FAS/FAE: A Practical Guide for Parents

(FAS/FAE is now referred to as FASD - Fetal Alcohol Spectrum Disorder)

1994

2.0 Training Hours

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FAS/FAE A Practical Guide for Parents

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PART I

Fetal Alcohol Syndrome (FAS) is recognized as the leading known preventable cause of mental retardation in the western world. FAS is a medical condition; to be diagnosed with FAS, a child must have each of the following:

1. characteristic facial features
2. growth deficiency
3. central nervous system dysfunction

A child who was exposed to alcohol prenatally and who has some, but not all, of the characteristics of FAS can be categorized as Fetal Alcohol Effect (FAE). The mother of a child diagnosed as FAE may not have drunk less than the mother of a child with FAS, but for some unknown reason the baby did not suffer as much physical damage. A history of drinking during pregnancy is the one factor that must be present for the diagnosis of FAS/FAE. Many FAS/FAE children are not diagnosed correctly, largely because of social and emotional taboos surrounding alcohol and alcoholism.

Common profile characteristics:

Facial Features:
1. Flat mid face
2. Short palpebral fissures
3. This smooth upper lip
4. Hypoplastic philtrum

Growth Deficiency:
1. Low birth weight
2. Failure to thrive
3. Short stature

Central Nervous System Dysfunction:
1. Microcephaly
2. Hyperactivity
3. Motor problems
4. Attention deficits
5. Cognitive disabilities
6. Mental retardation

It is important to not that children with FAS/FAE are individuals. While they may exhibit some of the profile characteristics, they may not exhibit all of them, or they may exhibit them to a
greater or lesser extent. As the children reach adolescence and adulthood many of the physical characteristics become less noticeable.

No one knows how much alcohol a woman may consume during pregnancy before the baby is affected. Some studies show that less than 50% of the women who drink heavily have children with FAS. Other studies have shown that women who drink only socially have an increased risk of having an affected child. One must assume, therefore, that there is no safe level of alcohol consumption during pregnancy.

**ABSTINENCE IS THE ONLY GUARANTEE!**

**PART II**

**DEVELOPMENTAL STAGE PROBLEMS**
The following is a list of developmental stages and problems common to each stage in children with FAS/FAE.

**INFANCY:**
1. Small, scrawny appearance at birth
2. Often tremulous and irritable
3. Weak sucking reflex
4. Hypotonia (poor muscle tone)
5. Failure to thrive
6. Feeding problems
7. Erratic sleep patterns
8. Poor differentiation between wake and sleep cycles
9. Slow to master motor milestones (both gross and fine)
10. Slow to start talking

**PRESCHOOL:**
1. Small size (both height and weight)
2. Elf-like mannerisms
3. Butterfly-like movements
4. Flitting from one thing to another
5. Interested more in people than objects
6. Delayed communication skills
7. Excessive talkativeness and intrusiveness, giving the appearance of normal communication skills
8. Hyperactivity (most pronounced during this stage)
9. Unresponsiveness to verbal restrictions
10. Fearlessness – gets into everything (safety problem)
11. In need of close supervision

**EARLY SCHOOL YEARS:**
1. First school experience difficult
2. Referrals for special education
3. Reading and writing may not be noticeably delayed
4. Math can be more of a problem
5. Appear to be achieving quite well relative to their IQ scores
6. Attention deficits become apparent as classroom demands increase
7. Emotional problems begin to develop
8. Poor impulse control becomes a problem
9. Memory deficits and inability to generalize become apparent
10. Lack of social skills causing poor interaction within their peer group
11. Social isolation within the higher function group
12. Excessive demands for physical body contact
13. Poor understanding of boundaries and personal space
14. Interest in sexual exploration and inappropriate sexual acting out, leading to risk of being victimized and of victimizing others

MIDDLE SCHOOL YEARS:
1. School achievement reaches a high point
2. Increased problems with attention deficit
3. Reading comprehension is below reading perceived level (word recognition)
4. Problems completing tasks
5. Problems mastering new skills
6. Poor social skills, causing peer problems (trouble making and keeping friends)
7. Referrals for psychological evaluation
8. As school and peer problems increase, school attendance becomes a problem
9. Verbal skills, superficially friendly manner, and good intentions can still mask the seriousness of the problem

ADOLESCENTS:
1. School achievement continues to decline
2. Increase in disruptive classroom behavior
3. Drop in school attendance (truancy)
4. Need to re-evaluate classroom placement and expectations
5. Child’s own increased awareness of poor social skills and peer relationships
6. Anxiety, depression, and the awareness of being different becomes a problem
7. Limited abstract thinking hinders basic problem solving
8. Improvement in general performance not consistent with increase in age (falling farther and farther behind peers)
9. Poor prospects for independent living

To most parents and other professionals who deal with FAS/FAE children, behavior and emotional problems seem to be of greater concern than physical abnormalities. As with physical signs, the child may exhibit a wide range of behaviors, but some characteristics seem common.

Small children can be socially engaging, and are often chatty and active. They may also be hyperactive with short attention spans and may be highly distractible. They may act very impulsively and appear unable to learn from previous experiences, behavior that can be reason for great concern about the safety of the child. Impulsiveness can also cause a child to have difficulty with transitions. This behavior is often what prompts children with FAS/FAE to be evaluated for special services when they enter school.
As these children grow older their impulsiveness, hyperactivity, and attention defects show up as a tendency to leave a situation when things are not going their way. They may also show poor judgment and what seems to be an inability to predict the consequences of their behavior, good or bad. It is at this time that parents, caregivers and others also start to report problems such as lying and stealing with no sign of remorse. It is very important to remember that children affected with FAS/FAE can often show a large discrepancy between their tested verbal Intelligence Quotient (IQ) and their true ability to communicate. Thus, what we see as lying they might see as trying to please; what we see as stealing they might see as using something that nobody else was using at that time.

The lack of good communication skills, impulsive behavior, and inability to predict consequences can make it very hard for children with FAS/FAE to establish and maintain meaningful social relationships. This can cause them to choose friends who are younger than they are, whom they see as non-threatening. Within this group of peers they feel safe and secure. This tendency can be the source of later problems. As they approach puberty, they may start to act out sexually within their peer group. They may also show what, because of their size, appears to be over aggressive behavior toward these younger peers. Because of their wish to please and their need to be accepted, these children are also at risk of being victimized themselves not only sexually, but in many other ways as well.

As children with FAS/FAE approach late childhood or early adolescence, their behavior results in signs of frustration, depression, and anxiety over their feelings of being different. This frustration and anxiety may show up as more impulsiveness, more aggression, and poorer control of their anger. Typically, it is at this time that these youngsters are diagnosed as having some sort of mental illness and are treated with medication and hospitalization. At this time, it is important to be aware of the behaviors common to children with FAS/FAE. A diagnosis of Fetal Alcohol Exposure, whether FAS or FAE, can come as a relief to both the parents and the children because it helps explain the difficulties they are having.

During the early preschool years, many children with FAS and even more so those with FAE – are not seen as having behavior problems. It is when they reach school age that their behaviors become more of a problem. This has to do with both their developmental age and the added social demands that are placed on them by the school experience.

Studies have shown that children with FAS/FAE have a wide range of IQ’s from below 30 to over 100, with the average being somewhere between 65 and 70. With such a wide range of IQ’s and the discrepancies between their tested abilities and their true functioning levels, it is very hard to find an appropriate academic place for these children. Hence children with FAS/FAE can be found in almost all educational programs, from those for the most severely disabled to regular classrooms. For this reason, these children are the concern of both regular and special education teachers. Classes that work with FAS/FAE students exclusively do not yet exist.

Children with FAS/FAE start school burdened by a lot of excess baggage. Their academic picture is poor enough, given the wide discrepancy between their tested functioning levels and their true abilities. Compounding this are their poor social skills and behavior. Since these students seem to be rather concrete, they may do well in school during the first few years. But as the subject matter becomes more and more abstract, the students have an ever increasing problem keeping up. At this time their poor social skills, lack of impulse and frustration control,
and behavior problems start to disrupt the classroom. It is very important at this time for the people working with the student to recognize the behavior pattern associated with FAS/FAE and adapt the academic environment accordingly. Ways to do this will be discussed in the next part of this booklet.

The greatest area of concern is the inability of these students to generalize and transfer the skills they have learned from one area to another. This seems to be true even for students who have what appear to be normal academic abilities. This inability makes the transition into an independent living environment difficult if not impossible. It is important that people attempting to assist in the transition have a good understanding of the underlying deficit so that a positive transition can occur.

**PART III**

If we are to design appropriate programs for children with FAS/FAE, we must first have an understanding of two things. First, we must understand the nature of the deficits you’ll be dealing with, as briefly described in Part II. Second, as most professionals agree, we must understand that one of the main goals of both parents and educators is to see the children we care for become as productive and independent adults as possible.

Children with FAS/FAE are no different from children with other disabilities in that they benefit from early intervention, which depends largely on early diagnosis. However, obtaining a diagnosis can be difficult, because many problem areas do not show up until the children reach school age. Many of the children are no longer in their birth homes and a good prenatal history is hard, if not impossible, to obtain. Nonetheless, even with diagnosis is not possible, many of these children can still be identified by an observant professional. These identified-but-undiagnosed children would still benefit from, and should receive, the same types of programs as the children with the medical diagnosis. Since early intervention is one of the most important factors in reaching the goal, it may be necessary to examine and even modify some of the criteria for admission.

When looking for or designing your own program for children with FAS/FAE, keep in mind that these children are not simply learning-disabled. It is not a matter of giving them a push and watching them catch up. FAS/FAE is a lifelong disability caused by prenatal brain damage. With this in mind, it becomes imperative to both find a way to teach functional social and communication and to decrease the occurrences of inappropriate behaviors. You also need to consider whether an academic curriculum is appropriate. You may need to consider a broader definition of curriculum in light of the goals stated.

FAS/FAE children need to learn functional or “adaptive living skills.” They need to learn how to use the skills you are teaching them outside of school. The focus should be on the environmental settings the children may be living or working in, both now and in the future. They need to learn not only how to fill out an application and find a job, but also how to keep that job.

When teaching social skills, keep in mind that social isolation is all too common with these children. Many come from dysfunctional homes. Their poor communication skills, inability to predict the consequences of their actions, and poor impulse control make it hard to make and
keep friends and to interact with their peers, often leading to anxiety and depression. Thus the teaching of social skills must be an integrated part of any program for teaching children with FAS/FAE. When designing this part of the curriculum, remember that generalizing is very difficult for these children. The skills they learn from role-playing may not be carried over into their daily life. Social skills may need to be taught in the hall, the lunchroom, the playground – in fact anywhere and everywhere the opportunity occurs. Remember social skills are not add-ons to their curriculum – they are essentials.

Although children with FAS/FAE may seem to have normal cognitive skills and normal language development, their ability to understand and communicate may be severely impaired. As with tested IQ scores and true functioning abilities, there seems to be a large discrepancy between verbal language and the ability to communicate effectively. When designing the communication part of your curriculum, you need to include the skills that are necessary to communicate effectively – and not only verbally. These skills should include verbal expression as well as gestures and other behaviors used to communicate ideas in their culture. It is also important to remember that, as with social skills, this teaching should be done not only in the classroom, but anywhere the opportunity occurs.

The second part of teaching effective communication skills is teaching how to make choices. This is not always easy, in part because we must honor the child’s choice even if we do not agree with it. To do otherwise would be to communicate that the child’s choice had no meaning. Teaching how to make choices can also be very time-consuming and frustrating. It must be done in a very systematic way, beginning with giving the children a few concrete choices and slowly offering them more and more complex choices.

The last, and perhaps the most important, part of any program dealing with children who have FAS/FAE is behavior management. Ideas for dealing with this issue are presented in Part III. For now we should look at some of the facts that need to be considered.

When you are dealing with children with FAS/FAE, realize that you will be using some form of behavior management. With this in mind, you can understand that the largest and perhaps most difficult part of the behavior management curriculum is structure.

When working with children with FAS/FAE, the structure needs to be simple, well-defined, and consistent. Everything needs to be black and white; there can be very few gray areas. If behavior “A” equals consequence “Y” today, then it must also equal consequence “Y” tomorrow, next week, next month, and next year. The children with FAS/FAE also need to know what the consequence is for a certain behavior. The consequences generally need to be the same for everyone. Individualized behavior contracts do not generally work as well as a set of rules for the group, with the corresponding consequences written and posted.

It can also be useful if you look at behavior, in part, as being a form of communication. If you keep in mind that children with FAS/FAE have a hard time communicating, their inappropriate behavior no longer always seems malicious or simply geared to get attention. It can then become a real challenge for you to understand the meaning behind some of the inappropriate behavior and find a better way for them to communicate that message.
Another challenge in managing these children’s inappropriate behavior is in planning ahead. A crisis is not the time to decide how we are going to react to a certain situation or what the consequences for the behavior will be.

Finally, in dealing with these children and their behavior, always remember:

**IN ORDER TO KEEP CONTROL YOU MUST BE IN CONTROL!**

**PART IV**

Up to this point this work has been based on other papers about FAS/FAE listed in the bibliography. Part IV, however, comes from my personal collection of notes gathered at numerous conferences and workshops help in the Anchorage, Alaska area between mid-1990 and the end of 1993. It is the result of presentations by, and my conversations with, a large number of professionals and parents involved with children with FAS/FAE. I regret that I did not keep a list of all the people that took part in these activities so that I could give them the credit they deserve.

The following is a list of methods and strategies by Patricia A. Tanner, Ph.D., for working with children with Attention Deficit Disorder (ADD). A large number of people I have talked to over the past few years say that they have found them to be helpful in working with children with FAS/FAE.

The key to working successfully with ADD is to apply structure, consistency, brevity, variety, and persistence.

**ENVIRONMENTAL:**
1. Have well-defined areas.
2. Have all extraneous materials removed.
3. Use preferential seating assignments.
4. Use the same staff consistently.
5. Use pictorial cues as reminders of routines.
6. Adapt task and materials to their frustration tolerance.
7. Pair with high-tolerant peers for short periods.

**TRANSITIONS:**
1. Use an egg timer to clearly define the length of an activity.
2. Use song musical and/or rhythm cues.
3. Use visual cues.
4. Give plenty of advance warning before changing activities.

**ORGANIZATION SKILLS:**
1. Give short assignments with clearly stated objectives.
2. Have consistent follow-up on all assignments.
3. Use a positive approach.
4. Use a calendar and assignment books.
5. Break tasks into small pieces.
6. Adhere to consistent, firm rules with clearly understood consequences.
7. Post the rules with their consequences.
8. Give direct instruction in, and model, thinking skills.
9. Give brief, concrete, and carefully defined directions.
10. Have a well-defined place for the child to put completed work.
11. Limit the number and type of new situations the child encounters at one time.
12. Make visual lists.
13. Teach matching and sorting skills.
14. Teach and model alternative behaviors.
15. Have peers model alternative behaviors.
16. Have positive incentive for completing tasks.
17. Post a schedule of daily activities.
18. Use highly structured and predictable routines and rituals.
19. Recognized the child’s correct, not incorrect, responses.
20. Teach how to recognize important details from those that are less important.
21. Spend time describing and comparing objects, events, and details.
22. Use a tape recorder.
23. Teach and model analyzing and synthesizing skills.
24. Use a whole language approach when teaching reading.

OVERCOMING DISTRACTIBILITY:
1. Give individual directions.
2. Give directions on direction at a time.
3. Be firm and supportive.
4. Use earphones.
5. Use eye contact when giving directions.
6. Be sure to have the child’s attention by calling their name and touching them before giving directions.
7. Have the directions repeated back to you.
8. Be sure that the child has completed one task before moving on to the next.
9. Make sure you are testing for knowledge, not attention span.
10. Remember – variety is an excellent attention-getter.
11. Focus the child’s attention by using pictures, objects, and facial expressions.
12. Vary the tempo of your speech.
13. Use incomplete sentences and rhymes with key words missing.
14. Use accented key or focus words.
15. Vary the volume and quality of your voice.

CONTROLLING IMPULSIVITY:
1. Redirect inappropriate behaviors.
2. Teach and model how to take turns.
3. Teach, model, and rehearse (role play) social skills.
4. Look at the cause and effect relationship between various behaviors.
5. Teach and use a system whereby a child can evaluate an act before they do it (S.T.A.R., stop, think, act appropriately, reward yourself).

CONTROLLING HYPERACTIVITY:
1. Use as little unstructured time as possible (desk work).
2. Balance structure and free time.
3. Use a teaching style that emphasizes manual and physical expression.
4. Allow a physical outlet for excess energy.
5. Establish an environment that is not over-stimulating to the child.
6. Teach and model ways that the child can monitor their own behavior.
7. Physically assist the child to regain control, if necessary.

OTHER IDEAS:
1. Teach the child to be aware of danger signs and situations.
2. Label obnoxious behaviors.
3. Try not to get into debates over rules or infractions.
4. Be calm and natural (don’t loose your cool).
5. Be neutral.
6. Use some kind of token economy.
7. Be creative.
8. Have a respite plan for both yourself and the child.
9. Encouragement can sometimes work better than praise.
10. Work with solutions not problems.
11. Acknowledge the child’s right to their feelings, then slow them an appropriate way to express their feelings.
12. Teach the child to be aware of their own personal space and that of others.
13. Have clearly defined boundaries (this is your and this is mine).
14. Have quiet times using soft background noise (music or environmental tapes).
15. Remember that while working with children with FAS/FAE can be very stressful, it can also be very rewarding (look for the successes).

SOME OTHER IDEAS:
1. Teach the child ways to be independent by teaching self-help, play, and learning skills.
2. Allow the child to help in the group so that they feel like a valued group member.
3. Establish hello and good-bye rituals.
4. Set up routines so the child can predict upcoming events.
5. Teach, model, and encourage independent decision-making skills.
6. Intervene before behavior escalates.
7. Help the child establish clear, well-defined limits and follow them.
8. Alternate active times with quiet times.
9. Use positive self-talk and encourage the child to do the same.
10. Work with the child on body and self-image.

PROGRESSIVE TIME-OUT
This is a rather involved system where the people involved have agreed that the consequences for certain target behavior will be time-out and there will be a time within which the child must comply. The program is generally set up with three or four steps; each one progressing in severity. The following is one idea.

To start the program, the child is told that their behavior is not acceptable and that there will be a time-out unless they change their behavior. The child is then given a chance to comply with the request. If after the preset length of time, the child has not complied, the child is told to go to step one.
**Step One** – The child is to sit in a special area set for time-outs. The child may be allowed to observe the group, but may not take part in the group’s activities. The child is to remain there for a preset time (the same as the time allowed before Step One), they are to go to Step Two.

**Step Two** – The child goes to the same place as in Step One, but now is not allowed to observe the group’s activities. This step is to last for a preset time longer than that of Step One (10 minutes). If the child still refuses to comply within the preset time, they are to go to Step Three.

**Step Three** – In Step Three, the child is to remove himself from the area altogether (out to the hall). The child is to stay in Step Three for a preset time longer than Step Two (15 minutes). If the child still does not wish to comply, the child goes to Step Four.

**Step Four** – With Step Four, the child is physically removed from the area and remains there with a staff person until they are ready to comply with the request (no time limit).

**NOTES:**
1. In order for the child to return to the group, the child must complete all the steps (if the child is in Step Three, they must complete Steps Two and One).
2. If at any time during the program the child becomes verbally abusive, the child is to go to the next step.
3. If at any time during the program the child becomes physically abusive, the child is to go to Step Four.
4. It has been found that if you are using a program that has preset times it is bets to use a timer. That way the timer becomes the control and it is very hard for the child to argue with a timer.
5. It is best if the same person who starts the time-out program sees it through.
6. It is also very helpful if at each step in the program the child is reminded about making good choices and what is expected of them (please go to Step One; think about what you are doing; think about your choices).
7. Do not argue with the child. The interaction needs to be very cut and dried. Either the child complies or not – they know what is next, and what is expected of them.
8. When this program is used, it runs for one instance of that behavior; which the steps are completed, the process is over and has not compound effect. After the child is out of steps he or she starts back at Step One again even for the same behavior and even if that behavior starts again as soon as he or she returns to the group.

**SELF-TIME-OUTS**
This is a good program to use when the child’s behavior is escalating but has not reached the point when a more advanced program is needed. The child is told that their behavior is becoming unacceptable and they need to take a time out in order to get their behavior under control before they get into trouble. There may or may not be a time period for this time-out and the choice of taking the time out is up to the child. Again, however, it may be helpful to remind the child about making good choices.
PROBLEMS AND METHODS FOR DEALING WITH THEM

The following are problems that parents and other professionals who work with children with FAS/FAE have reported as troublesome, and methods that have been found useful in dealing with them.

**Bedtime:** This problem has been reported from very early ages and seems to continue into adulthood. It is due to the problem these children have with transitional periods and periods where there is little or no structure. Bedtime has some of both. Because it is easier to handle, I will look at the problem of transition first.

1. Establish a definite bedtime and stick to it.
2. Establish a bedtime routine that starts an hour before bedtime (they pick up their toys, get their bath, brush their teeth, get in their pj’s, get their good night hugs, and go down to their room for story time and then quiet time. Use an egg timer at this point so they can see how much time they have left before they must be in bed and lights out.)
3. Avoid arguing with them during this routine. Arguing at this time can prolong the routine and make their bedtime later.
4. If you need consequences for problems at this time try not to use a time-out. This generally extends bedtime and can be used against you. You might wish to look at a point system instead. Say if they get to bed without a problem they can earn 10 points and the points equal extra allowance at the end of the week or even the next morning.

Remember – the child’s bedtime must be clearly understood and there should be very little change in it. Some parents have said that they have set two bedtimes – one on school nights and another for weekends and vacations. The results have been mixed.

Now what to do about the unstructured time after they are in bed and before they go to sleep. This is a very hard one to solve, but I have found two things that can help. First is to let the child take something to play with into the bed with them. The rules on this are that it must be something that they can play with quietly and they can not get out of bed to get something else. You also need to accept the fact that they might be in bed, but not sleeping. The good thing about this is that the child is in compliance with the house rule and is learning about making acceptable choices. The other method some parents have used is to play music very softly at bedtime so the child has to concentrate in order to listen. The music itself does not have to be soft. If fact the parents who use this approach seem to think that it works best if you let the child pick the type of music, so they will be more willing to work at listening. This helps relax them so they can go to sleep.

**Mealtime** – Parents report that mealtime is troublesome – in particular family meals. Table manners are unacceptable and what should be good quality time turns out to be a real fight. Some parents have gone as far as saying that the child does not eat with the rest of the family. This does not take care of the problem.

Before we look at ways to make mealtime more enjoyable, let’s look at why this time is so hard for the child with FAS/FAE. The child with FAS/FAE has a problem with impulse control. The dinner table is full of impulsive things – play things like silverware, napkins, glasses, and food. In order to deal with behavior it is necessary to deal with the problem of poor impulse control. This can take a lot of creative thinking on our part, and some give and take as well.
The most creative idea I have heard so far is to have the child serve, thus limiting the time the child has to sit at the table at any one time. This way the child has the chance to get up and do something physical three or four times during the meal and has an important part to play at meal time. His reward for serving was that he could choose which dessert dish he got (one would always have a larger quantity than the others). If, however he did not get to serve the dessert, someone else would get the largest dessert. For him to serve the entire meal he had to show acceptable behavior during the whole meal. If not, he would be fired on the spot and one of the other children would take over and get the reward. This seemed to be working very well for this family. They had been using it over 5 months when they told me about it and only five times in a three-month period did he need to be fired. The mother did say that many times she saw that he was getting antsy and she had to come up with a reason for him to do something (even answering the doorbell when nobody was there).

One other idea that a parent has told me about that worked is that the child was having a problem with playing with her silverware. To help control this behavior, no silverware was at her place when the table was set. She was given her silverware with her food and then only what she needed. This special service meant that she was generally the last to get her food and she did not like being the last. This continued for about six weeks. Then she and her mother made a deal where she would have silverware at her place like everyone else as long as she did not play with it. If she started to play with the silverware, it would be taken away and then come only with the food again.

Another idea is to give the child their own special place setting to use as long as they used it appropriately. The child is allowed to sit at a special place at the table if they can act appropriately. Of course, there is the old standby that they can stay at the table for only as long as they behave and if they have to leave the table before dessert they don’t get any.

**Completing a task** — One of the most common question I hear from both parents and teachers is “how can I get him/her to complete a task?” We all realize that children can be really great starters. They are always starting something and we have a house full of unfinished projects. So far I have only heard of one way to handle this without a lot of trouble. Remembering that these children have a poor memory, we need to try to understand how hard it is for them to keep track of the goal of a task or assignment for any length of time. Remember also that children with FAS/FAE have trouble with generalization and abstract concepts. If the reason for doing something is lost or not clearly understood the child loses interest. To help keep their interest you can do three things: break the task or assignment into small parts that can be done quickly; post the goal where it is in full view while the child is working on the task; or give small rewards when certain parts of the task have been completed. The system that I have see that works well uses all three ideas. First, the goal is clearly stated and written down. Then the assignment is broken down into smaller parts and written down. As each of the smaller parts is completed, it is marked off with a star, a happy face, or sticker. These can then be saved until the assignment is completed or be turned in for a reward. The more stars or stickers that the child has to turn in, the better the reward. If may be helpful sometimes to place a time limit on some of the parts or even on the whole assignment. If the assignment is going to last for a long period of time, you may wish to set up a number of check points with a reward at each one.
Personal Space – Children with FAS/FAE have a real problem with the concept of personal space. In fact, it appears that these children have a poor ability to understand and accept boundaries in general. This appears to go along with their poor ability to understand abstract concepts. There are really two big problems here that need to be looked at individually. One is the concept of their own body image and their personal space. The other is other people’s personal space. In order for them to develop any understanding of personal space, they must acquire some understanding of their own body. They need to see themselves as individuals, and see that they have an effect upon their surroundings.

A physical education teacher who works with emotionally disturbed children has given me some ideas on how to help these children acquire a better concept of their bodies and the space around it. She sets up an obstacle course that requires the child to move through it by going over, under, around, and between obstacles without knocking into anything. As the child improves, the obstacles are placed closer together. The child is also asked to do the obstacle course with their arms out so they get an idea of the space that is theirs. When they have an understanding of this space around their bodies, you have a starting point to work with in helping them accept personal space. The first thing is that nobody is allowed to come into your personal space. Once they seem to understand this, work on the idea that if you don’t allow anybody into your personal space then you should not enter into anyone else’s space because to do so would mean that they would enter into yours as well. To help them understand about other people’s personal space the children set up the obstacles for another child so that the other child does not knock anything over. This helps the child understand the personal space around other people.

Boundaries – The concept of boundaries is much harder to help them understand. I have not come across any really good ways to help here. One teacher reported that she used a color code system. Each child’s desk was outlined in a different color as was the place they put their coats and book bags, their space in the lunchroom, their spot to line up, and their cubby. The teacher then marked each child’s hand with the same color. The children were not allowed outside their colored boundaries. This idea might work well in a school setting, but would be very hard it set up within the home setting.

An offshoot of this program that I have told to some parents is to place the child’s name on the places they are allowed to go: the bathroom, living room, dining room table, even their chair and place at the table, seat in the car, and drawers in the dresser. This program does have one very big drawback. If you are going to use it, you must face the fact the child could think of the spaces marked as their own and try to establish ownership rights. These owner’s rights could cause some trouble, if you are not ready. The child might see them as personal space and anyone else in that space as an intruder.

Personal Belongings – In the same way they have trouble understanding personal space, they also have a hard time accepting the concept of personal belongings. There is hope there, however. The color coding system works very well with helping these children understand that things belong to someone. The child is asked to choose a favorite color and then all their things are marked with that color. They seem to understand very quickly that if anything is marked with their color it is theirs and here ownership rights are allowed. This color coding can be helpful in setting consequences. If the child has something that is not marked with their color, then they have broken a rule and consequences will follow.
Time – The idea of time and the passage of time also comes up a great deal. I have not come across a good way to teach children with FAS/FAE to understand the idea of long periods of time and the idea of past and future, but there is some hope that they can understand the passage of short periods of time and the present. As in most programs with these children, the earlier you can start the better. This seems to be especially true with the concept of time. When you are trying to teach about time, try to do it in small segments like five minutes each. Something that takes longer than five minutes is then done in X number of five minute segments; for example, break up an activity that lasts 30 minutes into six five-minute periods. One parent has said that they would have their son count to a certain number and time was expressed in that number. Say the child would count to 50 in one minute and the time that they needed to wait for their turn was five minutes. Then he would be told to count to 50 five times and it would be his turn. This works fine until the child understands that if they count faster then they can get what they want faster. You can see the problems this could cause.

Past and future are not as easy. One idea that does work to some extent is to talk about past and future in terms of special events like holidays, birthdays, vacations, and the seasons. For example, your family is planning a trip at the end of June. That’s six months away and does not compute. Try saying, “we are going on vacation two weeks after school gets out for the summer.” In the same way you can talk about the past. Instead of saying we got the dog last May, try saying, we got the dog just after your birthday last year.

Fear – A problem area I have with my son is fear. Something happened to someone else and he is afraid it will happen to him, or something happened somewhere else and he is afraid it will happen here. One approach I have used that helped is to show him on a map where the event took place. (Hurricane Andrew hit Florida. We live a long way from there. I show him on a map where Florida is and where we live.) We also talk about the differences in the weather between Florida and here. (We have snow storms and it gets very cold. Florida has hurricanes and can get very hot.)

I use very much the same type of approach in dealing with him when he is afraid that something bad will happen to him because it happened to somebody else. I help him look at things such as: who did it happen to, where do they live, what were they doing when it happened, and who was with them. I get him to look at himself, where he lives, what he does, and who he does things with. Then I point out the differences to him.

Showing him differences also helps when he has a hard time understanding why there are different rules and consequences for his brother or classmates than there are for him.

Body Contact – The seemingly excessive need for body contact is another area that can become rather troublesome. This, at first, would seem to be the same as the problem with personal space. A second look shows that there is more to the need for body contact than just a lack of understanding about personal space. This could also have to do with their need to feel loved, safe and needed. A counselor who works with a lot of these children has explained to me that this is common with a lot of children who have been in this social system for long periods and who entered the system at an early age. Both of these factors apply to many of the children with FAS/FAE. We know that many of these children are not living with their birth families and were taken out of the birth home at an early age due to abuse or neglect. Understanding why these
children have this type of behavior is not as hard as trying to deal with it the way it is expressed in children with FAS/FAE.

The counselor did have some ideas on how to deal with this behavior. They do help somewhat, but are a far cry from controlling the behavior. Some of her ideas are that physical contact be very structured, so that there can be no misunderstanding regarding what is acceptable and what is not. She also said that physical contact should not be for prolonged periods. Verbal praise is also a big part. The example she used was the child who always wants to sit on your lap. She said to allow the lap-sitting in the beginning. While the child is on your lap you give them a strong hung and verbal assurances. As time goes by you cut the lap-sitting and increase the hugs with more verbal praise. In time lap-sitting should become a hug with verbal praise. One way to help cut lap-sitting is to make your lap less accessible. Have your lap occupied with something – a book, a cup or glass, your eye glasses, the newspaper, anything that you can have lying on your lap. The next step is to pick a key word, phrase, or sign that could be used for the verbal assurance. She also felt that it was important not to wait for the child always to come looking for a hug and assurance. Rather you should give it spontaneously whenever you notice the child is behaving in an appreciated way. In this way you meet the child’s need first, so the child ides not need to come looking for assurances as much. I have not seen that this system totally controls this behavior, but it does seem to decrease it somewhat.

By this time you might be asking yourself, do I want this or need it, can I handle this type of child, and is it worth it? No one can answer these questions for you. You have come this far and I know (being a parent of two children – one with FAE and another with FAS) that a lot of what is said is very bleak. Up to this point, children with FAS/FAE have been misdiagnosed as attention deficit disorder, attachment disorder, oppositional, or lazy. This has resulted in the development of ineffective parenting an teaching techniques. The failure of professionals to recognize organic brain damage as a part of FAS/FAE has frustrated all of us who work with these children.

There is hope. Dian B Malbin writes that, contrary to present beliefs about children and adults with FAS/FAE that picture them as having limited abilities and poor prognosis, there is a very different picture emerging - one of hope, joy and success.

She points out that there are a growing number of children and their families who thrive and flourish. She also states that these are not one or two families or reports from a small group of professionals. Rather, a number of professionals from around the country are reporting successes and positive outcomes.

The basic point in these successes is early intervention made possible by increased awareness and identification of affected children. Increased awareness has improved understanding of the organic brain damage that results in many of the behaviors associated with these children. This better understanding has allowed professionals to change their perception of these children as bad, lazy and willfully irritating. This change in perception has helped professionals see these children as individuals in need of help. The treatment approach has changed from one of punishment to one of support. The change in perception has led to the development of more effective parenting and teaching techniques and the setting of more realistic goals and expectations.

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## PART IV

### NATIONAL RESOURCES FOR FAS/FAE CHILDREN

<table>
<thead>
<tr>
<th>Resource Centers</th>
<th>National Perinatal Information Center</th>
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<tbody>
<tr>
<td>Center for Disease Control</td>
<td>One State ST STE 102</td>
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<tr>
<td>1600 Clifton RD</td>
<td>Providence, RI 02908</td>
</tr>
<tr>
<td>Mailstop F-29</td>
<td>Phone (401) 274-0650</td>
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<tr>
<td>Atlanta, GA 30333</td>
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<tr>
<td>Phone (404) 488-7370</td>
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<tr>
<td>National Organization on Fetal Alcohol Syndrome</td>
<td>Center for Substance Abuse Prevention</td>
</tr>
<tr>
<td>1815 H ST NW STE 750</td>
<td>National Resource Center for the Prevention of</td>
</tr>
<tr>
<td>Washington, D.C. 20006</td>
<td>Perinatal Abuse of Alcohol and Other Drugs</td>
</tr>
<tr>
<td>Phone (202) 785-4585</td>
<td>9300 Lee HWY</td>
</tr>
<tr>
<td>Toll Free (800)666-6327</td>
<td>Fairfax, VA 22031</td>
</tr>
<tr>
<td>Native American Development Corporation</td>
<td>Phone (703) 218-5600</td>
</tr>
<tr>
<td>1001 Connecticut AVE NW #1206</td>
<td></td>
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<tr>
<td>Washington, D.C. 20036</td>
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<tr>
<td>Phone (202) 269-0685</td>
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<tr>
<td>National Indian Board on Alcohol and Drug Abuse</td>
<td>Women for Sobriety</td>
</tr>
<tr>
<td>PO Box 8</td>
<td>PO Box 618</td>
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<tr>
<td>Turtle Lake, WI 54889</td>
<td>Quakertown, PA 18951</td>
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<tr>
<td>Association for Retarded Citizens of the United States</td>
<td>Toll Free (800) 333-1606</td>
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<tr>
<td>2501 Avenue J</td>
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<tr>
<td>Arlington, TX 76006</td>
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<tr>
<td>Phone (817)640-0204</td>
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<tr>
<td>National Clearinghouse for Alcohol and Drug Information</td>
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<tr>
<td>National Institute on Alcohol Abuse and Alcoholism</td>
<td>Children of Alcoholics Foundation</td>
</tr>
<tr>
<td>PO Box 2345</td>
<td>540 Madison AVE</td>
</tr>
<tr>
<td>Rockville, MD 20852</td>
<td>New York, NY 10022</td>
</tr>
<tr>
<td>Phone (301)468-2600</td>
<td>Phone (212) 980-5394</td>
</tr>
<tr>
<td>Toll Free (800) 726-6686</td>
<td></td>
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<tr>
<td>National Association for Perinatal Addiction Research and Education</td>
<td>Alcoholics Anonymous</td>
</tr>
<tr>
<td>11 E Hubbard ST STE 200</td>
<td>PO Box 495</td>
</tr>
<tr>
<td>Chicago, IL 60611</td>
<td>Grand Central Station</td>
</tr>
<tr>
<td>Phone (312) 329-9131</td>
<td>New York, NY 10163</td>
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<tr>
<td>Toll Free (800) 638-2229</td>
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</tr>
<tr>
<td>National Council on Alcoholism and Drug Dependence</td>
<td>Adult Children of Alcoholics</td>
</tr>
<tr>
<td>12 West 21 ST</td>
<td>PO Box 3216</td>
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<tr>
<td>New York, NY 10010</td>
<td>Torrance, CA 90510</td>
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<tr>
<td>Phone (212) 206-6770</td>
<td>Phone (310) 534-1815</td>
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<tr>
<td>Toll Free (800) 622-2255 / (800) 475-4673</td>
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<tr>
<td>National Association for Native American Children of Alcoholics</td>
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<tr>
<td>PO Box 18736</td>
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<tr>
<td>Seattle, WA 98118</td>
<td>Phone (202) 322-5601</td>
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National Black Alcoholism Council  
1629 K ST NW STE 802  
Washington, D.C. 20006  
Phone (202) 296-2696

Al-Anon/Alateen Family Group  
PO Box 862  
Midtown Station  
New York, NY 10018  
Toll Free (800) 356-9996

NEWSLETTERS:  
Iceberg  
PO Box 95597  
Seattle, WA 98145

Growing with FAS  
7802 SE Taylor  
Portland, OR 97215

Fetal Alcohol Network Newsletter  
158 Rosemont AVE  
Castville, PA 19320

Clearinghouse for Drug Exposed Children  
Newsletter  
The Clearinghouse for Drug Exposed Children  
Division of Behavioral/Development Pediatrics  
University of California, San Francisco  
400 Parnasses AVE RM A203  
San Francisco, CA  94143

BOOKS:  
The Broken Cord  
By Michael Dorris  

ARTICLES:  
“F.A.S.: Parent and Child”  
By B.A. Morse and L. Weiner  
Fetal Alcohol Education Program (publisher; 1992)  
Boston University School of Medicine  
Brookline MA

Educational Classroom Resources:  
The Walker Social Skills Curriculum  
The Accept Program, Pro-Ed  
Austin, TX (512) 451-3246

The Rochester Social Problem Solving (SPS) Program  
A Training Manual for Teachers for 2-4 Grade Children  
Primary Mental Health Project  
Center for Community Study  
Rochester, NY 14620

The Winning Colors Program  
Aeon Communications Inc.  
Los Angeles, CA 90046

The Optimum Resource Reading Program  
Optimum Resource Inc.  
Norfolk, CT 06058

Managing Attention Disorders in Children  
A Guide for Practitioners  
Sam and Michael Goldstein  
Wiley Interscience

The Teachers’ Guide to Behavioral Interventions  
Hawthrone Educational Services, Inc.  
Columbia, MO 65201

Think Aloud (Primary and grades 1-2, 3-4, 5-6)  
Research Press  
Champaign, IL

Stop and Think Workbook  
P. Kendall  
238 Meeting House Lane  
Merion Station, PA 19066

Skills for School Success  
Curriculum Associates Inc.  
North Billerica, MA 01862

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Tanner, P.A. Methods/Strategies for Educating Children with ADD.
ALASKA CENTER FOR RESOURCE FAMILIES
SELF-STUDY QUESTIONNAIRE FOR FOSTER PARENTS

SUBJECT: ALCOHOL: FASD TOPICS

COURSE: FAS/FAE: A PRACTICAL GUIDE FOR PARENTS

2.0 HOURS TRAINING CREDIT

Please read the book FAS/FAE: A Practical Guide for Parents, by Jim Slinn. Then complete the questionnaire found on the following pages. Try answering the questions first from your understanding of the material before referring back to the book. These questions pertain specifically to the course, which you have read.

After you have answered all the questions, please send your completed questionnaire to the Alaska Center for Resource Families, 815 Second Avenue Suite 101, Fairbanks, AK 99701. We will score your answers and credit 2.0 training hours to your training record. A score of 70% correct or better will entitle you to receive training hours credit. In the event your score is less than 70% correct, we will contact you to determine if you wish to review the material and retake the questionnaire. If so, the book will be returned to you with a new questionnaire.

If you have questions or concerns about this self-study course, please call us on our toll-free line at 1-800-478-7307. Fairbanks/North Pole call: 479-7307; Anchorage: 279-1799.

The following section is an evaluation of the self-study materials. Please fill it out upon completion of the questionnaire, and return this page to us with the rest of the course materials. Thank you for your time and comments. It helps us provide appropriate training to meet the needs of foster parents.

***************EVALUATION OF SELF-STUDY MATERIALS***************

Please complete the following questions.

1. Did this self-study course meet with your expectations? _____YES _____NO

2. How would you rate the written presentation of information on the topic?
   _____Excellent _____Good _____Fair _____Poor

3. Did this course add to your knowledge and/or skills? _____YES _____NO

4. Comments/Concerns:
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   _____Excellent  _____Good  _____Fair  _____Poor

3. Did this course add to your knowledge and/or skills? _____YES _____NO

4. Comments/Concerns: