services context, rather than duplicating already available services.

As with any set of research projects, strengths and weakness were identified. Inclusion of parents as active participants and collaborators in the intervention process, either by direct intervention or adjunct parent training, was a tremendous strength of these research projects. Finally, these projects all benefited from the collaborative nature of the overall research consortium. The consortium allowed individual researchers to recognize problems common across all sites (e.g., recruitment or retention problems) and share solutions.

Intervention research is always a challenge with inherent weaknesses. First and foremost, these interventions were time-limited by funding constraints. A clear need remains to address the long-term effects and follow-up of each intervention. Whether children retained specific skills and knowledge beyond the intervention and follow-up periods could not be addressed in these studies. Further children's ability to generalize newly acquired skills could not be addressed either. For example, although they might learn a math skill or executive functioning technique appropriate for their current age, it is critical to know whether they retain that information as they enter the next developmental or academic stage. It is also important to know whether, once a skill is acquired within one domain, children are able to apply that skill to another domain. For example, if a child masters the skill of adjusting his or her readiness to learn through behavioral regulation techniques to complete mathematics assignments, will he or she be able to apply that skill to other assignments (such as writing) without specific instruction. Finally, because the overall population of children with FASDs is limited, the sample sizes in these studies were limited, although sufficient to demonstrate statistically significant effects. Thus, replication of these studies will be necessary to more solidly establish the reliability of the findings and strengthen their demonstrated effectiveness.

A major implication of these research studies for families dealing with FASDs is that they now have available tested interventions that can address their children's needs and that can be presented as

scientifically validated and efficacious to intervention agents such as schools, social services, or mental health providers. A common theme reported by families is that clinicians and professionals have been reluctant to diagnose their children because there were no known effective treatments. Results of these five studies clearly dispel that concern. An important next step includes each site partnering with a community agency to adapt its intervention program to the resources, infrastructure, and personnel of its community partner agency.

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