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Running head: FETAL ALCOHOL SPECTRUM DISORDERS

Fetal Alcohol Spectrum Disorders: Identifying Family Factors, Characterizing Child Behaviors,
and Evaluating a Parent Education Program

By

Lauren B. Davis

Submitted in partial fulfillment of the requirements
for Graduation summa cum laude

University of Louisville

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Abstract

Fetal Alcohol Spectrum Disorders (FASD) refers to the group of conditions that results when a developing fetus is exposed to alcohol and is considered one of the leading causes of mental retardation and birth defects in the United States. Children with FASD typically have emotional and behavioral disabilities as well as poor academic functioning. Few empirically supported programs have been specifically designed for parents of children FASD. The present work aimed to evaluate a new FASD intervention and to identify characteristics of families raising a child with FASD. Thirty-one families with children ranging from 2 to 11 years of age participated in a 3-hour parent education program, which included educational information, discussions with FASD experts and other parents, and an evaluation of the intervention. Results showed that parents felt a great deal of stress and more than a third had elevated symptoms of depression. In addition, children scored high on intensity and severity of behavior problems. Families reported that the education program was valuable and increased their understanding of their child both initially and after one year. A statistically significant decrease in problem behaviors was seen one-year after the intervention, but parent stress was found to stay the same.

Keywords: Fetal Alcohol Spectrum Disorders, Intervention, Parent Education, Foster Families, Child Behavior, Parent Stress, Parent Attitudes

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Fetal Alcohol Spectrum Disorders: Identifying Family Factors, Characterizing Child Behaviors,
and Evaluating a Parent Education Program

Fetal Alcohol Spectrum Disorders (FASD) refers to the group of conditions that occur when the developing fetus is exposed to alcohol, and includes Fetal Alcohol Syndrome (FAS), Alcohol Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defects. Fetal Alcohol Spectrum Disorders are considered one of the leading causes of intellectual disabilities and birth defects in the United States (Bertrand, Floyd, Weber, O'Connor, Riley, Johnson, Cohen & National Task Force on FAS/FAE, 2004). The Centers for Disease Control (CDC) has conducted studies that have suggested that Fetal Alcohol Syndrome, the most severe of the FASDs, is present in 1.5 of every 1000 live births in the United States (The Centers for Disease Control and Prevention, 2011). Some estimates suggest that as many as one in every 100 births is affected by prenatal alcohol exposure (Sampson, Streissguth, Bookstein, Little, Clarren, Dehaene, Hanson, & Graham, 1997). This means that thousands of children are born with alcohol exposure every year.

Despite this, Fetal Alcohol Spectrum Disorders are greatly under identified and thus often treated improperly. FASD is often referred to as an invisible disability, as frequently there are not obvious physical symptoms. In order to meet criteria for a diagnosis of Fetal Alcohol Syndrome, the individual must present with characteristic facial features including a smooth philtrum, a thin upper lip, and a short distance between the inner and outer corner of the eyes. Additionally, the individual must have growth problems and central nervous system problems. Known alcohol exposure is helpful for a diagnosis, but not required. Other diagnoses, which fall on the spectrum of FASD, can be given if the individual does not meet criteria for full Fetal Alcohol Syndrome, including Alcohol Related Neurodevelopmental Disorder and Alcohol

Related Birth Defects (Bertrand et al., 2004). These conditions can present in a variety of ways and their effects vary from mild to severe.

Symptoms and Impairments

The main impairment that is present in individuals with Fetal Alcohol Spectrum Disorders is a decrease in executive functioning. Executive functions are sometimes referred to as the “CEO of the brain” (McCloskey, Perkins & Van Divner, 2009) and are involved in a multitude of daily activities. The National Center for Learning Disabilities describes executive function as the set of mental processes that help connect past experiences with present actions (NCLD editorial team, 2012). Executive functions are used to perform day-to-day activities including planning, organizing, strategizing, paying attention to details, memory, and time management. Individuals affected by prenatal alcohol exposure often have behavioral challenges as well as learning impairments (Bertrand et al., 2004).

In addition to issues with executive functioning, individuals with fetal exposure to alcohol also may have central nervous system issues resulting from structural brain abnormalities. These impairments vary widely based on the individual, but can range from mild to quite profound. Some possible issues that may arise include memory deficits, poor academic skills, struggles with social skills, poor information processing, attention difficulties and delayed motor skills. These are in addition to potential behavioral and mental health issues (Bertrand, Floyd, O'Connor, Frankel, Paley, Coles...Astley, 2009). Each affected individual presents with a different set of symptoms and impairments based on how much alcohol was consumed during the pregnancy, the timing of the exposure, the environment, and genetic makeup of the individual (Streissguth, 1997).

Executive Functions

One study specifically looks at the executive function deficits that exist in children with prenatal alcohol exposure. This article defines executive functions as “a number of complex cognitive processes that are interdependent and essential to purposeful, goal-directed behavior” (Pei, Job, Kully-Martens & Rasmussen, 2011). These include self-monitoring, working memory, attention, and organization. The main executive function impairments that have been identified in this population are cognitive planning and set shifting. This study found that children with Fetal Alcohol Spectrum Disorders had more significant memory deficits than the control children (Pei et al., 2011).

Other researchers have defined executive functions as “future-oriented” processes. Executive functions differ from basic cognitive processes and are the integration of these basic processes. The resulting executive functions include planning and sequencing, organization of behaviors, self-regulation, and cognitive flexibility. These same researchers found that the executive function difficulties present in a sample of individuals with prenatal alcohol exposure are not better explained by the lower IQ of these individuals (Connor, Sampson, Bookstein, Barr & Streissguth, 2000).

As stated, many models of executive function exist. One of these (Figure 1) represents them in tiers of executive capacity. The tiers include an array of executive functions broken down into five main tiers. These include self-activation, self-regulation, self-realization, self-determination, self-generation, and trans-self-integration. This model gives a visual representation of how executive functions can be viewed (McCloskey et al., 2009).

Current Interventions

Fetal Alcohol Spectrum Disorders are lifelong conditions and there is no cure. Treatments and interventions exist to help in symptom management and allow children and families to better manage the resulting behaviors. Current treatments for FASD include medications to manage symptoms (including stimulants, antidepressants, neuroleptics, and anti-anxiety medications), behavior and education therapy, and parent training programs (Bertrand et al., 2004). Few programs have been specifically designed for families who are raising a child with a Fetal Alcohol Spectrum Disorder (Carmichael-Olson, Rudo-Stern & Gendler, 2011). Furthermore, very few empirically based interventions exist to address the needs of these families.

Empirically Based Programs

The CDC recently evaluated five empirically based studies that are designed for working with children who have a Fetal Alcohol Spectrum Disorder in response to the Healthy Children Act of 2000. Three of these programs focused specifically on the child, including a friendship training, specialized math tutoring, and executive functioning training. These will be described briefly in the following sections. Additionally, two studies were evaluated that focused on the family systems—a parent-child interaction therapy and a parent-training program designed to reduce parenting stress. These two studies will be explained in further detail as they most closely resemble the program utilized in this study. Prior to these studies, much of the known information about FASD has been gathered from anecdotal evidence from parents and clinicians (Bertrand et al., 2009).

Interventions focused on the child.

Project bruin buddies. The University of California at Los Angeles has evaluated a friendship training for children with FASDs that aims to alleviate some of the difficulties these

children have with engaging with others, which is often expected to continue into adulthood. This training teaches the children a variety of skills including interacting with friends, joining into a group, and negotiation. This training was conducted for 90 minutes each week over the course of twelve weeks. The parents received concurrent training on issues related to FASDs and discussed the skills being taught to their children. This training resulted in improvement in the child's knowledge of acceptable social behaviors and parent reports confirmed this. This was found also to be true three-months post-training. Additionally, parents reported that they found the information they received to be useful (Bertrand et al., 2009; O'Connor, Frankel, Paley, Schonfeld, Carpenter, Laugeson, & Marquardt, 2007).

MILE program. The Marcus Autism Center in Atlanta, Georgia evaluated the effects of a specialized math-tutoring program to increase math skills in children with FASD. The program consisted of two parts. The first of these included an intensive psychoeducational program that provided learning strategies to the child. The second component was a training for the child's teacher and guardian. Parents that participated in this program were required to attend two training workshops. The first workshop educated parents on FAS, special education, and methods for being an advocate for their child. The second workshop was a training on building positive behavioral regulation skills. After the parents completed the workshops, the children received six weeks of tutoring and the educator met with the child's teacher to discuss the effects of prenatal alcohol exposure.

This program was found to increase knowledge of FASDs, topics related to advocacy, and behavior regulation. After participation, caregivers reported fewer behavioral problems. A full 58.6% of the children who participated in the MILE program showed a gain in math skills,

compared to 23.1% of those in the control group (Bertrand et al., 2009; Kable, Coles, & Taddeo, 2007).

Executive function training. The Children's Research Triangle in Chicago, Illinois developed a program to educate and support families caring for a child with a diagnosis of FAS or ARND as well as to improve executive functioning skills. The executive function training taught self-control and behavioral awareness through the metaphor of a car engine. This program was conducted in weekly seventy-five minute sessions over the course of twelve weeks. The parents participated in a parent education group concurrently. Children who participated in this program were found to have a significant improvement in their executive functioning and story narration. (Bertrand et al., 2009). These results have been replicated in a recent follow-up study (Wells, Chasnoff, Schmidt, Telford, & Schwartz, 2012)

Interventions focused on caregivers.

Parent-child interaction therapy (PCIT). Parent-Child Interaction Therapy has been empirically evaluated for children ages 2-7 who have disruptive behaviors. The focus of the therapy is to change the interactions between the parent and the child and improve their relationship. Parents are taught a variety of skills to help them have a strong and positive relationship with their child while also increasing pro-social behaviors in the child. This is aimed at reducing or eliminating unwanted behaviors in the child. PCIT has been shown to be an effective treatment model for children 4-12 who have a history of abuse or neglect and children who have prenatal substance exposure (OU Medicine, 2012).

The University of Oklahoma Health Services Center evaluated a group-based PCIT aimed to reduce behavior problems and decrease parenting stress in a FASD population. This therapy is designed to enhance the relationship between parent and child and increase social

skills, thus decreasing problem behaviors. This intervention lasted for fourteen weeks, with weekly ninety-minute sessions. During the majority of the sessions, skills were practiced with coaching through a one-way mirror and a listening device placed in the parent's ear. Families received feedback after each session. Over time, parent distress decreased as a result of this program and child behavior problems were reduced. The study also reports evidence of a parent-only education intervention being effective (Bertrand et al., 2009).

Families moving forward (FMF). The University of Washington developed a training to improve caregiver self-efficacy and meet the needs of the family, thus reducing negative child behaviors. This program was designed to modify attitudes of the parents and their response towards problematic behaviors. Additionally, there was an emphasis on advocating for accommodations for their child and reframing the parents' understanding of their child. This intervention took place in 16 every-other-week sessions, each lasting ninety minutes. In total, it lasted between nine and eleven months. This model resulted in a self-reported improved sense of efficacy in the parents, but no reduction in parenting stress was found. Additionally, there was a decline in negative child behaviors (Bertrand et al., 2009).

During this intervention, an FMF Specialist listened to the concerns of the parent and helped prepare the family for what can happen and what needs to be done in the future. One FMF specialist commented that one of the positive results of this program is that the caregiver feels more optimistic, yet realistic, about his or her child's future. In addition, this program aimed to connect families with sources of support and educate the parents on advocacy skills. The listed goals of the Families Moving Forward Program in relationship to FASD included helping parents better understand their children, giving parents new strategies and skills to

utilize, encouraging positive progress, fostering hope and optimism in families, and training health care providers in evidence-based practices (Olson).

Limitations of Present Trainings

Current trainings for FASD are all very lengthy, with some time commitments of up to sixteen weeks. This can be difficult for families to commit to, especially when raising a child with behavioral issues. These studies do not address the caregiver relationship to the child. This is important because as many as 85 percent of children with FAS are being raised by adoptive or foster parents, or other non-parental relatives (National Organization on Fetal Alcohol Syndrome, 2006). A recent study estimated that the prevalence of children with FAS (or a related disorder) in the foster care system is 10 times that of the general population (Astley, Stachowiak, Clarren, & Clausen, 2002). These trainings also did not specifically address both increasing caregiver self-efficacy and education regarding executive functioning. In studies specifically focused on the child, researchers often had to exclude children with an IQ below 70, as it was assumed they would be unable to retain the presented information. Finally, no long-term evaluation was done of several of these interventions to determine their utility after the initial trainings. It is evident through the variability in the present trainings that little is known on how to best work with these families. However, each study adds more to the growing body of literature regarding these disorders.

The most promising of these evaluated trainings is the Families Moving Forward training, which focused on reducing parent stress, increasing caregiver self-efficacy, meeting family needs, and reducing child behavior problems. However, the education program in the present study also addresses the deficiencies caused by FASD and specific impairments that may

exist. In addition, parents were given a booklet to fill out in order to help them engage in the material, and also to be able to share with others who play a role in the child's life

Current Study

As described above, the current interventions for children with FASD and their parents are time intensive and have not been implemented for community samples. The current project was developed in order to determine the feasibility of developing a short educational training for parents of children with FASD. The CDC has recognized that developing scientifically validated interventions as vital in order to help not only these families, but as being an educational and public health need. (Bertrand et al., 2009)

The goal of this short FASD education program is to provide parents additional information about their child's disability, as well as offer different parenting strategies to help their child. This information was presented in a way that encourages parents to look at the child's behavior from a new perspective. Across a one-year period, parents were invited to a one-day workshop in small groups. This descriptive pilot study focused on three main goals.

Goal 1: The first goal was to better characterize parenting strategies and parenting stress in a sample of families who are raising a child diagnosed with a Fetal Alcohol Spectrum Disorder. Relatedly, researchers were interested in characterizing parent ratings of child behaviors and the challenges faced by these parents. This information was obtained using standardized questionnaires.

Goal 2: The second goal of this study was to evaluate the parent's response to a one-day parent-education program using training elements which have been conducted statewide for several years with developmental disabilities professionals. As far as is known, no formal evaluation of this program has been conducted. The FASD parent education program is designed

to heighten parents' understanding of their child's disability and provide them with techniques for working with their child to overcome social and educational barriers. The centerpiece of this program is the completion of a workbook titled "All About Me" that encourages parents to view their child's behavior from a different perspective. Following the education program, parents provided their assessment of the program. A focus of the assessment is whether the education program was informative and in their judgment would have an impact on parenting.

Goal 3: The third goal of this descriptive pilot project was to evaluate the utility of this education program after one year. To address this, parents were sent a second assessment of whether the education program has had an impact on parenting approximately twelve months following the parenting education program. At this time, parents also completed assessments on aspects of parenting stress and child behavior.

Method

Participants

Thirty-one families participated in this study. These families were recruited through the Weisskopf Child Evaluation Center within the University of Louisville Department of Medicine in Louisville, Kentucky. The children recruited had previously been evaluated by trained clinicians and all had a diagnosis within the spectrum of FASD. The children in these families ranged from 2 years to 11 years of age (24.3 months to 134.8 months, $M = 83.79$, $SD = 28.6$) at the time the initial assessments were completed. A histogram representing the distribution of ages can be seen in Figure 2. There were 8 female and 23 male children in this study. The majority of these families had incomes ranging from \$30,000 to \$75,000. Two male and twenty-seven female caregivers (ages 25 to 61 years of age, $M = 46.54$, $SD = 9.30$) attended the sessions, and two children had both a male and female caregiver present. These sets of parents filled out

one set of assessments together. Sixteen of these caregivers were adoptive or foster parents while the remaining fifteen were relatives (such as grandparents, fathers, or aunts). The mean amount of education for the caregivers was 13.85 years ($SD = 2.60$). Each family was given a ten-dollar Thornton's gas card to cover travel expenses as well as a fifteen-dollar Wal-Mart gift card as compensation for their participation. As compensation for completing the follow-up assessments, each family was given a second fifteen-dollar Wal-Mart gift card.

Human Subjects Approval

This study was approved by the University of Louisville Institutional Review Board. Informed consent was obtained from the legal guardian of the child participating prior to the collection of data.

Materials

Child Assessments. The Eyberg Child Behavior Inventory (ECBI; Eyberg & Pincus, 1999) was used to measure children's behavior (See Appendix A). The Eyberg is a thirty-six item measure that gives scores on two scales. The first scale, ECBI Intensity scale, indicates the severity and frequency of conduct problems as rated by the parent. Scores on this scale range from 36 to 252 with a higher score reflecting higher intensity of conduct problems. The ECBI Problem scale identifies how problematic the conduct problems are to the parent. Scores on this scale range from zero to thirty-six with higher scores indicating that the parents see the conduct problems as problematic (Eyberg & Pincus, 1999).

Parent Assessments. Four parent assessments were used. Three assessments were focused on aspects of parenting and the fourth was a screening for depression.

Parent stress. Parent stress was measured by the Parenting Stress Index, 3rd Edition (PSI) with thirty-six questions on three scales, which are combined to give a measure of total parenting

stress (Appendix B). The PSI Parental Distress scale assesses the anxiety and other emotional stressors brought about by parenting in the caregiver's life. The PSI Parent-Child Dysfunction Interaction scale indicates how much satisfaction the parent derives from interaction with their child and how much the child meets their expectations. The PSI Difficult Child scale assesses the temperament and the ability to tolerate the child in certain situations. Each subscale has twelve items scored between 1 and 5 with higher scores indicating more stress (Abidin, 1995).

Parenting strategies and attitudes. Parenting strategies were measured using the Adult-Adolescent Parenting Inventory, 2nd Edition (AAPI; Bavelok & Keene, 1999). This measure has subjects answer forty questions on a five-point Likert scale from strongly agree to strongly disagree (see Appendix C). The AAPI-2 provides scores on five constructs. The AAPI Expectations of Children construct indicates the parent's understanding of the child's developmental capabilities and limitations. The AAPI Parental Empathy towards Children's Needs construct indicates parent's awareness and priority of the child's needs. The AAPI Use of Corporal Punishment indicates the parental views towards discipline practices and thus the use of physical force. The AAPI Parent-Child Family Roles construct relates to an understanding and acceptance of the needs of the parent and children. Finally, the AAPI Children's Power and Independence construct assesses the parent's idea of child empowerment and obedience. Scores are interpreted as sten scores (which are parameters identified by the creators of the assessment) ranging from 1 to 10. Low sten scores (1 to 4) typically indicate high risk parenting practices, such as abuse. Mid-range scores of 4 to 7 and typical of the general population. High scores (7 to 10) are indicative of non-abusive, nurturing parenting styles (Bavelok & Keene, 1999).

Self-efficacy. The Parenting Sense of Competence Scale (PSOC) uses sixteen items to measure parenting self-esteem with two subscales (Appendix D). The PSOC Sense of

Competence scale indicates the degree to which the parent feels frustrated, anxious, or poorly motivated in the parenting role. The PSOC Efficacy scale reflects the degree to which the parent feels competent, capable of problem solving, and familiar with parenting (Johnston & Mash, 1989).

Parent Mental Health and Wellness. The Center for Epidemiologic Studies Short Depression Scale (CES-D; Radloff, 1977) is a self-report scale used to measure symptoms associated with depression within the last week (Appendix E). Higher scores relate to higher levels of depressive symptoms.

Evaluations of Program. Parents evaluated the parent-education program with a satisfaction survey. This was specifically developed for use with this program. For initial reactions to the program, parents were given the Parent Satisfaction Survey (PSS-1; Appendix F). For the one-year followup, parents were given a similar survey, PSS-2 (see Appendix G).

Procedure

On the day of the FASD education program, parents came to the Weisskopf Child Evaluation Center where they completed the assessments, were provided lunch, and then participated in the FASD Parent Education Session. At the conclusion of this one-day session, parents completed an assessment of the FASD education program.

After the parents provided informed consent, they were taken to a private room with a research assistant to complete the assessments. Parents were given the option to complete the assessments on their own or have them read by a research assistant. The assessments included a family demographics form followed by the child assessment (ECBI) and parenting assessments (AAPI-2, PSOC, and PSI-3). Finally, an assessment of the parent's mental health was given via an assessment of symptoms of depression (CES-D).

After all assessments were completed, parents gathered together for the FASD education program which was led by two FASD professionals and several research assistants. The initial portion of this program gave basic information about Fetal Alcohol Spectrum Disorders and their effect on an individual. This included images of a brain affected by prenatal alcohol exposure and slides with statistical information. The parents were also educated on potential emotional or behavioral problems that may arise from in utero alcohol exposure. Parents were encouraged to ask any questions they may have regarding this information throughout the session.

Parents were given a booklet titled “All About Me” to complete about their child (see Appendix H). The various sections of the booklet were discussed with the parents as they completed them. During this time, parents were given additional information in order to help reframe their perspective on their child. Parents were given the opportunity to talk with other parents who are raising a child with a similar diagnosis and ask questions. These discussions on the “All About Me” booklets were frequently very lengthy, often lasting several hours.

An assessment and evaluation of the FASD education program (PSS-1) was completed by all parents immediately following the session. Approximately twelve months after the initial session, each family was sent a parent survey (PSS-2) to assess the utility of the parent education session. At this time, they also completed one assessment related to parenting (PSI-3) and one assessment of child behavior (ECBI) in order to evaluate behavioral changes in the child and changes in parenting stress after the program.

Results

Parenting Assessments

The first goal of this study was to better characterize parenting strategies and parenting stress as well as parent judgments of challenging child behavior in a sample of families who are raising a child diagnosed with a Fetal Alcohol Spectrum Disorder.

Parenting stress was measured using the PSI. Mean scores for the scales of the PSI can be seen in Table 1. Twenty-four parents (77.4%) scored above the normative range (scores greater than 85) for the Total Stress scale. Ten parents (32.3%) scored at or above the normative range (greater than 33) for the Parental Distress scale. Twenty-four parents (77.41%) scored at or above the normative range (greater than 26) for the Parent-Child Dysfunctional Interaction scale. Twenty-six parents (83.87%) scored above the normative range (greater than 33) for the Difficult Child scale. The scores on four of the subscales (Total Stress, Parental-Child Dysfunctional Interaction, and Difficult Child) had a statistically significant difference from the norm population when compared using a one sample *t*-test (see Table 2). Overall, it seems parents of children with FASD have a great deal of parenting stress.

Mean scores on the parenting strategies scale (AAPI-2) can be seen in Table 1. One-third of parents ($n = 10$) had a high mean sten score (between 8 and 10), which represents a low-risk parenting attitude. Sixty percent of parents ($n = 18$) had a mid-range sten score (between 4 and 7), which correlates with the parenting attitudes of the general population. Two parents (6.7%) had a low sten score (between 1 and 3) which indicate a high-risk style of parenting. Taken together the parents were in the range of the general population on parenting strategies, such as views on corporal punishment and expectations of the child. Scores varied on the specific subscales (as can be seen in Table 3).

Parents' sense of competence was measured with the PSOC questionnaire. The mean score obtained on the PSOC satisfaction scale was 4.06 ($n = 31$, $SD = 0.904$). The mean score on

the PSOC efficacy scale was 4.05 ($n = 31$, $SD = 0.730$; See Table 1). Scores can range from 1 to 6, with 1 meaning a very low evaluation of parenting. The correlation between these two scores was .400, suggesting they have a strong correlation ($p = 0.0233$), which is expected of this type of evaluation.

One additional parenting measure focused on depression. The mean score obtained on the CES-D was 12.22 ($n = 30$, $SD = 7.451$; See Table 1). Scores can range from 0-60. Eleven parents (36.67%) scored a 16 or greater, which is the cutoff for high levels of depressive symptoms. More than a third of parents had elevated symptoms of clinical depression. Figure 3 shows a distribution of the scores. In a general population, it is expected that 20% of people will score above the cutoff range. There was a statistically significant difference between the scores of the tested sample and expected mean of this assessment (See Table 2).

Child Behavior

In order to assess child behavior, the Eyberg (ECBI) was employed. This assessment provides a score on intensity of behaviors and whether the parents view the behaviors as a problem. The means gathered from this assessment can be seen in Table 4. During the pre-education assessments, 90% ($n = 27$) of children scored above the normative cutoff t-score (60) on the Eyberg Intensity scale. Additionally, 81.48% ($n = 22$) scored above the normative cutoff of 60 on the Eyberg Problem Scale. Standard mean score on the intensity scale is 96.6 with a problem score of 7.1. The difference between the tested sample and the normal population was statistically significant for both subscales (see Table 2). Overall, parents reported significant problems with significant intensity. A Pearson product-moment correlation coefficient was computed to assess the relationship between the intensity and problem scores. As is typically

found in this kind of work, there was a statistically significant positive correlation between the two variables [$r = .854, n = 27, p = 0.0001$].

Response to FASD education program

The second goal of this descriptive pilot work was to obtain feedback on the FASD education session. One-hundred percent of parents ($n = 30$) reported that they found the education session to be useful. When asked how useful they found the education session on a scale from 1 to 5, the mean response was 4.72 ($n = 29, SD = 0.455$). When asked if they felt the education session would have a positive impact on their relationship with their child, 100% of parents said yes. When asked how much of an impact the session would have on their relationship from 1-5, mean score was 4.57 ($n = 30, SD = .626$). Only one subject said “somewhat” (scoring a 3), while the remaining stated “much” or “a great deal”. One-hundred percent of parents responded that they had learned something from the training, with the mean response of 4.37 ($n = 30, SD = .688$) when asked how much they had learned.

The second focus was on how applicable the education session was for day-to-day life. Parents were asked “How easy do you feel it will be to apply the information you learned from the training in your day to day life?” The mean response to this question was 4.21 ($n = 30, SD = .94$), which correlates with the response of somewhat easy. When asked, “How often do you think you will apply the ideas from your training into your everyday interactions with your child?” the mean response was 4.76 ($n = 30, SD = .396$), which represents a response of once a day.

Finally, parents were asked if they would recommend this program to other parents with children who have prenatal alcohol exposure, one parent responded “probably”, with the remaining 29 stating “definitely”.

Evaluation of Education Program One Year Later

The third goal of this descriptive pilot project was to evaluate the utility of this education program after one year. Our response rate to a follow up set of questionnaire completed by mail was 68%. Post-intervention, 100% of parents ($n = 13$), stated that they found the education program session useful. When asked how useful they found the session from 1 to 5, the mean response was 4.62 ($n = 13$, $SD = 0.65$). When asked how much parents remembered from the education program from 1 to 5, mean response was 4.08 ($n = 12$, $SD = 0.79$). When parents were asked if they learned anything from the education program, 100% stated yes ($n = 13$), with the mean response on how much being 4.23 ($n = 13$, $SD = 0.83$).

Parents were asked how easy the application of information learned has been. The mean response was 3.62 ($n = 13$, $SD = 1.33$), which is representative of the response of *neither difficult nor easy*. One parent giving a score of 1 (very difficult) qualified their response by stating, “FAS/FASD is a challenge to any parent serious about appropriately meeting their child’s needs. I think if someone says it is easy, they’re not doing a good job.” One-hundred percent of parents ($n = 13$) stated that the education program has had a positive impact on their relationship with their child. Mean response when asked how much of an impact it had was 4.15 ($n = 13$, $SD = 0.69$). Parents were asked how often they had applied the ideas to everyday interactions. Mean response to this question was 4.5 ($n = 12$, $SD = 0.80$), which corresponds to a response of once a day.

Finally, parents were asked if they would recommend this program to other parents. Ninety-two percent of respondents ($n = 12$) stated they “definitely would” and the other respondent stated “probably”. Comments included responses such as: “Those of us who have children with FAS need to learn all we can about this. We need to be able to help out children the

best we can.” As well as, “It help[s] them to know what is going on in there [*sic*] child[s] life and it show[s] us parents how to cope and understand our child”.

Parent Assessments of Stress and Child Behavior One Year Later

Parents provided an assessment of their child’s behavior approximately 12 months after the parent-education program again using the ECBI. Assessments were reevaluated given the child’s ages and normative scores. At this time, mean score obtained on the Eyberg Intensity scale was 64.73 ($n = 15$, $SD = 10.46$). Eighty-percent of these scores ($n = 12$) fall above the normative cutoff score (60). The mean score obtained on the Eyberg Problem scale (as can be seen in Table 5.1) was 59.58 ($n = 12$, $SD = 11.85$). Fifty percent of these scores ($n = 6$) fell above the normative cutoff score. A Pearson product-moment correlation coefficient was computed to assess the relationship between the intensity and problem scores. There was a statistically significant positive correlation between the two variables ($r = 0.872$, $n = 12$, $p = 0.0001$).

A paired-samples t-test was conducted to compare child behavior before and after the parent education program. There was a statistically significant difference in the intensity scores for time one and time two, $p = 0.0188$. There was also a statistically significant difference in the problem scores for time one and time two, $p = 0.0076$ (see Table 6). Table 5.2 shows the pre-education program mean scores on the ECBI for those subjects who participated in the followup assessments. Although not conclusive these data suggest that the Eyberg could be used effectively in an experimental study of the impact of parent education on child behavior in this population. The comparison of scores for pre and post intervention can be seen in Table 7.

Researchers were also interested in understanding any changes in parenting stress across this one-year period. Parents provided an assessment of parenting stress using the PSI approximately 12 months after the parent-education program. The mean score obtained on the

Total Stress scale was 92.0 ($n = 14$, $SD = 24.76$). Mean scores on the various subscales can be seen in Table 8.1. Nine parents (64%) scored above the normative range (scores greater than 85) for the Total Stress scale. One-third of parents ($n = 5$) scored above the normative range (greater than 33) for the Parental Distress scale. Eight parents (53.3%) scored above the normative range (greater than 26) for the Parent-Child Dysfunctional Interaction scale. Nine parents (64.3%) scored above the normative range (greater than 33) for the Difficult Child scale.

A paired-samples t-test was conducted to compare parent total stress before and after the parent education program. Table 8.2 shows the pre-education program means for those subjects who participated in the followup assessments. There was not a significant difference in the scores for time one and time two, $p = 0.4441$ (See Table 9).

Additional paired-samples t-tests were conducted to compare scores on the other subscales, resulting in no statistically significant results. These scores can also be seen in Table 9. Again, while not conclusive, this does show the utility of employing such assessments. Comparisons of scores from pre and post education program can be seen in Tables 10-13.

Discussion

This study examined a one-day parent education program and its potential utility in a larger sample. In addition, researchers aimed to characterize families raising a child diagnosed with a Fetal Alcohol Spectrum Disorder. Current research does little to address the family stressors that occur for these families and specifically does not focus on the fact that many of these children are being raised by someone other than their biological parents.

Goal 1: Characterize families

The first goal was to better characterize parenting strategies and parenting stress in a sample of families who are raising a child diagnosed with a Fetal Alcohol Spectrum Disorder.

Relatedly, researchers were interested in characterizing parent ratings of child behaviors and the challenges faced by these parents. This goal was accomplished by utilizing standardized and normed self-report measures. In evaluating the responses to these measures, it is apparent that these families are facing a great deal of stress. In over 77% of families, the scores on a total stress measure were higher than that of the norm. Additionally, almost 84% of parents had ratings greater than the norm on the difficult child scale. This shows that stress is high and parents feel they have a challenging child.

Most of the parents in this study scored in the range of the general population in regards to parenting attitudes. This suggests that while they are facing a great deal of stress, there is not necessarily an elevated risk of abuse in these families. Additionally, parents scored relatively high in response to measures parenting satisfaction and parenting efficacy. This is interesting to note in relationship to high measures of stress and problematic child behaviors; it shows that despite feeling stressed and having a challenging child, parents feel they are successful parents. A final measure of parenting characteristic revealed that there was a statistically significant difference between symptoms of depression in the sample population and the norm population. This was found utilizing a t-test, which resulted in a p value of 0.0043. This shows that there may be more depressive symptoms in this population of parents than what is expected in the general population.

On measures of child behavior, parents in the sample report a great deal of problematic behaviors. Ninety percent of parents rated their children above the norm on a measure of problem intensity. Additionally, 81% of parents reported that their child's behaviors were more problematic than that of the norm. This shows the severity of behavior problems that are present in this sample.

In this study, no statistically significant differences were found between foster or adoptive families and relative guardians on any of the utilized parenting measures (PSI, PSOC, CES-D, and AAPI). Differences may be expected when taking current research on this area into account. One study reports that adoptive parents have six common stages of feelings towards having a child with FASD. These are feeling delight upon adoption, not knowing (that the child had alcohol exposure), identifying problems, concerns and difficulties, feeling frustrated, feeling pride, and feeling devoted (Granitsas, 2004). For all FASD caregivers, their child's future is full of questions in regards to what they may face and what they may be able to accomplish. One may expect that these feelings of uncertainty, coupled with not knowing the child had alcohol exposure, may lead to greater feelings of distress and more high-risk parenting attitudes. This was not found in this sample of parents. Since no other known study addresses the difference between these families, more research needs to be done to further conclusions on this topic.

Goal 2: Evaluate the program

The second goal of this study was to evaluate parent's response to a one-day parent-education program using training elements, which have been conducted statewide for several years with developmental disabilities professionals. In this program, parents completed a booklet titled "All About Me". This booklet is designed to be given to other's present in the child's life such as a teacher or babysitter, but while completing this booklet, parents often discovered things about their child they had not previously recognized.

Parents seemed to be very pleased with this program, but were given the opportunity to suggest additional feedback for improving this program. One parent suggested that there be planned discussion times in the afternoon to "break up" the time. Another parent said they would like more focus on coping skills for parents. Most other parents responded that they liked the

training as-is and really enjoyed it. When parents were asked why they enjoyed the training, responses included, “Lots of good info and love the ‘All About Me’ books!”, “Good info in a safe environment”, and “very informative, gave chance to share and hear from others with similar children”. From these responses, it seems that the qualitative feedback on the program is consistent with parent ratings of the program. One parent responded “This training should be given to all Foster Parent(s) plus even the school teachers.” and many asked facilitators how they could get this information to others in the child’s life. When contacting parents for the followup assessments, many parents commented that they felt empowered by the information they had been presented.

On an anecdotal note, one couple came into the training reporting that they felt they were out of options for their child and were considering disrupting the placement. In conversing with these parents after the session, they seemed to be refreshed and stated they were not ready to give up yet. Due to confidentiality, it is not certain what the outcome of this family will be. However, the clinician did not note any disruptions in placements at the one-year follow-up, which suggests that disruption did not occur.

Goal 3: Evaluate the Long-Term Effects

The third goal of this pilot project was to evaluate the utility of this education program after one year. This was done by sending parents an assessment of the program and having parents complete two self-report measures. After one year, parents still reported positive feelings about the program and reported that they felt it had a positive impact on their relationship with their child. Quantitative results also suggested that there might be some long term utility of this program in addition to positive feelings. There was a statistically significant decrease in scores of both intensity of child behaviors and how problematic these behaviors were.

There was not a statistically significant decrease in parenting stress, despite parents reporting the program helped their relationship with their child. The current researchers were not necessarily surprised by this, as implementing behavior modification systems can be challenging and may themselves result in some stress. Additionally, while reports of aversive child behaviors did decrease, they were still higher than that of the general population which would likely result in parenting stress and frustration.

All About Me Booklet

The facilitator of the education program assisted the parents in completing the All About Me booklet, and discussions often lasted several hours. During this time, some parents were able to share the problems they faced with other parents, and all had the opportunity to discuss their child with a FASD professional. The facilitator discussed each area of the booklet at length with the parents.

Parents said that they really enjoyed listing the strengths of their child, which is the very first part of the booklet. They said that it was useful to remember the many strengths of their child in order not to become overwhelmed with the challenges they face. The first page also includes interests of the child and parents were encouraged to utilize these interests to help promote success in their child and to praise their child for any accomplishments and successes.

The second page of the booklet looks at the emotional responses of the child. Parents and facilitators discussed the importance of not trying to rationalize with the child when they have reached a point of having a meltdown. Parents expressed that they often would try to do this and just become more frustrated, which caused the child to become more upset. Additionally, families discussed the importance of recognizing how their child displayed certain emotions in order to best help them regain control of themselves.

Many of the parents were specifically interested in the next page of the booklet, which discusses some of the areas where children with prenatal alcohol exposure can struggle. The listed areas are thinking abstractly, brain pace, learning from experience, and understanding cause and effect. Examples were given to help better explain some of these concepts. For the area of thinking abstractly, parents were encouraged to think about and name some of the things they may say that could be misunderstood or confusing. One example that was mentioned was the concept of time and how it can be challenging to explain to a child. Some solutions the group came up with were providing a timer and giving the child reminders before it was time to transition to another activity. Parents often collaborated to problem solve the issues others brought up.

The next page discussed more areas in which child may struggle, including rigid thinking, reading body language, memory, and sensory integration. Since memory was discussed more fully on the following page, facilitators focused mainly on the other topics for this page. The main area parents listed that they noticed an issue with their child was sensory integration. It was recommended that parents who had a child that struggled in this area seek an occupational therapist to help with this. Additionally, parents noted that they had to be hyper vigilant about the environment around their child and several parents were amused to discover they were not the only ones who cut the tags out of their child's clothes and made sure socks were inside out so the seam did not bother their child. Parents enjoyed hearing stories from other parents on what accommodations they made and often expressed that they were relieved to know they were not alone in making such environmental changes.

Often, there were lengthy discussions on the sections about what works, which are covered in the next two pages. There were several examples listed in the booklet. These were:

use concrete language, expect to reteach things, provide external memory tools, speak slowly, and use fewer words, understand what routine means to the child, provide extra supervision, use the same words, and be as specific as possible. Frequently, using external memory tools was discussed in length. One mother brought in the picture schedule she used with her child and other parents were excited to hear what she did to help her child in this area. In addition, parents discussed putting reminders in places where there was significant struggle with memory, such as posting steps to taking a shower and steps to cleaning up the child's room. Parents also mentioned it would be helpful to include pictures of their actual child (in a bathing suit) doing these steps in order to help with the struggle of relating abstract concepts or ideas.

The final section of the booklet discussed changing the environment to help make it more accessible for the child. The facilitator discussed how it is easy to figure out what needs to be changed for a child with a physical disability, such as a child in a wheelchair, but it can be different to figure this out for a child with an "invisible disability". The area parents listed as the most problematic for them was helping their child filter out distractions. Some parents said that they provided their child with earplugs or earmuffs to help lessen auditory stimuli.

Some parents expressed concern that making some of the suggested environmental changes or implementing some of the discussed techniques would enable their child to perform poorly and not learn to cope with the issues they face. Parents were reminded that the diagnosis that their child has is simply an explanation for the struggles they have and not an excuse not to hope for the best for their child. Parents were urged to encourage their child to be successful, but also to implement techniques so that success can be a reality for their child.

Evaluation of Assessments

The PSI seemed to be an effective measure of parenting stress to utilize with this sample. Scores varied across the subjects, but trends were seen across the sample. While the AAPI is a standardized and validated measure, it did not seem to add much to the data set as it was difficult to discern the source of “high-risk” parenting attitudes. In addition, some of the subscales on this measure may not be relevant to this population (such as expectations of children and children’s power and independence) because of the level of functioning of these children.

The PSOC is an insightful measure as it showed how parents evaluated their own role as parents. This measure would have been interesting to utilize in follow-up assessments to see if parents’ satisfaction with their parenting changed over time. The CES-D also gave insight into the reality of the parents in this population and the impact their child has on their life. The Eyberg (ECBI) was a beneficial tool as it allows one to see the changes in child behavior; however, some challenges arose with this measure as some of the items were not relevant to several of the subjects (such as dresses himself as some children were physically incapable of doing so)

Relationship to Existing Research

Existing research suggests that children who are affected by prenatal alcohol exposure have significant impairments in executive functioning (Bertrand et al., 2004; McClokey et al., 2009; Pei et al., 2011, etc.). This is also likely in the sample in this study, as impaired executive functioning often presents as behavior problems.

In the present study, no difference was seen in the levels of stress between adoptive/foster parents and relative guardians. This is different from the findings of a study conducted in 2006. This study found that adoptive and foster parents reported higher levels of stress than biological parents. The researchers of the prior study posited that the adoptive or foster parents might not

have been as prepared for the difficulties their child would have or even that they had prenatal alcohol exposure (Paley, O'Connor, Frankel, & Marquardt, 2006). However, the relative guardians in the present study may more closely resemble foster or adoptive parents due to not being biological parents, rather biological relatives.

Implications

While the design of this study does not allow us to state unequivocally that this training program is directly causing a decrease in problematic child behaviors, the results do suggest that there may be some benefits resulting from this program/intervention. Parents seemed very satisfied with the program and self-reported that it improved their relationship with their child. This suggests that this program could be utilized in a larger setting to obtain more conclusive evidence for its efficacy.

Limitations of Present Study

In order to further evaluate the utility of this intervention, randomized control tests would be necessary, which would have a control group to which the group that participated in the program could be compared. In addition, a larger sample size would be useful to allow the researchers more power to explore potential effects of the program. However, it seems that there may be some benefit from this parent-education program in evaluation of feedback both initially after the intervention and after one-year post intervention. A causal link cannot be stated between the intervention and reduction in child behavior; however, there is a strong relationship between the two.

Another limitation is that only nineteen of the thirty-one families received follow-up assessments and only fifteen responded. Due to time constraints, not all families were able to

participate in the followup assessments. Including these families could expand the findings of this study

It is important to consider the fact that participants in this study did so on a volunteer basis. Parents were not required to attend and were recruited for this study. However, many of the parents did express feeling exasperated and hopeless about change in their child's behavior. This may account for the high levels of problematic behavior in the sample, as those who do not see a problem in their child's behavior would be less likely to seek a new program to help manage their child's behavior. On the other hand, those who did participate may have represented those families in greatest need of an intervention.

Future Research

A main area where data are lacking on this topic is the difference between foster/adoptive families and biological parents raising children with prenatal alcohol exposure. One study is known that specifically addresses this issue. The present study looked at the differences between biological and adoptive families, but did not include any biological mothers. This would be an interesting area to gather further information.

Additional studies could also address the interactions between family variables and child outcomes. Using a larger sample size would allow researchers to utilize other parametric measures to find relationships between specific parent variables and child behavior. Things to look at would include the relationship between parent stress and child behavior, levels of depression and sense of competence, among others. This would be useful to help pinpoint the areas that are most related to child outcomes and future interventions could target these areas.

Table 1

Parent assessments pre-education program

	<i>N</i>	Min.	Max.	<i>M</i>	<i>SD</i>
PSI					
Total Stress	31	56	138	98.87	19.230
Parental Distress	31	14	46	28.03	7.990
Parent Child Dysfunctional Interaction	31	16	41	29.03	6.264
Difficult Child	31	21	60	41.65	9.196
AAPI (mean)	30	4	9.60	6.09	1.587
PSOC					
Satisfaction	31	2.11	5.56	4.06	0.904
Efficacy	31	2.63	5.50	4.05	0.730
CES-D	30	0	32	12.22	7.451

Table 2

Scores Compared to Norms Time One

	Paired Differences						t	df	p
	Means		Difference	SEM	95% CI				
	Sample	Hypothetical			Lower	Upper			
PSI									
Total	98.871	71.000	27.871	3.454	20.817	34.925	8.070	30	< 0.0001
PD	28.030	26.400	1.630	1.435	-1.300	4.560	1.138	30	0.264
P-CDI	29.032	18.170	10.862	1.125	8.565	13.159	9.656	30	< 0.0001
DC	41.645	26.000	15.645	1.652	12.272	19.018	9.472	30	< 0.0001
CES-D	12.217	8.00	4.217	1.361	1.435	6.999	3.0999	29	0.0043
Eyberg									
Intensity	160.83	98.472	62.361	5.589	50.378	74.345	10.644	29	< 0.0001
Problem	19.407	6.740	12.667	1.383	9.825	15.510	9.160	26	< 0.0001

Note. These comparisons were made using a one-sample *t*-test. Statistically significant values are in boldface. Subscales on the PSI are abbreviated as follows: Parental Distress (PD), Parent-Child Dysfunctional Interaction (P-CDI), and Difficult Child (DC).

Table 3

AAPI Subscale Percentages

	Low Sten (<i>n</i>)	Medium Sten (<i>n</i>)	High Sten (<i>n</i>)
Expectations	16.7% (5)	53.3% (16)	30% (9)
Lack of Empathy	10% (3)	63.3% (19)	26.7% (8)
Physical Punishment	3.3% (1)	53.3% (16)	43.3% (13)
Role Reversal	50% (15)	6.7% (2)	43.3% (13)
Independence	46.7% (14)	13.3% (4)	40% (12)
Mean Score	6.7% (2)	60% (18)	33.3% (10)

Note. Low sten scores (1 to 4) typically indicate high risk parenting practices, such as abuse.

Mid-range scores of 4 to 7 and typical of the general population. High scores (7 to 10) are indicative of non-abusive, nurturing parenting styles. “Sten” is the term the creators of this assessment used for standardized scores.

Table 4

Eyberg Scores- Pre-Education Program

	<i>N</i>	Min.	Max.	<i>M</i>	<i>SD</i>
Intensity					
Raw Score	30	57	223	160.83	32.092
T-Score	30	39	86	68.13	9.119
Problem					
Raw Score	27	5	36	19.41	7.186
T-Score	27	47	88	65.89	9.415

Note. T-scores for this assessment are assigned by the developers of this measure and represent a comparison of scores to the normed population.

Table 5.1

Eyberg Scores- Post-Education Program

	<i>N</i>	Min.	Max.	<i>M</i>	<i>SD</i>
Intensity					
Raw Score	15	50	220	148.40	36.88
T-Score	15	37	85	64.73	10.46
Problem					
Raw Score	12	0	34	14.33	9.16
T-Score	12	41	85	59.58	11.85

Table 5.2

Eyberg Scores- Pre-Education Program for Follow-up Subjects

	<i>N</i>	Min.	Max.	<i>M</i>	<i>SD</i>
Intensity					
Raw Score	14	57	223	157.71	37.66
T-Score	14	39	86	67.29	10.69
Problem					
Raw Score	13	9	33	19.00	6.90
T-Score	13	52	84	65.38	9.19

Table 6

Paired Samples t-Test- Eyberg T-Scores Time 2 vs. Time 1

	Paired Differences							
	<i>M</i>	<i>SD</i>	<i>SEM</i>	95% CI		<i>t</i>	<i>df</i>	<i>p</i>
				Lower	Upper			
Intensity	-3.3571	-0.3287	1.252	-6.0616	-0.6527	2.6818	13	0.0188
Problem	-5.5455	1.8325	1.664	-9.2540	1.8369	3.3318	10	0.0076

Note. Statistically significant values are in boldface.

Table 7

Changes in Eyberg T-Scores

	Time 1	Time 2	Change (2-1)
Intensity			
	79	85	+6
	60	63	+3
	60	59	-1
	70	69	-1
	70	68	-2
	39	37	-2
	64	61	-3
	71	67	-4
	65	61	-4
	67	62	-5
	73	67	-6
	71	65	-6
	67	58	-9
	86	73	-13
Problem			
	76	85	+9
	63	60	-3
	52	49	-3
	63	58	-5
	69	64	-5
	56	49	-7
	71	63	-8
	84	75	-9
	72	62	-10
	65	55	-10
	64	54	-10

Table 8.1

PSI Scores- Post-Education Program

	<i>N</i>	Min.	Max.	<i>M</i>	<i>SD</i>
Total Stress	14	43	132	92.00	24.76
Parental Distress	15	12	44	27.53	8.64
Parent Child Dysfunctional Interaction	15	16	51	29.40	10.68
Difficult Child	14	13	53	36.43	12.38

Table 8.2

PSI Scores- Pre-Education Program for Follow-up Subjects

	<i>N</i>	Min.	Max.	<i>M</i>	<i>SD</i>
Total Stress	15	56	138	95.73	21.75
Parental Distress	15	14	44	27.40	8.58
Parent Child Dysfunctional Interaction	15	16	41	29.47	7.28
Difficult Child	15	21	53	39.47	8.77

Table 9

Paired Samples t-Test- PSI Time 2 vs. Time 1

	Paired Differences					<i>t</i>	<i>df</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>SEM</i>	95% CI				
				Lower	Upper			
Total Stress	-3.7143	2.1891	4.706	-13.8812	6.4527	0.7892	13	0.4441
Parental Distress	0.13	0.06	1.910	-3.96	4.23	0.0698	14	0.9453
Parent Child Dysfunctional Interaction	-0.0667	3.3969	1.769	-3.8601	3.7268	0.0377	14	0.9705
Time Difficult Child	-3.2143	3.3141	2.118	-7.7897	1.3611	1.5177	13	0.1530

Note. Statistically significant values are in boldface.

Table 10

Changes in PSI Total Stress

Time 1	Time 2	Change (2-1)
106	131	+25
77	87	+10
91	107	+16
56	61	+5
116	132	+16
96	96	0
83	82	-1
82	80	-2
110	104	-6
115	103	-12
61	43	-18
98	75	-23
138	108	-30
111	79	-32

Table 11

Changes in PSI Parental Distress

Time 1	Time 2	Change (2-1)
18	30	+12
28	36	+8
27	34	+7
17	23	+6
33	38	+5
17	22	+5
24	28	+4
44	44	0
14	14	0
26	23	-3
39	33	-6
31	24	-7
34	25	-9
26	12	-14

Table 12

Changes in PSI Parent-Child Dysfunctional Interaction

Time 1	Time 2	Change (2-1)
34	50	+16
41	51	+10
38	43	+5
26	28	+2
18	20	+2
16	17	+1
28	29	+1
32	31	-1
31	30	-1
27	25	-2
19	16	-3
30	25	-5
35	27	-8
34	25	-9

Table 13

Changes in PSI Difficult Child

Time 1	Time 2	Change (2-1)
36	49	+13
39	43	+4
50	53	+3
29	32	+3
53	53	0
43	42	-1
43	40	-3
21	18	-3
44	39	-5
48	43	-5
40	32	-8
33	24	-9
35	23	-12
28	13	-15
46	30	-16

Figure 1. Tiers of executive function as described by McCloskey et al.

Figure 2. Children's ages at time of study (in years)

Figure 3. Distribution of CES-D scores

Appendix A

Eyberg Child Behavior Inventory (ECBI)

Directions: Below is a series of phrases that describes children’s behavior. Please (1) circle the number describing **how often** the behavior **currently** occurs with your child and (2) circle either “yes” or “no” to indicate whether the behavior is **currently a problem for you**.

	How often does this occur with your child?							Is this a problem for you?	
	Never	Seldom	Sometimes	Often	Always				
1. Dawdles in getting dressed	1	2	3	4	5	6	7	YES	NO
2. Dawdles or lingers at mealtime	1	2	3	4	5	6	7	YES	NO
3. Has poor table manners	1	2	3	4	5	6	7	YES	NO
4. Refuses to eat food presented	1	2	3	4	5	6	7	YES	NO
5. Refuses to do chores when asked	1	2	3	4	5	6	7	YES	NO
6. Slow in getting ready for bed	1	2	3	4	5	6	7	YES	NO
7. Refuses to go to bed on time	1	2	3	4	5	6	7	YES	NO
8. Does not obey house rules on his own	1	2	3	4	5	6	7	YES	NO
9. Refuses to obey until threatened with punishment	1	2	3	4	5	6	7	YES	NO
10. Acts defiant when told to do something	1	2	3	4	5	6	7	YES	NO
11. Argues with parents about rules	1	2	3	4	5	6	7	YES	NO
12. Gets angry when doesn’t get own way	1	2	3	4	5	6	7	YES	NO
13. Has temper tantrums	1	2	3	4	5	6	7	YES	NO
14. Sassses adults	1	2	3	4	5	6	7	YES	NO
15. Whines	1	2	3	4	5	6	7	YES	NO
16. Cries easily	1	2	3	4	5	6	7	YES	NO
17. Yells or screams	1	2	3	4	5	6	7	YES	NO
18. Hits parents	1	2	3	4	5	6	7	YES	NO

	How often does this occur with your child?							Is this a problem for you?	
	Never	Seldom	Sometimes	Often	Always				
19. Destroys toys and other objects	1	2	3	4	5	6	7	YES	NO
20. Is careless with toys and other objects	1	2	3	4	5	6	7	YES	NO
21. Steals	1	2	3	4	5	6	7	YES	NO
22. Lies	1	2	3	4	5	6	7	YES	NO
23. Teases or provokes other children	1	2	3	4	5	6	7	YES	NO
24. Verbally fights with friends own age	1	2	3	4	5	6	7	YES	NO
25. Verbally fights with sisters and brothers	1	2	3	4	5	6	7	YES	NO
26. Physically fights with friends	1	2	3	4	5	6	7	YES	NO
27. Physically fights with sisters and brothers	1	2	3	4	5	6	7	YES	NO
28. Constantly seeks attention	1	2	3	4	5	6	7	YES	NO
29. Interrupts	1	2	3	4	5	6	7	YES	NO
30. Is easily distracted	1	2	3	4	5	6	7	YES	NO
31. Has short attention span	1	2	3	4	5	6	7	YES	NO
32. Fails to finish tasks or projects	1	2	3	4	5	6	7	YES	NO
33. Has difficulty entertaining self alone	1	2	3	4	5	6	7	YES	NO
34. Has difficulty concentrating on one thing	1	2	3	4	5	6	7	YES	NO
35. Is overactive or restless	1	2	3	4	5	6	7	YES	NO
36. Wets the bed	1	2	3	4	5	6	7	YES	NO

Appendix B

Parenting Stress Index (PSI)

	SA = Strongly Agree	A= Agree	NS = Not Sure	D = Disagree	SD = Strongly Disagree
1.	I often have the feeling that I cannot handle things very well.			SA	A
2.	I find myself giving up more of my life to meet my children's needs than I ever expected.			NS	D
3.	I feel trapped by my responsibilities as a parent.			SD	
4.	Since having this child, I have been unable to do new and different things.			SA	A
5.	Since having a child, I feel that I am almost never able to do things that I like to do.			NS	D
6.	I am unhappy with the last purchase of clothing I made for myself.			SD	
7.	There are quite a few things that bother me about my life.			SA	A
8.	Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).			NS	D
9.	I feel alone and without friends.			SD	
10.	When I got to a party, I usually expect not to enjoy myself.			SA	A
11.	I am not as interested in people as I used to be.			NS	D
12.	I don't enjoy things as I used to.			SD	
13.	My child rarely does things for me that make me feel good.			SA	A
14.	Sometimes I feel my child doesn't like me and doesn't want to be close to me.			NS	D
15.	My child smiles at me much less than I expected.			SD	
16.	When I do things for my child, I get the feeling that my efforts are not appreciated very much.			SA	A
17.	When playing, my child doesn't often giggle or laugh.			NS	D
18.	My child doesn't seem to learn as quickly as most children.			SD	
19.	My child doesn't seem to smile as much as most children.			SA	A
20.	My child is not able to do as much as I expected.			NS	D

21. It takes a long time and it is very hard for my child to get used to new things. SA A NS D SD

For the next statement, choose your response from the choices "1" to "5" below.

22. I feel that I am: 1 2 3 4 5

1. not very good at being a parent
2. a person who has some trouble being a parent
3. an average parent
4. a better than average parent
5. a very good parent

23. I expected to have closer and warmer feelings for my child than I do and this bothers me. SA A NS D SD

24. Sometimes my child does things that bother me just to be mean. SA A NS D SD

25. My child seems to cry or fuss more often than most children. SA A NS D SD

26. My child generally wakes up in a bad mood. SA A NS D SD

27. I feel that my child is very moody and easily upset. SA A NS D SD

28. My child does a few things which bother me a great deal. SA A NS D SD

29. My child reacts very strongly when something happens that my child doesn't like. SA A NS D SD

30. My child gets upset easily over the smallest thing. SA A NS D SD

31. My child's sleeping or eating schedule was much harder to establish than I expected. SA A NS D SD

For the next statement, choose your response from the choices "1" to "5" below.

32. I have found that getting my child to do something or stop doing something is: 1 2 3 4 5

1. much harder than I expected
2. somewhat harder than I expected
3. about as hard as I expected
4. somewhat easier than I expected
5. much easier than I expected

For the next statement, choose your response from the choices "10+" to "1-3".

Think carefully and count the number of things which your child does that bother you.						
33.	For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc.	10+	8-9	6-7	4-5	1-3
34.	There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
35.	My child turned out to be more of a problem than I had expected.	SA	A	NS	D	SD
36.	My child makes more demands on me than most children.	SA	A	NS	D	SD

Appendix C

Adult-Adolescent Parenting Inventory (AAPI)

INSTRUCTIONS:

There are 40 statements in this booklet. They are statements about parenting and raising children. You decide the degree to which you agree or disagree with each statement by circling one of the responses.

STRONGLY AGREE – Circle **SA** if you strongly support the statement, or feel the statement is true most of all the time.

AGREE – Circle **A** if you support the statement, or feel this statement is true some of the time.

STRONGLY DISAGREE – Circle **SD** if you feel strongly against the statement, or feel the statement is not true.

DISAGREE – Circle **D** if you feel you cannot support the statement or that the statement is not true some of the time.

UNCERTAIN – Circle **U** only when it is impossible to decide on one of the other choices.

When you are told to turn the page, begin with Number 1 and go on until you finish all the statements. In answering them, please keep these four points in mind:

1. Respond to the statements truthfully. There is no advantage in giving an untrue response because you think it is the right thing to say. There really is no right or wrong answer – only your opinion.
2. Respond to the statements as quickly as you can. Give the first natural response that comes to mind.
3. Circle only one response for each statement.
4. Although some statements may seem much like others, no two statements are exactly alike. Make sure you respond to every statement.

If there is anything you don't understand, please ask your questions now. If you come across a word you don't know while responding to a statement, ask the examiner for help.

PLEASE TURN THE PAGE AND BEGIN...

1. Children need to be allowed freedom to explore their world in safety.	SA	A	D	SD	U
2. Time-out is an effective way to discipline children.	SA	A	D	SD	U
3. Children who are one-year-old should be able to stay away from things that could harm them.	SA	A	D	SD	U
4. Strong-willed children must be taught to mind their parents.	SA	A	D	SD	U
5. The sooner children learn to feed and dress themselves and use the toilet, the better off they will be as adults.	SA	A	D	SD	U

6. Spanking teaches children right from wrong.	SA	A	D	SD	U
7. Babies need to learn how to be considerate of the needs of their mother.	SA	A	D	SD	U
8. Strict discipline is the best way to raise children.	SA	A	D	SD	U
9. Parents who nurture themselves make better parents.	SA	A	D	SD	U
10. Children can learn good discipline without being spanked.	SA	A	D	SD	U
11. Children have a responsibility to please their parents.	SA	A	D	SD	U
12. Good children always obey their parents.	SA	A	D	SD	U
13. In father's absence, the son needs to become the man of the house.	SA	A	D	SD	U
14. A good spanking never hurt anyone.	SA	A	D	SD	U
15. Parents need to push their children to do better.	SA	A	D	SD	U
16. Children should keep their feelings to themselves.	SA	A	D	SD	U
17. Children should be aware of ways to comfort their parents after a hard day's work.	SA	A	D	SD	U
18. Children learn respect through strict discipline.	SA	A	D	SD	U
19. Hitting a child out of love is different than hitting a child out of anger.	SA	A	D	SD	U
20. A good child sleeps through the night.	SA	A	D	SD	U
21. Children should be potty trained when they are ready and not before.	SA	A	D	SD	U
22. A certain amount of fear is necessary for children to respect their parents.	SA	A	D	SD	U
23. Spanking teaches children it's alright to hit others.	SA	A	D	SD	U
24. Children who feel secure often grow up expecting too much.	SA	A	D	SD	U
25. There is nothing worse than a strong-willed two year-old.	SA	A	D	SD	U
26. Sometimes spanking is the only thing that will work.	SA	A	D	SD	U
27. Children who receive praise will think too much of themselves.	SA	A	D	SD	U
28. Children should do what they're told to do, when they're told to do it. It's that simple.	SA	A	D	SD	U
29. Children should be taught to obey their parents at all times.	SA	A	D	SD	U

30. Children should know what their parents need without being told.	SA	A	D	SD	U
31. Children should be responsible for the well-being of their parents.	SA	A	D	SD	U
32. It's OK to spank as a last resort.	SA	A	D	SD	U
33. Parents should be able to confide in their children.	SA	A	D	SD	U
34. Parents who encourage their children to talk to them only end up listening to complaints.	SA	A	D	SD	U
35. Children need discipline, not spanking.	SA	A	D	SD	U
36. Letting a child sleep in the parents' bed every now and then is a bad idea.	SA	A	D	SD	U
37. A good spanking lets children know parents mean business.	SA	A	D	SD	U
38. A good child will comfort both parents after they have argued.	SA	A	D	SD	U
39. "Because I said so" is the only reason parents need to give.	SA	A	D	SD	U
40. Children should be their parents' best friend.	SA	A	D	SD	U

Appendix D

Parenting Sense of Competence of Scale

Instructions: Listed below are a number of statements. Please respond to each item, indicating your agreement or disagreement with each statement.

1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

2. Even though being a (parent) could be rewarding, I am frustrated now while my child is at his/her present age.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

3. I go to bed the same way I wake up in the morning—feeling I have not accomplished a whole lot.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

4. I do not know what it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

5. My (parent) was better prepared to be a good (parent) than I am.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

6. I would make a fine model for a new (parent) to follow in order to learn what she/he would need to know in order to be a good (parent).

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

7. Being a (parent) is manageable, and any problems are easily solved.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

8. A difficult problem in being a (parent) is not knowing whether you're doing a good job or a bad one.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

9. Sometimes I feel like I'm not getting anything done.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

10. I meet my own personal expectations for expertise in caring for my child.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

11. If anyone can find the answer to what is troubling my child, I am the one.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

12. My talents and interests are in other areas, not in being a (parent).

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

13. Considering how long I've been a (parent), I feel thoroughly familiar with this role.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

14. If being a (parent) of a child were only more interesting, I would be motivated to do a better job as a (parent).

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

15. I honestly believe I have all the skills necessary to be a good (parent) to my child.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

16. Being a (parent) makes me tense and anxious.

1	2	3	4	5	6
Strongly agree	Agree	Mildly agree	Mildly Disagree	Disagree	Strongly Disagree

Appendix E

Center for Epidemiologic Studies Depression Scale

		Rarely or not at all	Some or a little	Occasionally	Most or all of the time
1	I was bothered by things that usually don't bother me.				
2	I did not feel like eating; my appetite was poor.				
3	I felt that I could not shake off the blues even with help from friends and family.				
4	I felt that I was just as good as other people.				
5	I had trouble keeping my mind on what I was doing.				
6	I felt depressed.				
7	I felt that everything I did was an effort.				
8	I felt hopeful about the future.				
9	I thought my life had been a failure.				
10	I felt fearful about the future.				
11	My sleep was restless.				
12	I was happy.				
13	I talked less than usual.				
14	I felt lonely.				
15	People were unfriendly.				
16	I enjoyed life.				
17	I had crying spells.				
18	I felt sad.				
19	I felt like people disliked me.				
20	I could not get "going".				

Appendix F

Parent Satisfaction Survey (1)

Circle the number that corresponds with your response to each statement.

1. Overall, did you find the training useful?

Yes	No
-----	----

If yes,

1	2	3	4	5
Very Little	Little	Somewhat	Much	A Great Deal

2. Do you feel the training session will have a positive impact on your relationship with your child?

Yes	No
-----	----

If yes,

1	2	3	4	5
Very Little	Little	Somewhat	Much	A Great Deal

3. Do you feel you learned anything from this training?

Yes	No
-----	----

If yes,

1	2	3	4	5
Very Little	Little	Somewhat	Much	A Great Deal

4. How easy do you feel it will be to apply the information you learned from the training in your day to day life?

1	2	3	4	5
Very Difficult	Somewhat Difficult	Neither Difficult nor Easy	Somewhat Easy	Very Easy

5. How often do you think you will apply the ideas from your training into your everyday interactions with your child?

1 Rarely	2 Once a Week	3 Couple Times a Week	4 Once a Day	5 More than Once a Day
--------------------	-------------------------	---------------------------------	------------------------	----------------------------------

6. What were your expectations of the training session prior to starting?

7. What do you think could have been changed to improve the training?

8. Are there particular areas that you liked and wished would have been focused on more? Less?

9. Would you recommend this program to other parents with children that have had prenatal alcohol exposure?

1 Definitely not	2 Probably	3 Definitely
----------------------------	----------------------	------------------------

a. Why?

Appendix G

Parent Satisfaction Survey (2)

Circle the number that corresponds with your response to each statement.

1. Overall, did you find the training session useful?

Yes	No
-----	----

If yes,

1 Very Little	2 Little	3 Somewhat	4 Much	5 A Great Deal
-------------------------	--------------------	----------------------	------------------	--------------------------

2. How much do you remember from the training?

1 Very Little	2 Little	3 Somewhat	4 Much	5 A Great Deal
-------------------------	--------------------	----------------------	------------------	--------------------------

a. What things in particular do you remember?

3. Do you feel you learned anything from this training?

Yes	No
-----	----

If yes,

1 Very Little	2 Little	3 Somewhat	4 Much	5 A Great Deal
-------------------------	--------------------	----------------------	------------------	--------------------------

4. How easy do you feel it has been to apply the information you learned from the training in your day to day life?

1 Very Difficult	2 Somewhat Difficult	3 Neither Difficult nor Easy	4 Somewhat Easy	5 Very Easy
----------------------------	--------------------------------	--	---------------------------	-----------------------

5. Do you feel the training session had a positive impact on your relationship with your child?

Yes

No

6. How often have you applied the ideas from the training in everyday interactions with your child?

1

Rarely

2

Once a Week

3

Couple Times a Week

4

Once a Day

5

More than Once a Day

7. Has the one day session affected any aspects of your parenting, your child, or the relationship between you and your child? If yes, in what ways?

8. What were your expectations about the effects of the training in your day to day life or between you and your child?

a. Have those expectations turned out to be correct? In what ways?

9. What do you think could have been changed to improve the training?

10. Are there particular areas that you wished would have been focused on more? Less?

11. Would you recommend this program to other parents with children that have had prenatal alcohol exposure?

1

Definitely not

2

Probably

3

Definitely

a. Why?

Appendix H

All About Me Booklet

Dear Supporter of Me,

This book is a way to help you get to know me a little bit better.

I have some struggles because my brain was affected by alcohol before I was born. Alcohol changed the way my brain developed, and this can show up as a *BEHAVIOR issue* instead of a *BRAIN issue*.

I want to do my best. I want to wake up in the morning feeling excited about my day, and I want to go to bed at night feeling good about myself.

Thank you so much for reading this booklet, and for learning as much as you can about Fetal Alcohol Spectrum Disorders and the ways that prenatal alcohol exposure can affect learning and behavior. I am so happy and grateful to have you in my life right now.

Sincerely,

Getting to Know Me...

I have people in my life who love me very much. Here are some of the things that the people closest to me like BEST about me:

When I am feeling down about myself, it helps me to be reminded of these things. You will find things that YOU like best about me, too.

My birthday is:

I have ____ brothers and ____ sisters.

My favorite ways to spend my time are:

These interests can help motivate me to learn and explore.

I respond best to people who are:

☐ patient	☐ structured	☐ calm
☐ fast-paced	☐ unstructured	☐ energetic
☐ positive	☐ organized	☐ consistent
☐ critical	☐ cluttered	☐ inconsistent
☐ _____	☐ _____	☐ _____

My Emotional Responses...

Sometimes I have problems expressing emotions in appropriate ways. This gets in the way of my learning, my friendships and my daily life. You can help me by recognizing my true emotions and supporting me to manage my emotions in healthy ways. I might not always be able to do this on my own.

All kids get upset. However, I can't always depend on the part of my brain that regulates emotions. My response to situations may be exaggerated or inappropriate, and I may not be able to regain control on my own. Please recognize how hard I try, even though my behavior may be challenging.

I get upset when:

- ☐ I don't understand
- ☐ Things move too fast for me
- ☐ I feel like I don't fit it
- ☐ I can't remember something
- ☐ Someone touches me
- ☐ I'm overwhelmed
- ☐ I don't know what questions to ask

I show my emotions by:

- ☐ acting defiant
- ☐ raising my voice
- ☐ pestering
- ☐ physical movement
- ☐ physical aggression
- ☐ giving up
- ☐ withdrawing
- ☐ talking too much

You can help me by:

- ☐ Noticing my cues of frustration
- ☐ Speaking slowly and calmly to me
- ☐ Gently reminding me that I'm losing control
- ☐ Guiding me to a quiet place where I can regain control with dignity
- ☐ Listening to the feelings behind my behavior

Sometimes my emotions bring me past the point of being rational. This is called a Meltdown. If I reach this point, I NEED you to calmly remove me to a quiet space so I can regain control. Trying to talk to me or reason with me when I'm in the middle of meltdown will only frustrate both of us. Wait until

I've calmed down before talking about what happened.

What Works.....

I CAN learn, I CAN get through my day feeling good about myself, and I CAN have successes. Here are some ideas that help create outside supports for my brain.

Use concrete language. I don't speak the language of abstractions, so I often don't understand what you mean. Pay attention to your words and try to use language that means exactly what it says.

Expect to reteach things to me. I struggle with my memory. I need to re-learn things over and over before they stick in my brain. Don't get frustrated with me for forgetting. I don't mean to forget.

Sometimes you will wonder if I am misbehaving on purpose or if I am acting from my brain differences. Here's an idea for you: Try assuming that my actions are from a brain difference, and put some supportive strategies consistently in place. If my behavior gets better, your strategies and your patience are **HELPING** me and my brain. Thank you!!

Provide external memory tools. It helps me not to always have to rely on my memory. Lists, reminders, cue cards—anything that can be an external memory for me will help me be more successful.

Speak slowly, and use fewer words. If you're wanting to explain something to me and I'm just not getting it, try slowing down and using fewer words. I process information at a slower pace, so it's easy for too many words to overwhelm me.

What Works.....

“Please don’t let what I **CAN’T** do interfere with what I **CAN** do!”

☐ **Understand what routine means to me.** Since my brain has trouble looking ahead, routine is what makes me feel secure. When my routine gets disrupted, I feel anxious because I don’t know what’s happening next. Prepare me for changes.

☐ **Provide extra supervision.** It helps to have people around me who understand that my brain works differently, and can help me navigate new and unfamiliar situations. Unstructured times are especially hard for me, so I might need extra help.

**Remember—
maybe it’s not
that I **WON’T**
do it. Maybe
it’s that I
CAN’T do it.**

☐ **Use the same words.** If you say, “Don’t run” “Walk, please” And “Slow down,” my brain may not understand that you’re wanting the same behavior each time. Use the exact same words / phrases to help my brain understand what’s expected.

☐ **Be as specific as possible.** I have a hard time figuring out all the steps that need to be done, and in what order to do them. Help me organize and break tasks down into small parts (and don’t expect me to rely on memory – write it down for me!)

The Environment.....

It's easy to figure out how to make the environment accessible to a person with a physical disability. Sometimes it's harder to look at my disability in the same way. There are simple changes in the environment that can make a big difference for me.

Help me eliminate clutter from my space.

A messy desk or locker can be overwhelming to me, but I have a hard time knowing what to throw away and what to keep. I also have a hard time organizing information.

Allow me to have ways to filter out distractions. Noise and visual stimulation make it hard for me to concentrate. Let me sit up front, where I will be less distracted. I might need earplugs or sunglasses to help me filter out my environment.

Keep the environment organized.

Clutter in the classroom or on the walls can be overwhelming to me. If my surroundings are tidy and organized, this will help my brain make sense of things.

Remember the question, "What has changed in the environment" if my behavior suddenly changes.

Even changes that seem very small can be dramatic in my life. Help me adapt to changes by showing me, rather than just telling me, what is expected of me.

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