

Living with Infants, Toddlers, and Children who have been Prenatally Exposed to Alcohol

This section includes practical information about what to look for and how to successfully deal with your infant, toddler, or child who has been affected by prenatal alcohol exposure. Much of the information comes directly from parent experiences. Also included is information that we encourage you to copy and share with your child's teachers and other caregivers.

It is crucial for everyone involved in the care and education of a child with disabilities to remember that they are first a child and second, a child with a disability. Children with FAS or ARND, like all children, will move through various stages of normal development. They may not move as quickly or as distinctly, but they will move and grow. With growth come struggles and challenges. A typically developing child may demonstrate some of the behaviors described in this section, but because he or she does not present a disability, their behavior is dealt with and accepted as a normal part of growing up. Conversely, children with disabilities often display appropriate or typically challenging behaviors for a child at their developmental level, but because they have a disability, their behavior becomes amplified by those who are working with and caring for them. Because this happens so frequently and unconsciously, readers are urged to balance their perceptions of their child's behavior with their knowledge and experience of normal/typical child development and behavior.

- How Parents Can Help
- Things to Try for an Irritable Baby
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- FAS Kids Respond Well to Special Strategies

How Parents Can Help

Adapted and reprinted from the FAS Educator's Packet (one of the six packets in this series), 1994

Children who may have Fetal Alcohol Syndrome (FAS) or Alcohol Related Neurodevelopmental Disorders (ARND) have been described as having similar behavioral characteristics. Some of these characteristics include difficulty learning from mistakes,

hyperactive behavior, poor social skills, aggressive behavior, developmental delay, and impulsiveness. Our experience has shown that children who have been prenatally exposed to alcohol have unique characteristics - both good and not so good - like any other children. Our experience has also shown that these children can do well in school and at home, though they may need a bit more structure and extra help.

Parents who have children with difficulties related to prenatal exposure to alcohol may find it helpful to keep a few simple ideas in mind.

FIRST, no matter what the cause of your child's difficulties, it is important to identify what he or she needs and then to find resources to meet those needs. For example, if your child has difficulty paying attention or is hyperactive, a behavior program and/or medical treatment may be needed. If your child is delayed in development, an appropriate school program should be identified.

- Make a list of your child's needs and talk with your doctor or your child's teacher to see where you might find the services to meet these needs.
- Find ways to help your child feel good about him or herself. If your child gets into trouble a lot, he or she may feel isolated.
- Encourage family activities where your child can shine - like helping with the garden, going for a walk, or caring for a pet.

SECOND, you should be aware of YOUR needs. If your child needs constant attention or supervision, you, as a parent, may feel drained or frustrated.

- Identify support services that can provide counseling or respite care in your community.
- Find someone to talk with about how you are feeling. Other parents probably feel the same way from time to time.

FINALLY, be creative in your approach to making your home a safe and nurturing place.

- Develop a consistent routine that works for you and your child. Make a schedule with words if your child can read, or use pictures if he or she can't read.
- Recognize your child in a positive way for doing what you asked and let him or her know how you feel.
- Don't be afraid to ask for help from, or share ideas with, your child's teachers, counselor, or physician. What works at home will also work in other settings and visa versa.

Sometimes there are no simple answers. Parenting a child with special needs often presents unexpected challenges. You, as a parent, may feel confused, alone, guilty, sad, frustrated, and at a loss for what to do if your child has learning or behavioral difficulties that require constant attention. Even family members and close friends find it hard to understand what it's like when a child frequently acts out, doesn't do well in school, or doesn't listen. These characteristics tend to overshadow the times when the child is happy and settled.

Remember, however, that there are people around you who have dealt with these difficulties before. It may take time to find out what works best for you and your child, but usually something will help.

Recognize that your child's needs may also change from time to time and don't get discouraged when what worked before no longer does. Be persistent in identifying both your child's needs AND the resources and support services to help. Be an advocate to help your child grow up feeling positive and secure about his or her life.

THINGS TO TRY FOR AN IRRITABLE BABY

1. Swaddle baby with hands exposed.
2. Swaddle baby with hands not exposed.
3. Swaddle baby with blanket warmed in the dryer.
4. Double wrap baby for added warmth.
5. Hold baby close; use a front carrier.
6. Bathe baby in warm water and follow with a gentle massage.
7. Try giving baby a pacifier; try different types of pacifiers.
8. Place baby on your tummy with skin to skin contact. However, never put a baby to sleep on his or her tummy.
9. Use gentle rocking - swing, cradle.
10. Play soft music in a dark and quiet room. Try a special tape with a heartbeat sound.
11. Sing or hum to baby.
12. Carry baby close to your body and go for a walk outside.
13. Take baby for a car ride.
14. Put a ticking clock in baby's bassinet or crib.
15. Leave baby with another caregiver and get some respite for yourself.

PROBLEMS AND METHODS FOR DEALING WITH THEM

Reprinted, with permission, from **FAS/FAE: A Practical Guide for Parents**, by Jim Slinn, pp. 16-22. Parents as Resources Engaged in Networking and Training Statewide, 540 West International Airport Road, Anchorage, Alaska 99518, (907)563-2246..

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 into 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. In 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 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 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 questions 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 seen 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. It 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 bookbags, 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 to 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 fights. These owner's fights 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 here, 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 period 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 segment 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 hug and verbal assurances. As time goes by you cut the lap-sitting and increase the hugs with more verbal praise. In time the 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 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 does 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 and 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. Diane B. Malbin writes that, contrary to present beliefs about children and adults with FAS/FAE that picture them as having limited abilities and a 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.

A DEVELOPMENTAL OVERVIEW OF THE BEHAVIORS OF TODDLERS AND CHILDREN DISABLED BY FETAL ALCOHOL EXPOSURE

Through the Eyes of Parents

Notes taken by Jocie DeVries at the July 1994 FAS/FAE needs assessment retreat

The following information is adapted and reprinted, with permission, from an information packet developed by The FAS Family Resource Institute, PO Box 2525, Lynnwood, WA 98036. Readers are reminded that what follows is a compilation of the perceptions and experiences shared by several different parents of several different children. None of it should be taken as definitive.

AGES 1-5

Parents reported that toddlers with FAS or alcohol related birth defects:

- Are sometimes medically fragile
- Are usually high-maintenance children keeping parents alert and on-duty 24-hours a day
- Are often exhausted and irritable from a lack of sleep due to uneven sleep patterns and unpredictable sleep-wake cycles
- Are a danger to self and others because they act before they think
- Are unable to comprehend how their behavior relates to consequences

- Are unaware of the universal laws of nature, such as cause and effect
- Are void of the normal sequential learning abilities in reasoning, judgment and memory
- Are initially perceived as normal, but have subtle and predictable developmental delays that are not understood or recognized by doctors and nurses
- Are highly manipulative and easily escalate out of control when out in public with gullible strangers who are unaware of the disability characteristics of toddlers with FAS or alcohol related birth defects
- Can't distinguish friend from enemy
- Are unrecognized and misunderstood by service providers as having a serious and permanent disability because their IQs appear to be developing normally

AGES 6-11

Parents report that children with FAS or alcohol related birth defects:

- Are often misunderstood and overlooked as permanently disabled because their IQs are normal.
- Are often exhausted and irritable from a lack of sleep. These children often do not outgrow their uneven sleep patterns and unpredictable sleep/wake cycles
- Are impulsive and totally unpredictable, creating multiple safety issues for themselves and other family members throughout the day.
- Are very mischievous and do not understand that their thoughtless pranks (like fire setting or running away) can endanger their own lives and the lives of others.
- Are highly skilled in manipulative tactics. Parents report that their FAS/ARBD children are innately skilled at knowing whose buttons to push and how to keep chaos and hysterics circulating in their environments.
- Seem void of a normal sense of justice.
- Have a high need for stimulation and excitement to keep them entertained and happy.
- Enter puberty at age-appropriate times, but their reasoning and judgment skills are a tragically impaired guide to appropriate times and places to express sexual curiosity
- Are emotionally volatile and often exhibit wide mood swings throughout the day.
- Are often disconnected from their own feelings and are unable to identify or express logical reasons behind their volatile outbursts.

- Are isolated and lonely because the desire to be loved and included in their peer group activities remains intact while the reasoning skills to figure out why they are excluded is lacking. Depression can become a serious problem as social opportunities become more and more rare.
- Are angry, defiant and resentful toward parents, unaware that the parents are often desperately searching for a balance between structure and supervision and fairness and freedom.
- Blame parents for the odd set of family rules which, to the child, are the cause of the loss of friends and social opportunities.
- Need constant reminders about personal hygiene issues much like during the toddler years.
- Are still unable to distinguish friends from enemies.
- Are void of natural empathy for another point-of-view, i.e., often lacking the cooperative quality of do unto others as you would have them do unto you. By late childhood this glaring gap in social development begins to alarm parents.
- Are moral chameleons. As adolescence approaches, parents notice that despite consistent and loving care, family values and even general rules of behavior are not being internalized. The chameleon quality is quite different from a typical/normal teenager which chooses anti-social gang values. Parents report that children with FAS/ARBD exhibit moral chameleon behavior, switching values and even facial characteristics according to their current peer group or social environment.
- Are often over-stimulated by their surroundings. Without understanding and support, the child with FAS/ARBD is often volatile and mentally unstable. Psychotic behavior which requires psychiatric hospitalization is not uncommon.

Special issues that trouble parent raising children with FAS/ARBD are the relationships between siblings.

- Parents describe the strain in their families from balancing the frictions between siblings. Parents must try to keep track of two sets of household rules.
 - * For example, some rules favor siblings who need less supervision and consequently are allowed more freedom to be alone with their peers. The child with FAS/ARBD who has a normal IQ will eventually recognize the unfair rules and can become very resentful and defiant toward their siblings and parents.

*Other rules favor the child with FAS/ARBD because the nature of the disability means the child with FAS/ARBD often has a volatile temper, has great difficulty controlling impulses and can't stay focused on any task. Parents must handle discipline differently, lavishing praise on the child with FAS/ARBD for the simplest task. Outraged, the normal siblings complain (you'd never let me get away with that kind of behavior!

*Parents are caught in the crossfire trying to emotionally absorb the anger and resentment from all sides.

- Parents describe their exhaustion which causes them to neglect the needs and activities of their normal children. Parents agonize over the unmet needs of all their children because the critical needs of the child with FAS/ARBD monopolizes both their time and energy. Siblings feel angry and resentful toward their unavailable parents while at the same time they resent the child with FAS/ARBD for embarrassing the family with outlandish behavior. Parents are not only exhausted physically from caring for a child with special 24-hour needs, but they are emotionally drained from the anger and bitterness they receive from everyone.
- Parents describe siblings that eventually realize that their brother or sister is not deliberately tearing the family apart, but is disabled. Emotionally confused and disoriented, siblings are often overcome by guilt for hating the child with FAS/ARBD. Parents can use this time to bond and grieve again with the sibling over the trauma of FAS/ARBD. However, without help, the whole family unit can become co-dependent with the child with FAS/ARBD as the needs of the healthy family members are forgotten in the chaos of FAS/ARBD.
- Parents describe siblings that are overburdened by guilt and turn their anger inward on themselves. (I'm such a terrible person for hating my brother.) Parents describe siblings who become depressed and sometimes suicidal.
- Parents describe destructive co-dependent relationships which can develop between siblings and children with FAS/ARBD. Sexual assault and incestuous relationships are not uncommon.
- Parents describe the intensity of the adrenal rush surrounding the charisma of the child with FAS/ARBD. This constant state of tension can become addictive, especially to siblings who may never have experienced life without chaos.

TEACHER/PARENT HANDOUT

FAS Kids Respond Well to Special Strategies

by Bill Hayne

Adapted from Western Center News, December 1993

Reprinted with permission from pp. 42-44 of **Assessment and Resource Guide for FAS/FAE: Fetal Alcohol Syndrome, Fetal Alcohol Effects**, Revised Edition, Fall 1995, by Mary Wemann, Linda Colfax, Mark Gray, and Barbara Reed, Callam County Health Department, Port Angeles, WA 98362.

The first and most important of all guidelines to supporting individuals with fetal alcohol effects involves understanding and accepting them as they are. This extremely crucial component of the process is actually somewhat difficult, particularly if the child has no apparent physical abnormalities and appears normal. The first step in changing the perception of a child seen as willfully disobedient or misbehaving is to view her or him as an individual whose central

nervous system is significantly damaged by alcohol. This is a process that involves looking behind what we see. It is a process that can allow us to accept these children exactly where they are in life and to understand what their life must be like on a daily, even hourly basis.

The world of a child with Fetal Alcohol Syndrome or Effects is so vastly different. Everyday common, seemingly simple processes are enormously difficult for a child with FAS/FAE. With a shift in our perception, we can more easily accept the child's need for structure and appropriate assistance. We can re-evaluate our expectations to better suit his/her ability level. This is the beginning of the development of any strategy for the empowerment of children with FAS/FAE.

ROOM ENVIRONMENT

Children with FAS/FAE have various environmental needs: stimulus reduction; a physical outlet when sitting, clear and visual boundaries. The classroom can be set up with a few changes to provide the needed external structures.

Stimuli Reduction. Children with FAS/FAE experience a heightened level of sensory assault from which they need escape.

Cocooning. Opportunities for the child to emotionally quiet and become still, are the essence of cocooning strategies. A set of headphones with no music or sound playing may provide enough quiet to allow them to reduce the external chaos entering their auditory system. Another possibility is to create an area for quiet or retreat, filled with blankets and pillows, where the child can go to escape and gain a sense of balance. We've heard of kids using blankets to cover themselves completely or getting inside large boxes or a pup tent where they just sit in the dark quiet. Still another option is a serenity lane walking area to allow physical release through walking and a degree of solitude. At home, parents have found success by giving the child a mummy bag to sleep in. These strategies allow a child the opportunity to cocoon, to find a protective retreat in order to gain some emotional balance or equilibrium.

Clear and Visual Boundaries. Children with FAS/FAE have difficulty with many aspects of boundaries.

Organization. There is a great need for clear organization. Areas should be clearly marked and identified through both written and pictorial descriptions to reduce environmental misinterpretation by the child. Stand in the child's bedroom or classrooms and imagine the entire room talking. Does it speak clearly and provide distinct direction or does it cry loudly with chaos and confusion?

Seating. Many teachers use masking tape to clearly mark or identify borders for individual students, especially when students are working in learning pods or groups at one table. Taping around a student's desk to create a corral in which the student has the earned ability

to move about without disturbing the rest of the class can be an effective technique- this technique may also work at the family dinner table.

Time. Most classrooms have face clocks which are difficult for affected children to interpret. Provide a digital clock for some of your children, as it is easier to read. Use digital clocks in the home.

Outlets for Physical Release. Children with FAS/FAE often are hyperactive.

Physical Outlet. Provide clay, kushy balls or anything soft to be held and manipulated by hand for the child to keep at his desk, or in his room and use when needed. This will allow him an outlet with his hands and give him the ability to maintain a longer sitting period. If the child knows there is an avenue of escape or outlet, he or she may be able to stay on task or seated longer.

CLEAR ROUTINES

The affected child needs the security of knowing/seeing what to do and when to do it. The unknown is cause for tremendous problems within these children's emotional makeup so it's important to provide structure to make tasks and routines clear.

Schedule. Most primary grades will post their schedule in the classroom through the use of large pictures that demonstrate the activity and the corresponding time period. Take this further into the upper grades by posting the daily schedule in a book, photo album or simple index cards featuring a pictorial display kept at the students desk. Utilize a similar structure at home to secure the child's routine from the moment she wakes up to when she goes to bed - breakfast, bath, chores, making the bed and so on. Try to maintain a consistent schedule, with little or no major changes. If there is a change coming up, understand the child's need for the security of consistency and plan for the change. If a fire drill or assembly is scheduled for Friday, practice the drill or assembly procedures Monday, Tuesday, Wednesday and Thursday at the same time each day.

Transition. Build transitions into the daily routine by using music, sing-alongs or chants. As an activity nears completion (three to five minutes before the period ends) begin a song or musical piece that signifies to the students they are nearing the end of a period. Follow this with another signal (clapping routine or chant) that indicates everyone should meet at a pre-arranged space. At the end of the music, students should be at their respective places to begin the next activity. For older students, who need to make a transition every 50 minutes, provide their schedule changes on color-coded index cards and a map for directions to each class. At home, wise parents regularly plan for transitions from one activity to another.

ACTIVE LEARNING

Children with FAS/FAE learn differently from other children and often at a slower pace. Accept and understand learning differences rather than viewing them as a learning disability. Yes, there is a disability, but if we can also view it as a learning difference we can move forward and empower the child with structures to tap into their difference.

Role Play/Physical Movement. An area of strength for children with FAS/FAE is Bodily-Kinesthetic intelligence. They often can process knowledge through bodily sensations dramatic and creative movement and physical activity. Use of carefully arranged role play can provide a strong avenue for learning social skills and appropriate behavior. Allowing movement or building movement into a lesson can make use of their learning strength. Parents may want to adopt role play techniques in the home whenever they are trying to teach a more adaptive behavior.

Use of Art/Pictures/Puppetry. Another area of strength for FAS children is spatial intelligence, wherein knowledge is processed visually through images, pictures and color. Breaking a reading text down into visual images by drawing out the story can help with understanding and comprehending the story. Pictures and photography can facilitate the learning process and stimulate a child's desire to learn. Puppetry is a great teacher of many concepts, social skills in particular. Become a puppeteer and have some fun with your class or at home while teaching important ideas.

Introduction, Facts, and Definitions

Dear Parent,

This is a packet of information and resources for parents of children who have been prenatally exposed to alcohol. It is a first effort, designed to fill a gap; but, hopefully, it will be a tool which will start each family more quickly on the journey of learning the most effective ways of raising their child(ren). It is only a beginning, since each family's needs will be different and will change over time. More detailed information and stories of other families' experiences and accumulated wisdom can be found in the resources listed in this packet. You may want to consider reading or contacting these other valuable guides in order to get the most complete and up-to-date information available.

We are at an exciting point in time. Previously much of the literature available concentrated on the gloom and doom. While not minimizing the problems of children affected by prenatal exposure to alcohol, or the difficulty of raising any child with special needs, more resources are now available and more is known about what works. Over the next decade, family support and knowledge of effective parenting and education techniques will continue to grow. Your advocacy for your child will make a huge difference as he or she grows and develops.

This packet is the sixth in a series of FAS resource packets developed for different audiences. This one was developed by Colorado Responds to Children with Special Needs of the **Colorado Department of Public Health and Environment**; the Alcohol and Drug Abuse Division of the **Colorado Department of Human Services**; and **The Colorado Fetal Alcohol and Substance Abuse Coalition**. Funding is from Cooperative Agreement

#U50/CCU808552 with the Centers for Disease Control and Prevention; the packet's development was coordinated by Tessa Davis, M.A., an independent consultant.

We wish you and your special child(ren) well and encourage you to contact any one of us for further information and support

Sincerely,

April Montgomery, M.H.A.

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Facts, and Definitions

This section includes current information about the prevalence and consequences of FAS/ARBD. Also included is a glossary with definitions of terms you will hear used as you and your child work with health and educational professionals.

- Facts and Figures on FAS and Alcohol Related Birth Defects
- 10 Common Misconceptions about Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)
- Useful Definitions

FACTS AND FIGURES ON FAS AND ALCOHOL-RELATED BIRTH DEFECTS

- In Colorado in 1995, 107,299 women of childbearing age (13.2%) reported that they drank frequently. Frequent drinking is defined as 7 or more drinks per week, and/or 5 or more drinks on one occasion.

(**BRFSS Brief**, April, 1997, Health Statistics Section, Colorado Department of Public Health and Environment)

- Only 55% of women of childbearing age have heard of fetal alcohol syndrome.
(Department of Health and Human Services, Pregnancy and Infant Health, **Health United States and Prevention Profile**, March 1990.)
- Various studies report that the occurrence of FAS ranges from 0.33 to 1.9 births per 1,000. Based on these rates, Colorado would expect to have between 18 and 109 births each year with the full fetal alcohol syndrome
(Abel, EL et al, Drug and Alcohol Dependence. 19:51-70, 1987.)
- The total lifetime cost per typical case of FAS for a child born in 1980 was estimated to be \$596,000 ...
(Stratton, K, et al, Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment, p.19. Institute of Medicine, National Academy Press, 1966.)
- The incidence of FAS among heavy' drinkers, variously defined,...ranges widely but has never been found to be more than 40 percent in any study...
(Ibid p.101.)
- In Colorado, 86 mothers of children identified with FAS or other prenatal alcohol exposure were interviewed, with the following results:
 - 85% had some prenatal care by the second trimester
 - 29% stated that they did not receive prenatal counseling about alcohol
 - 66% had received some treatment for alcohol abuse
 - 65% of the identified children were living with their mothers
 - 48% of the mothers experienced domestic abuse prior to the pregnancy
(Colorado Responds to Children with Special Needs, Colorado Department of Public Health and Environment, 1997.)
- The best advice for pregnant women is to abstain from alcohol. There is no data to establish a safe level of alcohol consumption during pregnancy.

FAS is only the tip of the iceberg

Fetal Alcohol Syndrome (FAS)

10%

Fetal Alcohol Effects, Alcohol-Related Birth Defects, Associated Learning and Behavioral Difficulties

40%

Not Affected by Prenatal Exposure to Alcohol

50%

This chart is a graphic estimate of children who are affected by prenatal exposure to alcohol.

FAS Educator's Packet 9/94

10 Common Misconceptions about Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)

Ann P. Streissguth, Ph.D.

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Reprinted and adapted with permission from The Iceberg Newsletter

1. That FAS means mental retardation.

- Some people with FAS are mentally retarded. Others are not.
- People with FAS can have normal intelligence.
- They are brain damaged and have specific areas of strengths and weaknesses.
 - It's more like people who have sustained brain injury from an auto accident.

2. That the behavior problems associated with FAS/FAE are all the result of poor parenting or a bad environment.

- No. Being born brain damaged can lead to behavior problems because brain damaged people don't process information the same way that other people do, so they don't always behave like others expect them to.
- Brain damaged children are hard to raise in the best environments.
- Their parents need help and support, not criticism.

3. That they will outgrow it when they grow up.

- Unfortunately, they do not. FAS lasts a lifetime, but the manifestations and type of problems change with each age.
- It takes a longer period of sheltered living for brain damaged children to grow up.

4. That to admit they are brain damaged is to give up on them.

- Have we given up on children with other defects?
- We need research to understand the needs of patients with FAS and how to help them. We haven't invested in that area yet. We will learn how to help them when we decide to invest in the problem.

5. That diagnosing them will brand them for life.

- A diagnosis tells you what the problem is, helps you figure out how to treat the problem and relieves the person of having to meet unrealistic expectations.

6. **That they are unmotivated when they don't keep appointments or act in a way that we consider responsible.**
 - Probably the explanation lies in memory problems, inability to problem solve effectively, or simply being overwhelmed.
 - Sometimes they misconstrue reality.

7. **That one agency can solve any or all of the problems alone.**
 - The multiple needs of patients with FAS/FAE require multiple fronts of intervention and intense interagency cooperation.

8. **That this problem will be solved with existing knowledge.**
 - Research is desperately needed.

9. **That the problem will go away.**
 - FAS is preventable, but alcohol is so much a part of our culture and so aggressively marketed to those least able to resist, that active prevention activities must continue on all fronts to safeguard our children's future and the future of our people.

10. **That their mothers had an easy choice not to drink during pregnancy, and through callousness or indifference, permanently damaged their children.**
 - Biological mothers of children with FAS need help with their alcoholism and/or with birth control.
 - Pregnancy is an excellent time for alcohol abusing mothers to stop drinking, but they need help.

Useful Definitions

The terms used to define prenatal alcohol exposure in children are changing. Some professionals feel that the term Fetal Alcohol Effects (FAE) has evolved to commonly mean a less serious condition than Fetal Alcohol Syndrome (FAS), and is too ambiguous. However, the term has been used widely in the past. The 1996 Institute of Medicine Report on FAS recommended the use of the terms Alcohol-Related Birth Defect (ARBD) and Alcohol-Related Neurodevelopmental Disorder (ARND). All of these terms appear in this packet and are defined below.

The following definitions are taken and/or adapted from glossaries in several publications: Spring/Summer 1995 issue of Prevention Forum (Diane Malbin, M.S.W.); First Steps to Discovery: Colorado's Early Intervention Entitlements for Infants, Toddlers & Preschoolers; Handbook of Rights to Special Education in Colorado: A Guide for Parents; and Fetal Alcohol

Syndrome (Institute of Medicine). References may be found in the Resources section of this packet.

Alcohol Related Birth Defects (ARBD): Clinical condition in which there is a history of maternal alcohol exposure and observed physical anomalies in the child. (IOM book)

Alcohol Related Neurodevelopmental Disorder (ARND): Clinical condition in which there is a history of maternal alcohol exposure and observed neurodevelopmental abnormalities in the child and/or evidence of a complex pattern of behavior or cognitive abnormalities which cannot be explained by familial background or environment alone. (IOM book)

Anomalies: Differences from the normal standard, especially those resulting from congenital, or birth defects.

Attention-Deficit Disorder (ADD)/Attention-Deficit Hyperactivity Disorder (ADHD): A diagnosis based on symptoms and behaviors that may involve distractibility, hyperactivity, and learning disabilities. Medication may be prescribed to minimize symptoms so that a child can participate more fully in academic activities. Attention problems may occur without hyperactivity.

Behavior modification program: A systematic approach to changing undesirable behavior and encouraging desirable behavior by changing events that come before or after the behavior. Also called behavior management, behavior training, behavior intervention, or behavior therapy.

Cognitive Skills: Ideas, thoughts, thinking processes and the skills related to them, e.g. counting, telling time, problem solving, etc.

Central Nervous System (CNS): The brain, spinal cord, and associated nerves.

Communication Skills: Expressive Language is communicating to others one's thoughts, needs and desires; Receptive Language is listening and understanding what someone else is saying.

Congenital: Existing at or dating from birth

Developmental Delay: A situation in which a child's skill in a given area is significantly below that acquired by an average child of his or her chronological age. The area could be speech/language, gross motor skills or fine motor skills as examples.

Developmental Disability: A disability which is present at birth or occurs before the age of 22, is likely to continue indefinitely, and affects one or more major life functions. Examples are: mental retardation, autism, and cerebral palsy.

Dysmorphology: The study of malformations, including birth defects.

Early Intervention Services: A set of coordinated services and supports to children birth through preschool and their families, designed to meet the needs of the child and enhance the child's strengths and abilities.

Embryo: Early stage of growth: the fertilized ovum which eventually becomes the offspring during the period of most rapid development. In humans, this period is from two weeks after fertilization until the end of the 7th or 8th week, after which time it is known as a fetus.

Epicanthal Folds: Vertical folds of skin on either side of the nose, covering the inner corner of the eye. Present as a normal characteristic associated with some people, it sometimes occurs as a congenital anomaly in others (i.e. FAS).

Fetal Alcohol Effects (FAE): Various detrimental effects caused by exposure to alcohol during gestation in individuals who cannot be identified as having the fetal alcohol syndrome. This term is falling out of favor.

Fetal Alcohol Syndrome (FAS): A specific, although variable, constellation of abnormalities which include facial features, growth retardation, and central nervous system (brain) abnormalities.

Fetus: Unborn offspring of an animal/human after major structures have been formed. In humans, from the 7th or 8th week after fertilization until birth.

Gross Motor Skills: The use of large muscle groups in a coordinated manner to accomplish such tasks as sitting, standing, walking, running, throwing, and jumping. Usually considered to be the areas addressed by physical therapy when there are gross motor skill delays.

Handicapping Condition: A physical or emotional barrier to a child's ability to receive reasonable benefit from ordinary education in the public school. A handicapping condition is often used to qualify an individual for a service.

Hyperactivity: An excessive level of physical activity which often causes a child to be easily distracted. Often associated with Attention Deficit Disorder.

Hypoplastic Mid Face: A flattened face - often a characteristic of children with FAS.

IDEA (Individuals with Disabilities): The federal law, that entitles children with Education Act) disabilities to early intervention services, special education, and related services based upon their individual needs.

Individual Education Program (IEP): A written education plan developed by a team composed of school personnel, other professionals and a child's parents, based on the needs of a child who is a special education student.

Individual Evaluation: An in-depth evaluation of a single child, conducted by a team, including the family, the purpose of which is to: (1) determine the child's current functioning and the family's resources and priorities, (2) establish the child's eligibility for early intervention services, (3) identify the services available, and (4) identify the services required.

Intelligent Quotient (IQ): A score derived from testing a child's performance on various tests relative to children of the same chronological age.

Intrauterine Growth Retardation (IUGR): Slower than average growth of a developing fetus. Such babies are born smaller than would be expected for their gestational age.

Learning Disability (LD): Any of several conditions which affect an individual's ability to record, organize, comprehend, store, or communicate information. Common learning disabilities include dyslexia (reading), dysgraphia (writing), auditory processing or visual processing weaknesses, and dicalculia (math). The term does not include learning problems that result from vision, hearing or motor handicaps, or mental retardation, or from cultural or economic disadvantage.

Learning Style: How a child approaches learning and how he or she learns best. Some children learn best by seeing materials (visual learner), some by hearing information (auditory), some by hands-on experience (tactile), others need to obtain information from all sources (multisensory).

Micrognathia: Smaller than anticipated chin.

Microcephaly: Abnormally small head.

Microphthalmia: Abnormal smallness of the eyes.

Multidisciplinary approach/multidisciplinary: The use of a team of professionals from different team disciplines to assess a child, such as a school psychologist, social worker, physical therapist, speech and language therapist, classroom teacher, and special education teacher.

Palpebral Fissures: Eye openings or slits

Perinatal: Period shortly before and after birth, generally considered to begin with completion of 28 weeks of gestation and ending 1 to 4 weeks after birth.

Philtrum: Vertical groove which runs from under the nose to the upper lip.

Placenta: Organ during pregnancy which joins the mother and the fetus and supports growth and development during gestation.

Section 504: A section of the Rehabilitation Act of 1973 which was passed to eliminate discrimination based on handicapping condition by federally funded programs. It applies to schools because they receive federal funds, and it requires schools to provide educational services, opportunities, and benefits equal to those provided to non-handicapped children.

Social Skills: Those skills needed by a child to interact successfully with other people.

Special Education: Educational services provided at no cost to parents, designed to meet the individual needs of a student whose handicapping condition prevents him or her from benefiting from regular education without supplemental aids or services. Students must qualify according to state guidelines.

Speech and Language Therapy: Services provided by a speech/language therapist to assist a child in correcting, improving, or developing language skills and communication with others.

Structure: An educational approach or setting that emphasizes predictable schedules, specific directions, defined limits, routines, well-defined expectations of students, and well-defined rules of classroom procedure.

Syndrome: Group of characteristic features caused by one underlying process; the features present allow identification of individuals as having a unique and specific disorder.

Tactile Defensiveness: Reacting negatively to being touched or to touching objects.

Teratogen: An agent (for example, alcohol) or condition which may cause birth defects.

Vocational Education: An aspect of a student's educational program that provides training and experience in one or more job settings for the purpose of developing job skills which the student can use in his or her adult life.

Vermillion: Bright red pigmentation or color. Lips are often referred to as the vermilion border which is often thinned in FAS/FAE.

Mandated Services and Advocacy

The information in this section provides you with an overview of applicable federal and state laws relating to individuals who have been affected by prenatal alcohol exposure. Also included are two pieces which address both the frustrations and the (best practices of advocating for these services.

- A Manifesto for Parents of Children with FAS/FAE
- You and I
- Summary of Federal and State Laws Related to Individuals with Disabilities

A MANIFESTO FOR PARENTS OF CHILDREN WITH FAS/FAE

Adapted and reprinted, with permission, from Jan Lutke's chapter, Parental Advocacy for Alcohol-Affected Children, in **Fantastic Antone Succeeds!**

- It is the educational system's job to educate my child. My job is to make sure the schools do their job, and to work with, not against, my child's teachers and school.
- I am in the best position to know what is working.
- School has a limited investment in my child. My investment is for life and I will be there long after the school is nothing more than a memory.
- Education must be useful to be valuable.
- Figure out what programming you want, design it to fit what the school already has, get inventive, and do it all in stages.
- Educate, advocate, and insist with every teacher in every class in every school in every year.
- Help in any and every way you can. Indicate you are available and visit in person often.

- Learn to work with people and not against them. Use their own arguments to prove your points. Do whatever you can to make their jobs easier.
- Deal with issues immediately and do not let them accumulate.
- Always follow through and always thank those who help you even minimally. Remember to thank in writing the people who have been especially helpful, effective, or taken a chance for you. Write to their superiors.

You and I

by Dorothy Beckwith

(reprinted with permission from the FAS Family Resource Institute's introductory packet)

This poem was written in December 1994. It reveals some of the common frustrations which parents face on a regular basis when trying to get services for their children.

I am the parent. You are the Professional.
I came to you out of respect. You treated me with disrespect.

I live with my child. I know nothing.
You've worked a few hours with her. You know everything.

We need to be evaluated. You are above reproach.
You wrote a report about me. It says everything I did wrong. Nothing I did right.

I raise my voice. I am losing control.
You raise your voice. You are compiling information.

I am noncompliant. You don't like my advice.
My child is egocentric. You are egotistical.

A child with Diabetes needs Insulin, a child with Epilepsy needs Dilantin,
A child with ADHD/Fetal Alcohol needs TIME OUT (?)

Christina's hospital room is messy and unorganized. She does not get the White Glove Award she tried so hard to earn.
Your area is unkempt. Housekeeping hasn't come through yet.

I hesitate to act. I am inconsistent.
You are indecisive. You need to consult.

I bring an advocate to the team meeting. I'm disrupting the agenda.
You bring staff. You are collaborating.

I give you important information about the disability of Fetal Alcohol Exposure. You don't have time to look at it.
You give me papers. I'm to read them and have them completely filled out by the next meeting.

I am honest and expose my life to you.
You ambushed me in meetings and couch your words in reports.

I comment on a behavior. I am over critical.
You comment on a behavior. You are observant.

I tell you she has organic brain damage.
You tell me you will test her IQ.

I talk to you about the challenges and our unconditional love for Christina.
You keep bringing up the possibility of a failed adoption.

I am invested in using Fetal Alcohol as a rationale for treatment failure.
You are invested in using The Parent as the reason for treatment failure.

STATE & FEDERAL LAWS RELATED TO INDIVIDUALS WITH DISABILITIES

The following is a summary of applicable federal and state law relating to individuals with disabilities. The information is taken and reprinted with permission from publications developed by The Legal Center: Advocacy for People With Disabilities and Older Persons. Parents are urged to make use of this valuable resource by calling 1-800-288-1376 or (303) 722-0300.

Federal Law

- **INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)** as passed in **PUBLIC LAW 94-142 (1973)** and amendments in **PUBLIC LAWS 99-457 (1986) & 101-476 (1990)**. These laws provide for standardized access to education for all children with disabilities and guarantees every child eligible for special education services free appropriate public education. These laws also provide for services to special needs children from birth through age 5 and require that transition services be addressed in Individual Education Plans (IEPs) of students when they turn 16

- **SECTION 504 OF REHABILITATION ACT (1973).** Section 504 (1) prohibits recipients of federal funds (including public schools) from discrimination based on handicapping condition or disability, and (2) provides for special services to students with temporary disabilities or any disability that constitutes impairment of a major life function. This is a broader basis than that called for in IDEA.
- **FAMILY EDUCATION RIGHTS AND PRIVACY ACT (FERPA).** This act (1) provides access by parents to all education records directly related to their child(ren); (2) provides the right to an administrative hearing to challenge information in records; and (3) limits disclosure of information by schools without parental consent
- **AMERICANS WITH DISABILITIES ACT (1990).** This civil rights legislation, which includes persons with mental impairments, covers employment, public services and transportation, privately owned public accommodations, and telecommunications

Colorado Law

- **EXCEPTIONAL CHILDREN'S EDUCATION ACT (ECEA).** This act mandates school districts to seek out, identify, and provide services for all children between birth and 21 who may be in need of special education and related services or programs.
- **HOUSE BILL 1137 (1990) - STATE IMPLEMENTATION OF PARTS B AND H OF FEDERAL INDIVIDUALS WITH DISABILITIES EDUCATION ACT.** This law ensures that infants, toddlers and preschoolers are provided the services mandated by federal law and provides the same rights to parents of infants and toddlers as those afforded parents of 3 - 21 year olds with special needs.

More detailed information and explanations of these federal and state laws and the entitlements that accompany them may be found in the following publications from The Legal Center, 455 Sherman Street, Suite 130, Denver, Colorado 80203 (303) 722-0300 or 1-800-288-1376.

Handbook of Rights to Special Education in Colorado: A Guide for Parents, Second Edition by Marjorie J. Long, Esq. and Randy Chapman, Esq., 1996, \$13.

First Steps to Discovery: Colorado's Early Intervention Entitlements for Infants, Toddlers and Preschoolers by Marjorie J. Long, Esq., 1993, \$7.50

Living with Adolescents and Adults who have been Prenatally Exposed to Alcohol

There is, unfortunately, very little published information about adolescents and adults who have been prenatally exposed to alcohol. Hopefully, this will change as parents, other care givers, and service providers shift their attention from infants and children to adolescents and adults. Much of the information that is included in this section comes directly from parent experiences. Also included is information that we encourage you to copy and share with your child's teachers and other caregivers.

It is crucial for everyone involved in the care and education of an adolescent or adult with disabilities to remember that they are first an adolescent/adult, and second an individual with a disability. Adolescents and adults with FAS or ARND, like all people, will move through various stages of normal development. They may not move as quickly or as distinctly, but they will move and grow. With growth comes struggles and challenges. A typically developing adolescent may demonstrate some of the behaviors described in this section, but because he or she does not present a disability, their behavior is dealt with and accepted as a normal part of growing up. Conversely, adolescents/adults with disabilities often display appropriate or typically challenging behaviors for a person at their developmental level, but because they have a disability, their behavior becomes amplified by those who are working with and caring for them. Because this happens so frequently and unconsciously, readers are urged to balance their perceptions of their adolescent or adult child's behavior with their knowledge and experience of normal/typical adolescent and adult development and behavior.

- A Developmental Overview of the Behaviors of Adolescents and Adults Disabled by Fetal Alcohol Exposure as seen through the Eyes of Parents
- Some Practical Recommendations for Managing the Psychosocial Needs of Adolescents and Adults Affected by Fetal Alcohol Exposure
- I Didn't Know... by Marceil Vadheim (reprint from Iceberg)

A DEVELOPMENTAL OVERVIEW OF THE BEHAVIORS OF TODDLERS AND CHILDREN DISABLED BY FETAL ALCOHOL EXPOSURE

Through the Eyes of Parents

Notes taken by Jocie DeVries at the July 1994 FAS/FAE needs assessment retreat

The following information is adapted and reprinted, with permission, from an information packet developed by The FAS Family Resource Institute, PO Box 2525, Lynnwood, WA 98036. Readers are reminded that what follows is a compilation of the perceptions and

experiences shared by several different parents of several different adolescents and adults. None of it should be taken as definitive.

AGES 12 - 17

Parents report that teens with FAS/ARBD:

- May still need limits and protection like a three-year-old because of their disability in reasoning, judgment and memory.
- Are demanding more and more freedom to be with their peers while they may still need the same structure as toddlers.
- Are at high risk for being drawn into destructive anti-social behavior such as running away to live on the streets, stealing, lying and addiction to legal and illegal drugs. Thrill-seeking peers are a total fascination to teens with FAS/ARBD.
- Seem to have an exaggerated sense of self-protection, always (landing on their feet. Almost a primal fear instinct related to understanding submission and power as in the law of the jungle.
- Seem to have innate ability to recognize raw power and to respond appropriately to it. this odd trait makes them extremely vulnerable to gang activities.
- Have great difficulty understanding who is a friend and who is an enemy.
- Have great difficulty recognizing the limitations of their disability.
- Are terrified of being forced into change of transition, especially big changes like moving into high school or junior high which involves meeting and dealing with large numbers of people and multiple classrooms.
- Are often fascinated by concrete issues such as sexual activity or setting fires.
- Are highly susceptible to gang membership which provides clear power and submission structure and consequently peer acceptance and loyalty. They are fascinated by the intense emotions and stimulation of gang activity. In gangs no one else is doing well in school, so teens with FAS/ARBD fit right in.
- Continue to have problems with their siblings. These problems escalate as they pass through the teen years. Big gap in family rules which must be applied differently to teens with FAS/ARBD and siblings. This gap often is so severe that out-of-home placement is critical for everyone's safety.
- Have innate traits which cause them to continually seek chaotic activity. However, parents describe that such traits which at first glance appear to be negative characteristics can sometimes be used by caregivers to produce positive results. Living arrangements, for example, in a group home or residential treatment program often have other stimulating kids that teens with FAS/ARBD love to be around. Such group homes have a high ratio of caregivers and have rotating (rested) staff to provide supervision 24-hours-a-day. Parents report that family bonds often improve during out-of-home care.

- Are able to recover (emotionally) from a confrontation with parents or siblings VERY quickly. Parents report that the discrepancy between the emotional recovery times of teens with FAS/ARBD and their parents is a significant factor in parent burnout.
- Are seriously impaired when it comes to making decisions. Parents describe teens with FAS/ARBD as not having the judgment or reasoning skills to logically make decisions.
- Continue to be a safety menace as they grow through the teen years. Parents report that their focus on safety shifts during the teen years from keeping the teen with FAS/ARBD and family safe to fearing for safety of the surrounding community.
- Have increasing anger toward their (unreasonable) parents who continue to try to get the kids to follow basic social rules of family, school and society.
- Continue to have uneven sleep patterns and sleep/wake cycles which are exhausting to both teen and parents.
- Are usually very negligent and defiant to parents about cleanliness and personal care issues. This can be very humiliating to the family of teenage girls who are menstruating.
- Need immediate rewards for motivation. The rewards that get results usually seem totally illogical to the rest of us.
- Are extremely vulnerable to suggestions from movies, TV programs and any kind of advertising campaign. Teens with FAS/ARBD have great difficulty handling money.
- Are able to advance in school - especially when in a self-contained classroom setting when the IQ is normal. However, all parents report that no matter what academic achievement level is reached, the disability of FAS/ARBD is not (cured, overcome or treated). but the teen with FAS/ARBD remains severely disabled in reasoning, judgment and memory.
- Are moral chameleons throughout the teen years and may need 24-hour supervision to keep them and the community safe.
- Are often totally enchanted with their own manipulation skills.

ADULTS - AGED 18 AND OVER

Parents report that adult children with FAS/ARBD:

- Still do not understand the value of money. The innate disability traits of FAS/ARBD in reasoning, memory and judgment are very noticeable in their lack of ability to take care of themselves financially.
- Are unaware of normal hygiene needs no matter how much parents have tried to instill the value of cleanliness. This often translates into serious problems, like sexually transmitted diseases, HIV infections and not remembering the needs for birth control or safe sex.
- Remain totally unreliable concerning safety issues surrounding fire, cooking, driving, HIV, infection, etc.
- Remain very volatile if pushed too far to do something they see as unfair or unreasonable (like taking their money to pay the rent or groceries).

- Are very impaired as to entertaining themselves and keeping out of mischief when left alone.
- Remain totally unrealistic and/or forget basic life needs.
- Are in desperate need of sheltered employment opportunities where employer understands that he/she has hired a person with a significant disability.
- Continue to appear much more intelligent and capable than they are. Parents describe an uncanny ability to appear high-functioning.
- Remain vulnerable to mental and emotional overload, i.e. psychotic breaks which can endanger themselves or others.
- Remain extremely vulnerable to anti-social behavior. Parents describe both male and female adult children as being at great risk for not finding the structure and supervision that they need in the criminal justice system.
- Are unable to distinguish friend from enemy.
- Become quite vulnerable to unhealthy co-dependent relationships which parents describe as all too often turning violent.
- Remain tragically unaware of sexually appropriate behavior.
- Are incapable of taking medication or birth control pills appropriately and on schedule.
- Are highly vulnerable to substance abuse problems. Therefore, young women with FAS/ARBD are at high risk for producing another generation of children with FAS/ARBD.

SOME PRACTICAL RECOMMENDATIONS FOR MANAGING THE PSYCHOSOCIAL NEEDS OF ADOLESCENTS AND ADULTS AFFECTED BY FETAL ALCOHOL EXPOSURE

Adolescents

- Accept fully your adolescents' limitations and world; acknowledge their special skills and talents.
- Educate adolescents and their caretakers regarding sexual development, birth control options, and protection from sexually transmitted diseases.
- Ensure that adolescent has a safe, stable and structured home environment
- Plan and implement residential placement if necessary.
- Make sure school IEP plans shifts focus from academic skills to daily living and vocational skills.
- Start planning early and implement vocational training and placement.
- Plan for appropriate mental health intervention as needed.

- Plan for respite care for parents and/or other caregivers.
- Join a caregivers' support group.
- Ensure careful monitoring of social activities and structuring of leisure time.
- Ensure adolescent is taught (at his or her own level) how to make healthy choices.

ADULTS

- Accept fully your adult child's world and limitations; acknowledge their special skills and talents.
- Plan for and implement specialized residential placement or other subsidized living arrangements.
- Arrange for guardianship of funds and/or other assets.
- Ensure that your adult child is enrolled in an appropriate job training and placement program.
- Act as advocates to ensure that your adult child receives the health and other services and financial resources to which s/he is entitled.

I Didn't Know

By Marceil Vadheim, MC, CCDCII

Sidney, my fifteen-year-old daughter, has Fetal Alcohol Syndrome because I drank alcohol heavily when I was pregnant with her. It doesn't seem to make much difference that I didn't know the alcohol I was drinking could harm her; that my doctor suggested an occasional cocktail might be good for me; that I had the disease of alcoholism and wasn't responsible for my behavior. My feelings of guilt, shame and grief have still been overwhelming.

Sidney was born two- and-a-half months early and weighed two pounds, eight ounces. She spent several weeks in an intensive care premie nursery. Her medical records included results of brain scans, a multitude of tests, procedures and comments about my visits and phone calls to the nursery. There was no mention of my drinking habits. Who would have asked a middle class professional woman who appeared to be successfully moving through the world, combining motherhood and a career as a Girl Scout Executive, if she had a drinking problem?

When Sidney was four years old, I was hospitalized with cirrhosis of the liver. A year later I was treated for alcoholism and have been abstinent since treatment. When I first heard about fetal alcohol syndrome, a cold, sick feeling lodged in the pit of my stomach. Sidney was six years old. However, I was able to convince myself that Sidney's small size, her immaturity (she was held back to do a second year in kindergarten), her difficulties with memory and her extremely short attention span were due to her prematurity... she must be slow catching up..and the stress of her dad's and my divorce.

When Sidney started the seventh grade, a teacher friend suggested she be tested for learning disabilities because of her ups and downs in school. Despite her erratic progress and difficulties in school, she was denied testing because, she is not two years behind in her class-work. My quest for testing led us to the Pregnancy and Health Study Clinic at the University of Washington and Dr. Sterling Clarren at Children's Hospital and Medical Center, where she was diagnosed as Fetal Alcohol Syndrome. My response to the diagnosis was horror. Sidney's response was, 'what a relief'.

That was two years ago. I told anyone who would listen that she was misdiagnosed. She doesn't even look like an FAS kid...she is on the honor roll in school...she can play the piano! At the same time I was reading everything I could find about FAS and trying to parent as if she had the problem. Sidney's tests at the University of Washington revealed her specific learning disabilities. Tests in hand, I went to her school counselor who has been very concerned and helpful, carefully scheduling her classes with teachers most appropriate for her learning styles. He also indicated that her diagnosis of FAS would guarantee more in-depth help, should that become necessary. The diagnosis also means we, as a family, have been able to help Sidney because we understand now what she can and cannot do. I have been able to temper my expectations, which previously had been either too high or too low, depending on each conflicting report from her teachers. I am sure Sidney's many successes in junior high school have been the direct result of our family working hard with the school and now, finally accepting, coming to grips with, and coping with the realities of her Fetal Alcohol Syndrome. I think I began to truly accept her diagnosis about six months ago. Of course, with that acceptance came the necessity to deal with the shame, guilt, grief and pain that acceptance brought to the surface.

Since I accepted my alcoholism in 1980, a large part of my recovery has been focused on working through the shame, guilt, grief and pain that the acceptance that I am an alcoholic brought. A big part of working through these feelings has occurred through sharing my story with others and with reaching out to help others whenever I could. I returned to school, obtained a Masters in Counseling degree with a special emphasis on working with chemically dependent individuals. For seven years I have been lucky to be working as a counselor and therapist for people impaired by alcoholism, drug addiction and mental illness. For three and a half years I have been the family counselor at an in-patient drug and alcohol treatment center for women.

In my search for services for children with FAS and their families, I discovered that very little was available. Consequently, I opened a private practice in October, 1990 so I could begin to

be of service to other mothers who have FAS children. I hope to be able to share my story and recovery with others; to work with FAS families to help them cope with the grief, with parenting issues, with advocacy in the schools and agencies. I have discovered that both natural and adoptive parents share many of the same issues and hope to assist in forming support groups for these parents.

I am willing and ready to speak, provide an inservice, workshop or training to any agency or group that would like to learn more about FAS/FAE.

Resources

This section contains information about key print and people resources. Make use of it! We emphasized those books and organizations which parents can use every day. These key resources will, in turn, lead you to other, more specialized resources, as you need them.

- Print Resources
- Organizational Resources

PRINT RESOURCES

The following print resources are the ones which we feel provide the most useful and valuable information for parents.

BOOKS AND BOOKLETS

A Child's Journey Through Placement (1991) by Vera I. Fahlberg, M.D. \$14.00 (paperback); \$21.95 (hardcover).

Available: Bookstores, or Perspectives Press
P.O. Box 90318
Indianapolis, IN 46290-0318
(317) 872-3055

This award winning book looks at issues concerning children who must spend time in out-of-home care. It offers tools and resources for caregivers who provide support for children who spend time in foster care, hospitals, residential therapy, the juvenile justice system, or other out-of-home placement. It is full of examples, stories and concrete recommendations.

Colorado Guide to Free and Low Cost Health Care for Pregnant Women and Children

Available FREE, in English or Spanish version, from:

The Piton Foundation
370 17th Street, Suite 5300
Denver, CO 80202
(303) 825-6246

Fantastic Antone Succeeds! - Experiences in Educating Children with Fetal Alcohol Syndrome (1993) by Judith Kleinfeld and Siobhan Westcott, editors., \$20.00.

Available: from bookstores or University of Alaska Press

P.O. Box 756240
Fairbanks, AK 99775-6240
(907) 474-6389 FAX: (907) 474-5502

While most of the books about FAS are full of doom and gloom, this positive book concerns itself with hope and successes. Full of strategies for handling the problems alcohol-affected children bring for parents, teachers, social workers, and the children themselves. A sequel, **Fantastic Antone Grows Up**, which focuses on adolescents and adults, is planned for publication in 1998.

FAS/FAE: A Practical Guide for Parents (1994), Compiled by Jim Slinn. \$2.50

Available: Parents
540 West International Airport Road
Anchorage, AK 99518
(907) 563-2246

This little booklet is full of practical advice for parents around the many day-to-day matters of living with a child who has been affected by prenatal exposure to alcohol. Part of the booklet has been reprinted, with permission, in one of the sections of this resource packet.

FAS: Parent and Child (1993) by Barbara A. Morris and Lyn Weiner. \$7.50

Available: The Fetal Alcohol Education Program
1975 Main Street
Concord, MA 01742
(508) 369-7713

This 33-page handbook provides answers to questions regarding the development of problems of children prenatally exposed to alcohol and other drugs. It is a useful tool to help parents understand and manage their children's behavior.

First Steps to Discovery: Colorado's Early Intervention Entitlements for Infants, Toddlers and Preschoolers by Marjorie J. Long, Esq., 1993, \$7.50; and **Handbook of Rights to Special Education in Colorado: A Guide for Parents**, 2nd Edition by Marjorie J. Long and Randy Chapman, 1996, \$13.

Available: The Legal Center
455 Sherman Street, Suite 130
Denver, Colorado 80203
(303) 722-0300 or 1-800-288-1376.

These booklets are full of good information and resources about the educational rights, entitlements and services available for children birth through age 21 in Colorado.

Start Here! A Guide to Resources and Services for Families of Children with Disabilities (1996) Colorado Developmental Disabilities Planning Council, Family Support Committee, and Rocky Mountain Resource and Training Institute. FREE.

Available: Colorado Developmental Disabilities Planning Council
777 Grant Street, Suite 304
(303) 894-2345

This booklet, which is periodically updated, is an indispensable starting place for all parents of children with disabilities. **The Source: A Directory of Resources for Human Services Workers Concerned with Maternal Substance Abuse and Children with Fetal Alcohol Syndrome or Perinatal Substance Abuse** (1993 and 1997). This resource book contains a wealth of information about organizational resources which is very useful to families and other caregivers. A FREE copy is available from

Colorado Responds to Children with Special Needs
Colorado Department of Public Health and Environment
4300 Cherry Creek Drive South - A3
Denver, CO 80220
(303) 692-2649 and from

Special Connections Program
Alcohol and Drug Abuse Division
Colorado Department of Human Services
4055 South Lowell Boulevard
Denver, Colorado 80236
(303) 866-7480

ARTICLES

A Long-Term Perspective of FAS, Ann P. Streissguth, in *Alcohol, Health & Research World*, Vol. 18, Number 1, 1994,

Abstract: Few people in their adolescent or adult years are diagnosed as having FAS. Studies have shown that most FAS patients outgrow the characteristic FAS faces after puberty. However, they may still have mental handicaps and poor age-appropriate life skills. Further research is needed to understand these patients' unique needs and to develop the most effective intervention strategies.

Fetal Alcohol Syndrome in Adolescents and Adults, Ann Streissguth, Jon Aase, Sterling Clarren, Sandra Randels, Robin LaDue, and David Smith, in *JAMA*, April 17, 1991, Vol. 265, No. 15, pp. 1961-1967.

From a follow-up study, the authors describe the changing facial morphology of the FAS patient, as well as important developmental, social, and academic issues that present as the patient matures.

Mental Health and Health Needs of Infants and Preschool Children with Fetal Alcohol Syndrome, Ann Streissguth and Carole Giunta, in *International Journal of Family Psychiatry*, 1988, Vol. 9, No. 1, pp. 29-47.

Diagnosis of an infant or young child with FAS indicates potential stress for a family. This paper discusses the characteristics and needs of children with FAS and their families, and opportunities for supporting them.

Patients with Fetal Alcohol Syndrome and Their Caretakers, Carole T. Giunta and Ann P. Streissguth, in *Social Casework: The Journal of Contemporary Social Work*, September 1988, pp. 453-459.

An excellent article which focuses on the often overlooked aspect of the social and psychological needs of children with FAS and their families.

Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE), Ann P. Streissguth, Helen M. Barr, Julia Kogan, and Fred L. Bookstein. University of Washington School of Medicine, Department of Psychiatry and Behavioral Sciences, Fetal Alcohol and Drug Unit, 1996.

This paper is the final report of a research project which examined secondary disabilities associated with Fetal Alcohol Syndrome and Fetal Alcohol Effects. It also looks at risk factors and protective factors which affect these secondary disabilities. Early diagnosis, a stable home environment, and receiving services from the state's Division of Developmental Disabilities, were all protective factors. This document is written as a research paper but has valuable information.

NEWSLETTERS

F.A.S. Times and Fetal Alcohol Syndrome/Adolescent Task Force Newsletter, available from FAS Family Resource Institute, P.O. Box 2525, Lynnwood, WA 98036 (206) 531-2878.

FEN Pen, \$5 a year (parent/family member), available from Family Empowerment Network, University of Wisconsin-Madison, 521 Lowell Hall, 610 Langdon St., Madison, WI 53703-1195 (608) 262-6590.

Growing with FAS, newsletter of the Growing with FAS/FAE Resource Coalition. \$20 a year; available from Pam Groves, 7802 SE Taylor, Portland, OR 97215 (503) 254-8129.

Iceberg, a grassroots newsletter, published quarterly, that provides support to parents of children with fetal alcohol syndrome. \$10 (family rate) a year from P.O. Box 4292, Seattle, WA 98104.

Organizational Resources

The following are key organizational resources for parents' use. Many publish newsletters and/or calendars, and you can ask to be put on their mailing lists.

4 Parents Help Line

The Work and Family Resource Center
Community College of Denver
1391 North Speer Boulevard, Suite 400
Denver, CO 80204
(303) 534-3789

A free and confidential phone service to help families deal effectively and confidently with issues of raising children. Offers support, information and referrals.

The Arc of Colorado

4155 East Jewell, Suite 916
Denver, CO 80222
(303) 756-7234 or 1-800-333-7690 (outside metro Denver area)

The twelve state Arc affiliates - some are known as ACL's (Association for Community Living) - provide information and referral to local resources as well as advice, advocacy and support for individuals with developmental disabilities and their families. To find the local Arc in your area, contact the state office above.

Attention Deficit Disorder Advocacy Group

1665 Grant Street, Suite 150
Denver, CO 80203
(303) 675-5337

Provides support, resources and advocacy for children with ADD and their families.

The Children's Hospital - Child Development Unit

1056 East 19th Street
Denver, CO 80218
(303) 861-6630

The multidisciplinary staff in the Child Development Unit (CDU) at The Children's Hospital evaluates children's specific weaknesses and strengths and provides techniques and methods to the children's parents and families to help them cope with these issues. The CDU staff visits children aged birth to eighteen who have developmental, learning, and/or behavioral problems. Upon referral by physicians, health care providers, schools, or social agencies, CDU staff provides a comprehensive evaluation and coordinates the management and treatment of children who exhibit problems such as Fetal Alcohol Syndrome, Attention Deficit Disorder, poor school performance, etc. For an appointment or for further information, call the number listed above.

Colorado Department of Education - Early Childhood Connections (Part H Network) and Child Find

201 East Colfax Avenue - Room 305
Denver, CO 80203-1799
(303) 866-6710

Early Childhood Connections addresses the priorities and concerns of families of children from birth to 3 years old. Centers are located throughout Colorado and are often staffed by experienced parents who can help other parents find and use the resources they need. Call the Colorado Department of Education office listed above for the Part H/Early Childhood Connections organization nearest to you.

Child Find is the program within the public schools designed to identify children from birth through twenty-one years who have special needs. It is the entry point for accessing educational and community resources for children with special needs. Child Find programs and coordinators are located in each school district or in the Board of Cooperative Services (BOCES) serving the rural districts. To contact the Child Find program where you live, call your local school district, BOCES, or the Colorado Department of Education office listed above.

Colorado Department of Education - Special Education Services

201 East Colfax Avenue - Room 300

Denver, CO 80203-1799

(303) 866-6694

Provides information about special education services that may be available to your child.

Colorado Department of Public Health and Environment: Locally Available Public Health Services

4300 Cherry Creek Drive South

Denver, CO 80222

(303) 692-2375

Local county health departments and community nursing services offer several programs for women and children. Some of them have financial eligibility requirements. The **Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) Program** is responsible for outreach and non-medical case management activities for children, newborn to 21, whose families receive Medicaid. A priority of EPSDT is removal or minimization of barriers preventing pregnant women and their children from receiving prenatal, obstetrical and general health care. **The Health Care Program for Children with Special Needs (HCP)** offers diagnosis and treatment, care coordination and referral to other services, hospital care, physician services, and some medical equipment. Other programs offered through county health agencies include **Child Health Immunizations, Prenatal Care Clinics, Women Infants and Children (WIC)**, and the **Supplemental Food Program**. Call your local health departments or county/community nursing services for more information.

Colorado Developmental Disabilities Planning Council

777 Grant Street, Suite 304

Denver, CO 80203

(303) 894-2345

This 24-member council has as its goal to support individuals with developmental disabilities to be a real part of their communities. The Council is appointed by the Governor and serves in an advisory capacity to the Governor and General Assembly. The Council publishes policy papers and the Start Here! booklet, both of which are available free of charge.

Colorado Division of Vocational Rehabilitation

600 Grant Street - Suite 302

Denver, CO 80203

(303) 894-2515

Colorado Domestic Violence Coalition

Various locations throughout the state. To protect their clients, shelters do not publicize their street addresses.

Call (303) 573-9018 for the program serving your area.

Domestic violence and alcohol and other drug abuse are interrelated and often occur in the same setting. Some women experiencing abuse will self-medicate with alcohol or other drugs. The problem occurs in all regions of the country with little variation in prevalence, in all cultural and socio-economic groups and among unmarried as well as married couples. Domestic violence and battered women's services differ from community to community but generally include a 24-hour crisis line, shelter, individual or group counseling, and advocacy.

Colorado Fetal Alcohol and Substance Abuse Coalition

Pam Gillen, contact person

(303) 315-3171 or 1-800-248-2344 (outside metro Denver area)

The coalition is made up of representatives from a number of different organizations within Colorado who are interested in issues related to prenatal exposure to alcohol and other drugs. Activities include community education, distribution of materials on FAS, ARBD, and ARND, and prevention efforts aimed at decreasing the incidence of prenatal alcohol exposure in the state.

Colorado Office of Resource and Referral Agencies (CORRA)

7853 East Arapahoe, Suite 3300

Englewood, CO 80112

(303) 290-9088

CORRA is a network of childcare resource and referral programs serving all Colorado counties. Particular attention is given to providing regularly scheduled and temporary (respite) care for children 0 - 18 with developmental disabilities or other special needs. Call the number above for the CORRA office in your community and/or for more information about their available services.

Developmental Disabilities Services - Community Centered Boards (CCB's)

Colorado Department of Human Services

3824 W. Princeton

Denver, CO 80236

(303) 866-7450

Community Centered Boards are private, non-profit agencies designated by Developmental Disabilities Services to (1) determine eligibility for services, (2) act as the single entry point for persons to receive developmental disabilities services, (3) provide case management/service coordination, and (4) provide authorized services and support either directly or through purchase of services from service agencies. CCBs serve people of all ages with developmental disabilities or children with specific risks for delay (which may include children with prenatal alcohol or other drug exposure). Call Developmental Disabilities Services at the number above for information on the CCB in your area.

Effective Parents Project

255 Main Street
Grand Junction, CO 81501
(970) 241-4068

Family-centered information, training and support services to parents of children of adults who have developmental disabilities.

FAS Family Resource Institute

P.O. Box 2525
Lynnwood, WA 98036
(253) 531-2878

A non-profit organization formed by parents in order to supply information, understanding and hope to families and professionals caring for individuals with FAS/FAE. They publish a free information packet. Family membership is \$15/year.

Family Empowerment Network

610 Langdon Street, Room 521
Madison, WI 53703
1-800-462-5254

A national organization serving families affected by Fetal Alcohol Syndrome and Fetal Alcohol Effects, and the professionals who work with them. Provides resource materials, technical assistance, an 800 advocate line, educational opportunities, an annual conference, and a teleconference series.

The Kempe National Center for the Prevention and Treatment of Child Abuse and Neglect

1205 Oneida Street
Denver, CO 80222
(303) 321-3963

The Center provides a clinically based resource for training, consultation, research, program development and evaluation in all forms of child abuse and neglect. Many programs have been developed over the years, including the Crisis Nursery and Home Visitor Programs which have been replicated throughout the U.S.

Learning Disabilities Association of Colorado (LDAC)

1045 Lincoln Street, Suite 106
Denver, CO 80203
(303) 894-0992

A non-profit organization dedicated to advocacy for learning disabled children and adults.

The Legal Center

455 Sherman Street, Suite 130
Denver, CO 80203
(303) 722-0300 or 1-800-288-1376

The Legal Center protects and promotes the rights of people with disabilities and older people in Colorado through direct legal representation, advocacy, education and legislative analysis. They have developed publications (noted in Printed Resources section) to help parents be active participants in planning their child's education and vocational training.

Mi Casa Resource Center for Women

Project Worth
571 Galapago Street
Denver, CO 80204
(303) 573-1302

Project Worth is a program designed for welfare recipients to address drug/alcohol issues and get them off welfare and into the work force. The program consists of three phases and includes education, training, counseling, and job readiness preparation.

Mile High Council on Alcoholism and Drug Abuse

1444 Wazee Street, Suite 125
Denver, CO 80202
(303) 825-8113

Assessment and counseling for women and a support group for female children of alcoholics called Of Wine and Women.

Parent Support Groups

Pam Gillen, contact person

(303) 315-3171.or 1-800-248-2344 (outside metro Denver area)

Support and educational groups for parents meet on a monthly basis in Denver and are forming in other areas of the state. The groups are made up of adoptive, foster and biological families of children prenatally exposed to drugs and/or alcohol. The format of the groups alternate between educational presentations and open group discussions. Child care and dinner are provided free of charge at some.

Partners in Leadership

(303) 665-2145 or 1-800-569-1825

A leadership training program concerning disability issues for adults with disabilities and parents of children with disabilities. Partners in Leadership develops leaders who become actively involved in systems change promoting the full inclusion and active participation of people with disabilities in our society.

PEAK Parent Center, Inc.

6055 Lehman Drive, suite 101

Colorado Springs, CO 80918

(719) 531-9400 or 1-800-284-0251

Peak is a resource center for parents and educators of children with disabilities throughout the state. Provides workshops, a lending library of books and videos, and publishes (with the Colorado Department of Education) a quarterly calendar or resources and training opportunities.

Women and Alcohol

This section contains information about women, alcohol, and alcoholism particularly among pregnant women as well as an overview of treatment service programs for substance involved-women.

- Alcohol, Alcoholism and (Pregnant) Women

- What Should I Ask When I'm Considering Going to an Alcohol or Other Drug Treatment Program?
- Barriers to Substance Abuse Treatment for Women
- Treatment Services for Substance Involved-Women

ALCOHOL, ALCOHOLISM, AND (PREGNANT) WOMEN

The discussion about alcoholism has been long and controversial. Some say it is due to inherent biochemical abnormalities (Milama & Ketcham, 1991). Others blame family dynamics (Steiner, 1971), social learning processes (Peele, 1985), and personal choice (Fingarette, 1988).

These facts are known. People drink because alcohol affects a specific reinforcement system in the brain. There are alcohol abusers and there are alcoholics. Alcohol abuse is problem drinking which may result in health or social problems, or both. Chronic exposure to alcohol can result in the development of tolerance for and physical dependence on alcohol. Alcohol dependence is alcoholism. While alcohol abusers may experience the same effects from excessive drinking as do alcoholics, alcoholics are distinguished by their physical dependence on alcohol and their impaired ability to control alcohol intake (U.S. Department of HHS, 1993).

The reasons people drink are many and complex. The following facts are known about drinking and women - especially pregnant women.

- Pregnant teens have different drinking patterns than pregnant adults. In a recent study comparing pregnant teens with pregnant adults, it was shown that adolescents were more likely to binge drink while young adults are more likely to have a higher daily volume of alcohol. Adolescents were also more likely to continue heavy and binge drinking through the first trimester than were the adults (MD Cornelius, GA Richardson, NL Day, JR Cornelius, D Geva, and PM Taylor, (A Comparison of Prenatal Drinking in Two Recent Samples of Adolescents and Adults,~ Journal of Studies on Alcohol, July 1994, pp. 412-419).
- A national survey of women's drinking found sexual dysfunction to be the most consistent predictor of chronic problem drinking (NIAAA, Eighth Special Report to US Congress on Alcohol and Health, 9/93, p. 21).
- A recent study linking victimization to alcohol problems found that almost 90% of alcoholic women were physically or sexually abused as children (BA Miller, et. al., Interrelationships Between Victimization Experience and Women's Alcohol Use, Journal of Studies on Alcohol, Supplement No. 11, 1993, pp. 107-117).

- Alcohol is present in more than one-half of all incidents of domestic violence, with women most likely to be battered when both partners have been drinking (J Collins & P Messerschmidt, Epidemiology of Alcohol-Related Violence, Alcohol Health & Research World {AHRW}, Vol. 17, No. 2, 1993, p. 95).
- An examination of admissions records in a variety of health care settings indicates that women with alcohol problems wait longer to seek help and are more likely than men to use mental health services and other non-alcohol specific treatment programs when they do (CW Weisner, et. al, Gender Disparities in Treatment for Alcohol Problems, JAMA, Vol. 286, No. 14, 1992, pp. 1872-1876).
- Lack of child care is one of the most frequently reported barriers to treatment for alcoholic women (NIAAA, (Women and Alcohol, Alcohol Alert, No. 10, 1990, p. 3).

What Should I Ask When I'm Considering Going to an Alcohol or Other Drug Treatment Program?

- What's the program about?
- How many weeks or months does the treatment program last? how many hours per session, sessions per week, etc.?
- What hours is the program available? Can I do it evenings and still keep my job?
- Where is the program located?
- Is transportation available? Is there a cost?
- Is child care available? Is there a cost?
- Is the program for women only?
- Is the program focused on women's problems?
- Can I work with women counselors?
- Would I be eligible for low or no cost treatment? ... like Medicaid?
- Can I make payments?
- How do you decide what kind of treatment I should have?
- What's the difference between your residential and outpatient treatment?

- Do I have any say or control over what kind of program I'm in?
- Is information about me kept confidential? Who will know about me?
- If I don't want my husband/partner to know I'm in treatment, will he still find out?
- Will I (and my children) be treated with dignity and respect?
- Does the program have housing for me (and my children)?
- Will I (and my children) be safe? Both physically and emotionally?
- Will my ethnic/cultural background be considered?
- If treatment is residential, can my spouse/partner visit me?
- Are there any specific requirements for me to participate?
- Can I quit the program if I want to?

A Comprehensive program for pregnant women includes:

- individual counseling
- group counseling
- family/children's counseling
- alcohol and other drug education
- child care
- transportation
- recreation
- nutrition counseling
- victimization counseling and prevention
- life skills training
- decision making/conflict resolution training
- assertiveness training
- access to prenatal care
- parenting classes
- family planning
- training on how to select child care providers
- access to community resources

- vocational rehabilitation
- if inpatient, housing for both moms and children

Barriers to Substance Abuse Treatment for Women

compiled by the
**Colorado Women's Task Force
on Substance Abuse Services,**
August 1990

Lack of Finances
Lack of Child Care
Lack of Transportation
Denial of Problem by Self, Family, Spouse, Courts, Physicians
Stigma of Being Alcohol Addicted
Fear of Losing Children
Fear of Incarceration, Going to Prison
Guilt
Shame
Dependency on Men
Lack of Family Treatment
Lack of Treatment Sensitive to Women and Women's Issues
Lack of Information Regarding Services and How to Access
Lack of Outreach to Women
Role of Woman as Servicer, Nurturer, Provider for Others
Illiteracy
Probation/Parole Status of Women
Lack of Affordable Services
Paperwork, Waiting Time
The Multi-Problems of Women for Treatment Providers

**TREATMENT SERVICES FOR SUBSTANCE-
INVOLVED WOMEN**

TREATMENT SERVICES FOR PREGNANT WOMEN

SPECIAL CONNECTIONS: Is a drug and alcohol assessment and treatment program for pregnant substance involved women in Colorado. This program is available statewide through selected treatment providers. The program focuses on the special needs of a pregnant woman involved with alcohol or drugs during her pregnancy. Services include (Outpatient only):

- Individual counseling
- Group counseling with other pregnant women
- Child care during treatment services
- Case management services to obtain other needed community services
- Information groups on nutrition, infant development, parenting, child safety, and health care
- Urine screening and monitoring
- Referral to appropriate aftercare and ongoing support
- Transportation assistance
- Linkage to primary, pediatric, and prenatal medical care

TREATMENT SERVICES FOR WOMEN WITH DEPENDENT CHILDREN

Colorado also provides specialized drug and alcohol treatment services for women with dependent children statewide through selected treatment providers. The treatment program focuses on the special needs of women with children who are having problems with alcohol or other drugs. **Services include (Residential, outpatient, and day treatment):**

- Women's specific individual and group counseling
- Child care during treatment services
- Case management services to obtain other needed community services
- Transportation assistance
- Linkages to primary and pediatric medical care
- Job skills development and other living skills training
- Urine screening and monitoring
- Referral to appropriate aftercare and ongoing support

For contact information, please turn over.

Call the Alcohol and Drug Abuse Division (ADAD) at (303) 866-7480 for a regional referral, OR, using the map below, call your regional treatment service provider directly from the list below. They will be able to refer you to the nearest treatment program.

Denver Metropolitan Service Area #2

Call: Signal Behavioral Health Network, Inc.
(303) 639-93230

Boulder County Service Area #2A

Call: Boulder County Health Department
(303) 441-1463

Colorado Springs Service Area #3

Call: United Health
(888) 845-2881

Southeastern Colorado (including Pueblo) Service Area #4

Call: Signal Behavioral Health Network, Inc.
(303) 639-9320

Northeastern Colorado Service Area #1

Call: Signal Behavioral Health Network, Inc.
(303) 639-9320

Central Mountain and Western Slope Service Areas #5 & 6

Call: West Slope CASA/Options
(970) 668-3478