

FETAL ALCOHOL SPECTRUM DISORDERS TRAINING



Lynne R. Frigaard, FASD Specialist
Arc Northland
424 W. Superior Street
Suite 201
Duluth, MN 55802
218-726-4746
1-800-317-6475
www.arcnorthland.org
lfrigaard@arcnorthland.org

EMOTIONAL ISSUES

Maturation is delayed in people who have Fetal Alcohol damage. These delays affect the emotional development & feeling processes in these same individuals. Therefore, all aspects of their emotional, family, work & social life are impacted by these emotional deficits.

In Childhood

- ◆ lack of bonding
- ◆ high strung, sound sensitive, easily over-stimulated, irritating to be around
- ◆ temper tantrums
- ◆ low threshold for frustration
- ◆ need more intense supervision & structure than other children
- ◆ require more direct instruction
- ◆ overly friendly & lacking normal sense of "stranger danger"
- ◆ can't distinguish differences in relationship (Mom no more important than the mail carrier)
- ◆ school too stimulating & challenging
- ◆ academic performance is the least of this person's problems
- ◆ play along side **but not with** others
- ◆ can't share, take turns, cooperate, etc.
- ◆ more likely to play with younger children or adults, **not** peers
- ◆ can't generalize learning
- ◆ don't connect actions with consequences
- ◆ don't learn from experience
- ◆ need close physical contact & touch (becomes increasingly inappropriate as the person ages)
- ◆ perseverative behaviors
- ◆ short memory
- ◆ have increasing difficulty as thoughts & processes go from concrete to abstract
- ◆ have trouble working with "ideas"
- ◆ exist in the present
- ◆ no internal clock system
- ◆ unable to separate fantasy from reality
- ◆ acts like a younger child & may show loss of previously mastered skills

In Adolescence

- ◆ problems with impulsive behavior
- ◆ too uninhibited
- ◆ lacking critical thinking & judgment skills
- ◆ inappropriate sexual behavior (either as victim or perpetrator)
- ◆ trouble establishing & maintaining lasting relationships of any kind
- ◆ easily manipulated by peers
- ◆ vulnerable to criminal elements
- ◆ drawn to "gang" behavior (concrete not complex social system)
- ◆ have grandiose aspirations (but no skills or knowledge to fulfill dreams)
- ◆ high degree of failure, truancy, problems with the law, etc.
- ◆ poor problem solving skills
- ◆ inability to use trial & error approach to new situations
- ◆ problems with math, money & other abstractions
- ◆ naive & gullible
- ◆ difficulty understanding similarities & differences
- ◆ problems within the family, extreme stress, family breakdown

In Adulthood

- ◆ problems holding a job, managing money, living independently
- ◆ difficulty parenting children
- ◆ extremely poor social behaviors lead to isolation & withdrawal
- ◆ unpredictable behavior
- ◆ depression & higher level of other mental illness
- ◆ have the appearance of capability without actual ability

- ◆ repeats unacceptable behaviors, regardless of consequences
- ◆ neurologically unable to evaluate people, places, things in any but the most basic of concrete terms
- ◆ unable to understand, interpret or respond to society's rules

Strategies

People with FASD may not internalize feelings or understand appropriate responses to them. They must be taught everything & they can learn to "fake" the correct social & emotional behavior. This is taught by constant repetition & practice. Possible tools to help identify feelings:

- Name the feeling & practice appropriate responses
- Use visuals such as pictures, puppets, face blocks
- Try tactile prompts (coarse sand paper for anger, velvet for calmness, etc.)
- Use colors & build on the interests of the individual
- Try role playing situations which are causing problems & possibly video tape them
- Practice body language & facial expressions
- Teach & practice appropriate verbal responses
- Make it as CONCRETE as possible!!

Cautions

- Understand what triggers inappropriate responses (sound, smell, light, touch, movement, etc.)
- Identify "shut-down" cues (glazed look, fussing, avoidance, etc.)
- Monitor & limit access to TV, radio, movies, etc. (emotional responses in the media can negatively influence)
- Be aware of excessive, unrealistic fears. For example, a person with FASD may be fearful of a typhoon hitting Minnesota after hearing about one in India.
- Monitor friends & relationships (people with FASD will model the behavior they see)
- Avoid setting person up for failure (success is a much better teacher)
- Give them rope & they will hang themselves
- 1st time activities should be closely monitored & structured
- Physical ability does NOT mean emotional & developmental maturity
(being old enough to drive a car & tall enough to see over the dash board does NOT mean that the person is mature enough to deal with the decisions & judgments required to safely operate a 3,000 pound moving pile of glass & metal)

FLAGS FOR PROFESSIONALS

In early childhood (1-5 years):

- ◆ Speech, fine and/or gross motor delays
- ◆ Extreme tactile sensitivity or insensitivity
- ◆ Poor habituation
- ◆ Erratic sleeping and/or eating patterns
- ◆ Limited abstracting ability
 - ◆ Lacking action/consequence connection
 - ◆ Poor judgement & reasoning skills
 - ◆ Little or no sequential learning
- ◆ Rage
- ◆ Lack of "stranger anxiety"
- ◆ Concern expressed by parent, pre-school staff, etc.

In the elementary years (6-11):

- ◆ Normal I.Q. (or borderline or high) but immature
- ◆ Volatile & impulsive, impaired reasoning
- ◆ Socially isolated & emotionally disconnected
- ◆ Blames others for all problems
- ◆ Vivid fantasies & perseveration problems
- ◆ High need for stimulation
- ◆ Possible fascination with knives and/or fire
- ◆ School becoming increasingly difficult
- ◆ May have behavior and/or emotional disorder(s)

Adolescent years (13-18):

- ◆ No personal or property boundaries
- ◆ High risk behavior, possible gang or criminal activity
- ◆ Naive, suggestible, a follower
- ◆ Poor judgement, reasoning & memory
- ◆ Isolated, sometimes depressed and/or suicidal
- ◆ Family in crisis
- ◆ Poor social skills
- ◆ Unable to link action & consequence, won't accept responsibility
- ◆ Unable to handle typical teenage freedom
- ◆ Doesn't learn from mistakes

Adulthood:

- ◆ Unpredictable & impulsive
- ◆ Highly volatile (poor problem solving, violent, co-dependent relationships, etc.)
- ◆ Unable to read environment, lacking social communication
- ◆ Doesn't understand laws, rules, codes of conduct, etc.
- ◆ Poor abstracting ability (lacks understanding of safe sex/birth control)
- ◆ Pathological liar
- ◆ Doesn't seem to understand right & wrong
- ◆ Spotty employment record (poor "soft" skills)
- ◆ Substance abuse
- ◆ Limited life skills & unrealistic goals
- ◆ Possible mental health diagnosis (depression, obsessive/compulsive, conduct disorder, etc.)

8 Magic Keys

Developing Successful Interventions for Students with FASD

While there is no recommended *cookbook approach* to working with students with FASD, there are strategies that work, based on the following guidelines:

1. Concrete

Students with FASD do well when parents and educators talk in concrete terms, don't use words with double meanings, idioms, etc. Because their social-emotional understanding is far below their chronological age, it helps to "think younger" when providing assistance, giving instructions, etc.

2. Consistency

Because of the difficulty students with FASD experience trying to generalize learning from one situation to another, they do best in an environment with few changes. This included language. Teachers and parents can coordinate with each other to use the same words for key phases and oral directions.

3. Repetition

Students with FASD have chronic short-term memory problems; they forget things they want to remember as well as information that has been learned and retained for a period of time. In order for something to make it to long-term memory, it may simply need to be re-taught and re-taught.

4. Routine

Stable routines that don't change from day to day will make it easier for students with FASD to know what to expect next and decrease their anxiety, enabling them to learn.

5. Simplicity

Remember to *Keep it Short and Sweet* (KISS method). Students with FASD are easily over-stimulated; leading to "shut-down" at which point no more information can be assimilated. Therefore, a simple environment is the foundation for an effective school program.

6. Specific

Say *exactly* what you mean. Remember that students with FASD have difficulty with abstractions, generalization, and not being able to "fill in the blanks" when given a direction. Tell them step by step what to do, developing appropriate habit patterns.

7. Structure

Structure is the "glue" that makes the world make sense for a student with FASD. If this glue is taken away, the walls fall down! A student with FASD achieves and is successful because their world provides the appropriate structure.

8. Supervision

Because of their cognitive challenges, students with FASD bring a naiveté to daily life situations. They need constant supervision, as with much younger children, to develop habit patterns of appropriate behavior.

When a situation with a student with FASD is confusing and the intervention is not working, then:

- **Stop action!**
- **Observe.**
- **Listen carefully to find out where he/she is stuck**
- **Ask – What is hard? What would help?**

Developed by Deb Evensen and Jan Lutke 1997

Primary and Secondary Disabilities Associated with Fetal Alcohol Spectrum Disorder

Prenatal exposure to alcohol can cause many abnormalities and disabilities that have lifelong physical, mental, behavioral and social consequences. Researchers have classified the disabilities into two categories: primary and secondary (1).

Primary Disabilities are defined as those that reflect the primary morphological and neuropsychological damages of Fetal Alcohol Spectrum Disorders. These disabilities include:

- Facial dysmorphology
- Growth retardation
- Central Nervous System neurodevelopmental abnormalities, with a complex pattern of behavior or cognitive dysfunction

Secondary Disabilities are those that appear later in life as a result of complications from undiagnosed or untreated primary disabilities. Examples of secondary disabilities include:

- Mental health problems (90%)
- Disruptive school experience (60%)
 - Trouble with law (60%)
 - Confinement (50%)
- Inappropriate sexual behavior (50%)
- Alcohol / drug problems (30%)
 - Dependent living (80%)
- Employment problems (80%)

Patients with fetal alcohol related abnormalities who demonstrated varying IQ scores were found to have similarities in impaired judgment and low adaptability.

BENEFITS OF EARLY DIAGNOSIS

Early diagnosis with proper intervention may decrease the appearance and attenuate the course of the secondary disabilities. A diagnosis of full-blown Fetal Alcohol Syndrome before the age of 6, can help to prevent some secondary disabilities.

Because more than 90% of children with FASD have mental health problems, psychiatric assessment should always be considered when diagnosing FAS OR FASD.

Reference

1. Streissguth AP, Barr HM, Kogan J, Bookstein FL. Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE). Final Report, Centers for Disease Control and Prevention Grant No. R04/CCR8888515. August 1996.

SOCIAL & BEHAVIORAL ISSUES

Learning is Not Automatic - "Typical" children do most of their learning by osmosis & require little teaching after early childhood because they are self-evident & have a sense of connection with societal rules. By age 5, typical children understand danger & know they can be killed if hit by a car. Persons with FASD are as likely to run in front of a car at 30 years as they are at 3.

Those with FASD may need to be specifically taught **everything**. By everything, we mean:

- * how to make friends
- * how to sit in church
- * how to ride safely in a car
- * boundaries, both personal & property
- * social graces & manners
- * feelings & values
- * moral codes & societal laws

Teaching must be done with modeling & practice. Words alone will not work. Teaching must be repetitious, consistent and life long.

Roots of the Problems: Why Do People With FASD Act Like they do.

Organic Brain Damage Results In:

Difficulty in understanding abstract concepts

abstractions include time, money & math

time – Some individuals with FASD have no "internal" clock.

This is not about being able to tell time, this is about being able to "feel" time, understand & internalize time

money – Many folks with FASD don't understand what money means to people or what money represents. To them, taking a penny from some one is the same as taking a \$100 bill. They don't understand the difference in purchasing power & therefore don't understand why the rightful owner would feel & act differently.

Math - In the beginning, math is visible & concrete. Once you move on to multiplication, division, fractions, etc. it becomes abstract. When doing fractions, you must be able to visualize in your mind, rather than actually seeing & touching while adding 2/3rds & 6/9ths.

Poor Short Term Memory

Because of brain damage, the individual may be unable to recall a specific memory when necessary. Instead, they lie just to come up with an answer. To an adult, the lying appears deliberate where as the person with FASD is trying to please by coming up with this answer, regardless of truth as others might know it.

Because the person with FASD frequently can't remember what they were doing when they got in trouble or what the consequences where of a certain act or behavior, they are destined to repeat behavior, with the same consequences.

Short term memory problems also so result in an inconsistent knowledge base which may mean sporadic & unpredictable performances throughout life. This problem spans all facets of the individual's life, school, home, social, work, etc. For example, it is as difficult for a person with FASD to remember the rules of baseball as it is for him/her to remember multiplication tables. So that person is not only in academic trouble, he/she may be kicked of the ball team for cheating or not following the rules.

Inability to Make Predictions

Predicting is an abstract skill which develops very early in typical people. Even very young children are able to predict what is likely to happen next. The brain damage caused by maternal alcohol use can make predicting very difficult for people with FASD. For example, a person with FASD is driving a car on an icy road might have an accident because he/she is unable to predict that the car will not stop as quickly as it would on dry pavement.

The ability to predict is one of the things that keeps us safe from harm & also keeps us out of trouble. Without the capacity to predict, people with FASD put themselves in dangerous & sometimes unlawful situations. They may live "high risk" lives because they are not able to vision what may happen next.

Poor Impulse Control

Impulse control is directly affected by a person's ability or inability to predict. If one is not able to predict, impulsivity & negative consequences are likely to be the result.

People have impulses on a daily basis. Individuals with FASD may not have "internal" controls on their behavior and are more likely to act on their impulses. For example, one poor impulse control and bad judging skills contribute to theft by people with FASD. An individual does not PLAN to steal. He/she just sees something they want and take it without even considering that the object might belong to someone else or that the act of taking the item is wrong.

The person **does** the crime but they do **NOT INTEND** to. They break laws but they don't intend to break laws. **They lack the intent to commit the crime & they also lack the skill to cover it up.** They act on impulse, with little or no planning and little or no understanding of the possible outcomes of their behavior.

Poor Judgment Skills

People who can't remember, can't predict & who have no internal controls for their impulsive behavior are likely to make poor decisions & judgments. As individuals with FASD pass through their adolescent phase and approach young adulthood, their poor judgment skills are likely to be recognized. They may be identified as irresponsible, undisciplined, immature, etc.

Chronological aging brings expectation of certain behaviors and skill development. For example, a seventeen year old is expected to get him or herself to school everyday. When a student is constantly truant, it is seen as a discipline or behavior problem, that the student is **choosing** not to attend school.

If the student has FASD, the "choice" issue is not a clear one. If a student with FASD is on his/her way to school & finds a lost puppy, they will not **choose** to care for the dog rather than go to school. They will simply deal with the immediate issue (the puppy) but can't consider the "big picture" of getting in trouble for not attending school. They think in compartments, meeting immediate needs and not projecting beyond the current compartment.

Undeveloped Sense Boundaries

Typical people have a sense of their own personal space & a respect for the space of others. This is not taught. It develops naturally in most people. It offers protection, physically, emotionally & behaviorally & provides us with a comfort zone.

This sense often does NOT develop in individuals with alcohol-related brain damage. They don't feel their own space nor do they respect the space of others. As children, they may seem friendly, funny, outdoing. Later, their invasion of other people's space is intrusive,

uncomfortable and even threatening. They may get too close, may touch inappropriately & yet have no sense of how people are reacting. Eventually, they are likely to be excluded, shunned by others.

This can also be true of property boundaries. They may not see objects as belonging to anyone. Things are just there for the taking. That car is not yours or mine, it's just there for anyone to take. The individual with FASD may take something & not understand why the rightful owner is angry. The "taker" might say something like, "I needed it & you didn't need it cause it had been sitting on the table for hours. What's the big deal?"

Inability to Manage Own Behavior

Behavior management interventions are based on age appropriate control. People with FASD may have problems in this area for obvious reasons. They have little or no impulse control and are usually not operating at an age-appropriate level. For example, a 22 year old woman with FASD may act more like a 13 year old, with the impulses & behaviors of a 13 year old.

DISCIPLINE ISSUES & TECHNIQUES

Consistent discipline & structure are key because:

- ⇒ Society has rules & people with alcohol-related disabilities have trouble learning or following those rules.
- ⇒ Folks with FASD generally don't internalize morals, ethics or values like other individuals & so they see no reason to modify their behavior to meet society's expectations.
- ⇒ Some individuals with FASD are not able to learn from past experience and so they are bound to repeat the same mistakes over and over again. Effective discipline may help break this pattern.
- ⇒ Learning to live with & abide by society's rules, laws & expectations is a life-long process for people affected by maternal alcohol use. Teaching & discipline must start in early childhood & continue through adulthood. The process & need for structure never ends.

Remember that:

- ◆ The rules are the same for everyone (in a household, a classroom, etc.). Consequences can be adapted or changed but not the rules themselves.
- ◆ No discipline technique will work all the time with any person.
- ◆ If a technique is NOT working, **don't try harder**. Change what you are doing.
- ◆ Be consistent & pick techniques that YOU are able to follow through with.
- ◆ Discipline should be immediate, not delayed. For example, if an individual misbehaves on Tuesday, don't take away Saturday's circus. They will probably have trouble making a connection between the behavior & the punishment.
- ◆ Avoid threats.
- ◆ Be brief, not lecturing.
- ◆ Never use physical discipline. People with FASD model what they experience.
- ◆ Negative behavior may be a symptom of unmet needs.
- ◆ Anticipate dangerous situations & recognize early signs of trouble so you can plan ahead.
- ◆ Avoiding problem situations is always better than having to react to those situations. For example, if Cindy (child with FASD) always becomes over-stimulated & violent when she attends large family gatherings, don't put her in that situation. Leave her home with a sitter or make some other arrangement.
- ◆ Don't debate rules or consequences.
- ◆ Constantly review & repeat consequences of behavior.
- ◆ Don't let sympathy interfere with discipline
- ◆ Don't use "chronological" age as a measurement of maturity
- ◆ Monitor friends, activities, free time
- ◆ Protect for as long as possible

Discipline Strategies

Time-outs can work in some cases. However this method could be disastrous if an individual responds by “trashing” the time-out area. For instance, one child tore all the stuffing out of his mattress while on a time-out in his room. If a person can't be trusted alone, time-out must occur in a more public area. Also, don't make the time period too long. Five minutes of time-out can be as effective (or more so) than 25 minutes.

Ignoring behavior can be effective, as long as the behavior is not injurious or damaging for the individual or others. Some behavior is for “effect” and if you don't respond, the person behaving in a certain way may just stop.

In some circumstances, using a prearranged gesture or signal can intervene. This could be a touch, hand sign or other cue which helps an individual understand they need to change their behavior. Sometimes, individuals are simply unaware of their behavior and, if signal or cue is prearranged, meaningful & understood, they may be able to change what they are doing without further action.

Behavior can also be altered by redirecting activity, offering another option, etc. This can be very effective in breaking up patterns & intervening with problems. Don't, however, offer too many choices. This can result in confusion or over-stimulation, poor decisionmaking & frustration, which can lead to more negative behavior.

Reward completion of tasks & good behaviors with “token” system. Yes this is bribery but it can also be effective. Determine with the individual (as appropriate) what the token/s will be and under what circumstances the token/s will be awarded. Keep in mind that the token or reward must be appropriate to the individual's situation. For example, if the person has a problem understanding fantasy from reality, an hour of playing the “Grand Theft Auto” video game would not be an appropriate “reward”.

Withdrawal of privileges can also work for some people. Just be sure that the privilege used is something the individual values, not something you value. In order for this method to work, the individual must really value or enjoy the item or activity being taken away.

Additional Information of Interest

4 Stages of Temper Tantrums in People with FASD

- 1) quickly escalates
- 2) any intervention will fuel the fire
- 3) can attempt to defuse by changing subject
- 4) individual has quick recovery & returns to normal while others are still stunned

SOCIAL COMMUNICATIONS
(Based Upon the research of Dr. Truman Coggins)

Language is a tool, a window into thinking and social skills. Many people with Fetal Alcohol Spectrum Disorders have problems with communications, especially social communication but the problems may be hidden behind strong verbal skills. Generally, when communication is tested clinically, the speech person is looking at vocabulary, grammar and the "sound system". Often times, people with FASD pass these components without difficulty.

So, what goes wrong?

- Concrete thinking leads to illogical problem solving.
- People with FASD make decisions intuitively rather than inferentially (logically)
- Folks with FASD can have high verbal output yet be limited in their ability to exchange information.
- Those with FASD may frequently interrupt others, even after being told repeatedly not to.
- He/she may make unrelated comments.
- It may be very difficult to plan and present a story or a series of events.
- People with FASD can have very compromised social interactions or skills
 - little desire to please "socially significant" people
 - problems adapting to new social relationships
 - limited social savvy
 - difficulty coping with change in social settings

What is Social Communication?

It is your brain's ability to interpret situations, environments, facial expressions, etc. without words. It is the brain's ability to

- Understand the underlying intentions of what people want or what they want to achieve.
- Understand the underlying interpretations.
 - Interpreting actions – Watching a toddler run and understanding they the child is likely to run, trip, fall, cry.
 - Interpreting behavior – Understanding why people act the way they do and predicting what will happen next.

How is Social Communication assessed?

- Observe the person in question during a structured social interaction. Can they manage the acceptable "scripts" Hello, How are you and so on?
- Check their mental state reasoning ability. Can they walk into a room, observe others and correctly determine appropriate behavior for themselves?
- Can they understand what different facial expressions mean?
- Can the person read and interpret body language?
- Can they tell a story that makes sense? Is it coherent? Is it cohesive? Coherence means the story is informative, the vocabulary precise, fundamental ideas are encoded and the storyteller presupposes appropriately. Cohesion means there is a logical progression in the story, including a logical sequence of events and a logical plot.
- For children and teens, try the book Frog Where Are You by Mercer Mayer. It is a book with not words. Ask the child/teen to tell you the story. Is it coherent and cohesive? Those with FASD are likely to describe each page but not tell a real story.

SELF-CALMING TECHNIQUES: Keys to a Safer, More Independent Future

Helping an individual develop skills in self-calming will make a huge difference in this/her future. Without self-calming abilities, people with FASD are at higher risk for behavior which will get them in serious trouble. The goal should be for individuals to recognize when he or she needs to get away, calm down, etc.

In the Beginning

- * start early (as soon as a child can participate)
- * use trial & error method
- * children know what feels good & what doesn't
- * listen, watch & learn
- * goal is to desensitize the individual to his/her environment, identify and avoid stressors, etc.

Suggestions:

- * establish a private place, area, etc.
 - * behind the couch
 - * in a large box
 - * in the individual's room or other private room
 - * use your imagination
- * offer soothing articles/furniture in that space
 - * bean bag chair
 - * large pillows
 - * blankets
 - * rocking chair
 - * ear protectors (sound proof or music)
- * other information on atmosphere
 - * quiet
 - * dim lighting
 - * Jacuzzi is calming for some
 - * no other stimulation

In this safe place, the individual may want to wrap a blanket tightly around him or herself, may want to be covered by large cushions, may benefit from wearing a heavy vest or life preserver. "Cocooning" is very helpful for some individuals. Repetitive motion such as rocking or squeezing a softball, etc. can help others. Sound blocking headphones or soft music can help reduce over-stimulation. These are just sample ideas. Each person is different & will respond differently. These techniques should be adapted for different environments: school, work, social settings.

When a private area is unrealistic, the individual must be taught other ways of getting out of over-stimulating situations.

- * Go from the classroom to the nurse's office, rest room, library, etc.
- * In the office, turn off the lights, shut the door & have uninterrupted time alone until calm.
- * Provide for flexible breaks during the workday, allowing an individual to get away when he or she needs to.
- * If out in the community, go & sit in the car or behind a tree.
- * In the homes of relatives or friends, establish a calming area which will always be accessible to the person with FASD.

Cautions:

- * If an individual cannot be trusted alone (he/she may harm self or damage property if unsupervised), adapt "private" space to work in the presence of another person.

- * If this system is not working, try something else. Try different, not harder.
- * Don't purchase special, expensive equipment before knowing whether this technique will work.
- * People with FASD can be very tactilely sensitive, especially around the head. If helping them wrap up, etc. avoid touching or covering the head or other sensitive area.
- * Individuals can be very sensitive to odors like perfume, paint, body odor

Tips:

- * Quiet space should not be treated as a punishment.
- * The individual should be respected by others, not stared at or teased.
- * It could help to tone down the entire home/school/work environment for a while.
- * If you can identify times of day when over stimulation often occurs, change the atmosphere on a more permanent basis. Establish a "quiet time" when no TV or music or other noise is allowed in common areas. No vacuuming or dishwasher or dryer, etc.
- * Don't touch the person lightly, use firm massage or firm hugs
- * Deep body massage can be calming
- * Try other techniques:
 - * warm water on the hands or feet
 - * petting the dog
 - * brush the body with material or a large, soft brush
 - * relaxation tapes or exercises
 - * experiment!!

TEACHING TECHNIQUES

Tips for Working with Students Who Might Have Alcohol-Related Brain Damage

➤ **Primary Factors in Building a Successful Educational Program**

- structure
- consistency
- simplicity
- modification of tasks, timelines, testing methods
- functional, realistic goals
- transitioning change
- build on individual strengths
- anticipation & planning
- teamwork

➤ **Mechanics**

- use preferential seating (2nd row, directly behind your best behaved student)
- use oversized toys
- use lined paper
- use white or pastel paper, NOT neon colors
- when using highlighter, use pink, not yellow
- clearly define spaces within the classroom
- use study carrels
- post classroom rules (in several places if necessary)
- provide student/s with pocket rules
- use items to define when an activity is ended (egg timer, etc.)
- use same staff consistently
- provide organizational equipment (baskets, giant paper clips, etc.)
- same assigned seat in cafeteria, auditorium, gym everyday

➤ **To Increase Attention & Control Impulsivity**

- use eye contact, appropriate touch & child's name
- vary your speech (loudness, inflection, speed, etc.)
- anticipate & explain
- use objects (puppets for example) & visuals (these are tactile & visual learners)
- be brief, concrete, carefully define directions, etc.
- ask child to paraphrase directions, etc.
- check for understanding mid-assignment
- give adequate time for task completion & transition from one task to another
- complete directions before handing out materials
- use an object to teach "turn taking", only the person holding the object (toy, ball, animal, etc.) can talk
- limit lag time

➤ **Improving Self-esteem**

- have peers model behavior
- model & rehearse social skills
- model alternative behaviors
- offer positive incentives for finishing work
- recognize partially correct responses
- give attention for proper, appropriate behavior
- test knowledge, not the attention span
- stress that repeated mistakes just mean that the child is getting another chance
- don't ask "why" questions (why is abstract)
- ask who, what, where, when
- build on child's strengths & knowledge
- encourage use of positive self-talk
- recognize success each day (or each hour if helpful)
- don't draw lines in the sand

- **To Improve Memory**
 - repeat & restructure continually
 - use short sentences
 - silly rhymes & songs help kids to remember
 - physical performance of sequential activities
 - teach one concept at a time
 - have child repeat what he/she just heard
 - with older students, have them take notes on verbal directions
 - show pictures/objects for 30-60 seconds & then have students talk about what they saw or answer questions
 - have student paraphrase instructions, etc., not just parrot back what was said
 - build on student's interests & likes
- **To Reduce the Impact of Hyperactivity**
 - limit the type & number of new situations
 - read the danger signs
 - when a student can't keep hands to self, find alternative activity (squeeze a ball, snap a rubber band, etc.)
 - lessons should emphasize manual & physical expression
 - avoid long periods of desk work (these children **MUST** move)
 - students need short breaks during day & **don't take away recess** (no matter what the student has done)
 - avoid overstimulating activities (TV, Nintendo, etc.)
 - develop & implement "respite" plan when student is overwhelmed
 - teach appropriate responses to overstimulation (self-monitoring)
 - when self-monitoring is not successful, assist immediately
 - keep tasks simple
- **With Older Students (after age 13)**
 - focus education on daily living & survival skills
 - continue to teach & model social skills & behaviors
 - student's ability should dictate the appropriate mix of academic & functional skills teaching
 - at least one team member **must** really know this student well (need someone to be realistic)
- **General Strategies**
 - I.Q & achievement tests are almost worthless in telling the future
 - movement may increase with concentration/thought
 - teach generalization of skills
 - use visuals, gestures & **fewer** words
 - avoid competition
 - catch students being good & doing right
 - maintain your sense of humor
 - remember that most behavior is not willful

ENVIRONMENT

At Home, Daycare, Residential Settings

- * bedroom should provide a calming atmosphere
 - * plain, stark walls, muted colors (pastels, beige, etc.)
 - * no posters, pictures, murals, wallpaper, etc.
 - * no “busy” bedspreads or curtains
 - * personal items, toys, etc. out of sight (in toy box or closet)
 - * no mobiles
 - * no breakable items
 - * no distractions
 - * no rearranging furniture
 - * have pets only if you can assure the animal’s safety

- * kitchen should be safe & user friendly
 - * sharp items, knives, matches, etc. secured (locked up if necessary)
 - * items used by the individuals should be easily accessible
 - * unbreakable dishes, glasses, etc.
 - * clear surfaces, plain walls, etc. cause less distraction
 - * post “rules of the kitchen”
 - * avoid situations which may result in “climbing” or other dangerous behavior (don’t put the cookie jar on top of the refrigerator)

- * bathroom should also be safe and accessible
 - * lock up medicines, cleaning supplies, etc.
 - * items used by the individuals should be easily accessible
 - * hot water regulator
 - * bathroom rules posted

- * the house/apartment in general
 - * all breakables & potential projectiles removed
 - * all dangerous items locked up (guns, knives, baseball bats, etc.)
 - * key locks on all rooms (especially bedrooms)
 - * stable environment (don’t rearrange the furniture or redecorate)
 - * minimize distractions
 - * less is more
 - * house rules posted
 - * digital clocks help with telling time but not with understanding it

At School, Day Program, Work Setting, etc.

- * classroom, shared work space, etc.
 - * plain walls (no posters, art work, etc.)
 - * no mobiles, wind socks, hanging plants, etc.
 - * cover lower part of windows (to limit view of outside)
 - * bookcases, shelves, etc. covered
 - * clear surfaces
 - * soft lighting
 - * lock up dangerous items
 - * as quiet as possible
 - * limit distractions (visitors, PA announcements, etc.)
 - * classroom/work place rules posted (best to use words & pictures)

- * “off limits” areas must be clearly marked (a big, red NO in the teachers closet)
- * individual desk, work space
 - * preferential seating (provide good role models as these individuals will do what they see)
 - * not near high traffic areas such as pencil sharpener, sink. etc.
 - * assistance in organizing personal space (baskets for items, large paper clips, limit number of pencils, etc.)
 - * allow use of “comfort” item (individual may need access to items such as a blanket, stuffed animal, favorite key chain, etc.)
 - * adequate space between desks, tables (to limit distractions & behavior triggers caused by bumping, etc.)
 - * classroom/work space rules taped to desk, table, individual space

Factors for All Environments

- * provide for a “self-calming” area
 - * separate space (behind couch/ bookcase, in corner, etc.)
 - * access to pillows, blankets, large box, rocking chair
 - * soft lighting, even semi-darkness
 - * limit sound (try target range ear protectors)
 - * private as possible (be safety conscious)
- * offer alternatives to “regular” individual work space when behavior starts to escalate or individual can’t focus
 - * desk facing the corner
 - * table surrounded by room dividers
 - * be creative
- * don’t arbitrarily change the environment
- * safety (for all) should be the first concern
- * foster independence by making environment accessible
- * ensure the privacy of others

Situations Best Avoided

- * standing in long lines
- * crowded hallways/spaces
- * unstructured environments (lunchroom, auditorium)

AN ENVIRONMENTAL CHECK LIST FOR STUDENTS WITH FASD
Adapted from Susan Doctor

Stimuli

- Are there decorations/displays on the walls or hanging from the ceiling?
- Are the selves open and cluttered? If covered, is the material "busy" or plain in a soft color? Is there an enclosed storage area for unused material/equipment?
- What colors are the walls, desks, shelves, etc? Are the colors bright or soothing? Are there multiple colors used?
- Are there bulletin boards that are decorated with many brightly colored items?
- What is the noise level in the room? Are there many interruptions during the day? Is the intercom used? Does the phone ring? Is the TV on?
- What kind of lighting is used? Do the lights flicker or hum? Is there glare from the lights?
- Is there noise outside the room on a routine basis (band, gym, kitchen, pipes, etc.)?

Self-Calming

- Is there a self-calming area in the room or close by? Is it private, secluded, safe and free of stimulus so children/teens can work, think and calm down?

Physical Space

- Are desks moved over holidays/vacations? How close are the desks to each other? Can the kids move around without bumping into each other?
- Do children work in groups and do the desks face each other? Are there any desks in a protected part of the room? Are all areas within the room clearly and concretely defined by rugs, tape, signs, pictures, tile, etc.?
- Is the furniture used to provide boundaries that delineate work/play areas? Are the areas labeled at child eye level?
- Is a daily schedule clearly visible and are the rules posted? Are the rules concrete or abstract?

Transitions

- What are the procedures for going to lunch? How do the children return after lunch?
- What are the conditions in the lunchroom? Are there a large number of students and do they stand in line for a long time? Is there a no talking rule and enough supervision? Is there a time limit?
- What happens in the halls and at the locker? Are the halls wide or narrow? Are there time limits and supervision?
- How many transitions are there each day? Class, recess, lunch, etc.?

Organization

- Can the student organize him/her self? Do they need to keep books and papers in the room rather than their locker? Do they need external organization?

Other

- How many assemblies, field trips and special events happen each week? Can the student stay home or do something else if events are stressful?
- How long is the school day? Is school year round?
- Is the student on the bus for a long time? Is it noisy, crowded, supervised?
- Is the student in the right classroom with the teacher best suited for his/her needs and who can/will work with the developmental or operational level of the student rather than the chronological level?

To Improve Learning & Function for Children With FAS/E

Giving directions...

Give one direction at a time & simplify. For example, a direction may have secondary instructions within it that confuses the message & makes it harder to comply. "Go to (action) the big (size) red (color) cupboard (object) & take out (action) the little (size) can (object) of soup (food)."

The child may have tuned out the directions, even when simplified. When children have brain damage & are easily over stimulated they will use avoidance, including auditory avoidance, to reduce stimulation.

Identify & Model Language

Say what you are doing. "I'm putting away the paints." "I'm getting my math book."

Schedules...

Try using a Job Card to "visualize" a schedule. Have the student work on the design, using pictures, symbols or words for each activity. Include behavior reminders on the card.

Rituals...

When children are "ritualistic" in their behaviors, it can be a way of organizing themselves. Though the behaviors may seem like a waste of time, you are better off encouraging them.

Consistency...

Order & predictability can help the child with FAS/E feel more secure & have better self-control. These children function best with very narrow limits.

Reading problems...

Reading requires a number of processes: auditory sequencing, visual-motor-spatial integration, auditory & visual integration & short-term memory. A deficit in ANY process can result in reading difficulty. (White/Miller, 1983)

Motivation...

Children with brain damage can lack motivation & interest. They need instruction that is heavily adult-directed. They need external motivation.

Individualized programming...

Children with FAS/E need more time than normal to learn & retain information. The classroom must change, the child cannot.

About Learning and Brain Damage

When a person with brain damage has behavior problems, the behavior is NOT caused by the damaged area but rather by the healthy brain structures that are performing in the absence of the damaged area. (Heilman, 1978)

Learning causes physical modifications in the brain and brain activity. This is how we learn to do things automatically, without thought or analysis. (Luria, 1970)

When one part of the brain is damaged, atypical cognitive strategies may be found to compensate.

Organized material is easier to learn. Most of what we need to learn comes to us in random order & we use our own brain to organize it. With brain damage, individuals will learn better if the curriculum considers process & organization strategies. (Baddeley, 1982)

Multisensory (visual, olfactory, kinesthetic, tactile & auditory) instruction helps. Accessing many sensory modalities takes advantage of all possible neurological pathways.

Memory

Immediate memory lasts only seconds & holds 5-7 items. Reinforce immediate memory by having the individual repeat what they just heard. The development of short-term memory can be reinforced by asking questions several minutes later. (Rapin, 1988)

In people with brain damage, interruption is a real detriment to learning. Refocusing attention after a disruption requires a review of recently stored information & is time consuming.

Cues or prompts improve the ability to retrieve information.

Happy moods are associated with higher memory performance.

Repetition

Repetition turns a conscious voluntary act into an unconscious, involuntary, automatic act. In other words, a habit (Mishkin & Appenzeller, 1987)

As the repetitions increase, the material being learned is engraved more deeply & indelibly. (Schacter, 1982)

The Curve of Forgetting is that most forgetting happens during the first few hours after the presentation of information & then decreases. (Ebbinghaus, 1964 & Schacter, 1982)

School Adaptations for Teens With FASD

- Cluster classes
- Same teacher for more than 1 class
- Stay in same room if possible
- Make maps, possibly color-coded.
- Avoid lecture classes
- Hands on, visual learning
- Swap academics (if frustrating) for woodworking, sewing, art.
- Identify a safe haven & an adult willing to help student calm down
- Have supervised tasks the student can perform around school
- Recognize signs of "shutting down" & get student to safe place
- Learn the difference between real disobedience & confusion
- Help student organize. For example, keep all materials for each class in a color coded bag.
- Identify a "peer helper" for assistance & problem solving
- Teach basic manners such as how to raise a hand to ask for help or what to say when you don't understand instructions.
- Give student easiest locker (end of hall, next to office door)
- Make lock combination very easy or have no lock at all
- Realize these students will need extra help to complete State requirements
- Try to prevent the kids with FASD from becoming the class goof-up
- Try to prevent teasing. Students with FASD may not react as good naturedly as others.
- Team with other students who can help with abstract concepts.
- Help short-term memory problems by having student take notes, tape record concepts just read, etc.
- Give copies of teacher notes or have another student give a copy.
- You may see "academic growth spurts".
- Use multi-sensory teaching methods such as songs, rhymes, pictures, etc.
- Separate home & school. No homework. No lectures about behavior & dress. No comments on working up to potential, participating, etc.
- School to work programs are good. See "soft" skills like calling in when sick & teach social skills like how to ask a co-worker for help.
- Fast-paced jobs like assembly lines of fast food likely to fail.
- Try slower paced work settings & work with the disability.
- Teens can & will work hard as long as directions are clear.
- More involved individuals may need a "speech wallet" that holds basic information, pictures, phrases, sources of help.
- For the less involved individual, continuous teaching & practicing of self-advocacy skills.
- In teen years, the need for physical closeness & lack of boundaries can lead to sexual inappropriateness.
- Control the environment rather than trying to control the behavior.
- Choose the right friends for the teen with FASD.
- Driving is not a right, it is a privilege. Make sure the individuals has adult like problem solving skills & judgment ability before allowing a license.
- "Check it out" before believing what the teen with FASD says.
- Redefine success.

FASD: Environmental Scan

Questions to guide identification and development of accommodations:

1. Who is the child? Neurocognitive characteristics including:
 - a. Strengths
 - b. Developmental level of functioning
 - c. Sensory systems
 - d. Processing pace
 - e. Additional cognitive characteristics

2. Identify one behavior – generally secondary – and keep an observation log* to identify the pattern and the setting(s) when this behavior occurs
 1. Identify characteristics in the environment where the behavior occurs
 - a. Physical space
 - i. Sight
 - ii. Sound
 - iii. Touch
 - iv. Smell
 - v. Taste

 - b. Identify the “invisible” elements of environments
 - i. Brain function
 - ii. Level of expectations
 - iii. Task, technique, activity
 - iv. Time of day, fatigue, hunger, change

 4. Identify where there is a poor fit between the person and their environment.
 - a. Setting where secondary behaviors are seen
 - b. “Fit” between person and settings
 - c. “Poor fit” and points of intervention

2. Specific accommodations
 - a. Build on strengths
 - b. Physical, environmental
 - c. Parenting, teaching, other

3. Just for you: Identify personal / professional
 - a. Your strengths
 - b. Needs: What do you need? What would help?
 - c. What are the barriers to providing accommodations, and how may they be resolved?
What would support for sustained implementation look like?

*Observation log: Requires specific instruction on observing without interpreting or assigning meaning to behaviors. This is distinct from functional behavioral analysis.

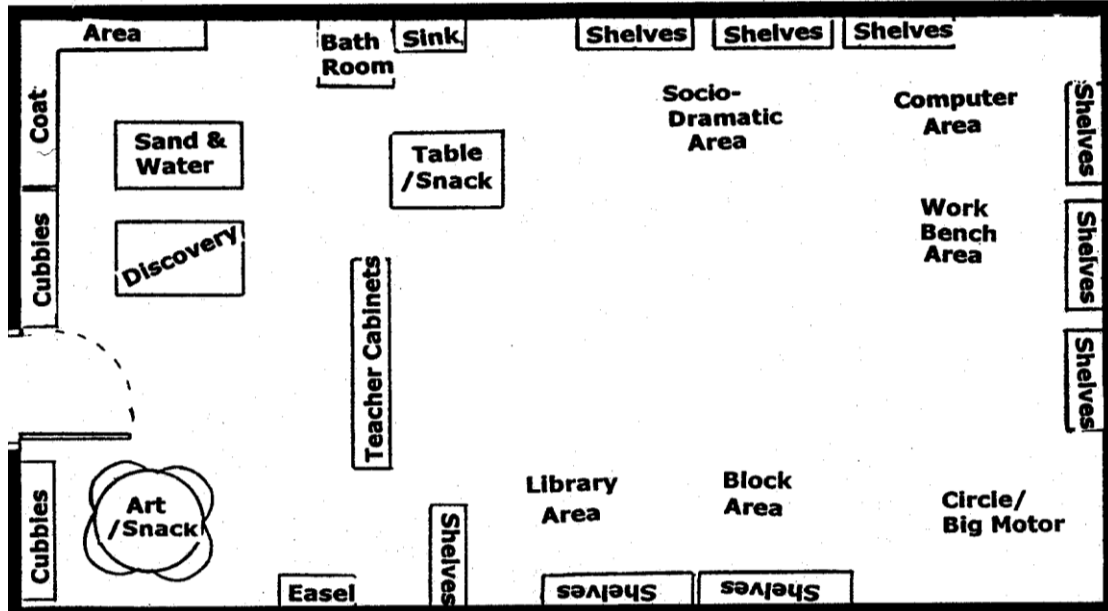


Arc
Northland

Tips for a Better Classroom Environment

- Limit long and wide open spaces by using furniture or placing visual boundaries.
- Limiting the number of students in a certain area can prevent fighting and other problems.
- Use visuals to help students recognize when an area is “full”.
- Close play areas during learning time.
- Mark circle on the floor and indicate where each student should sit.
- Keep noisy areas separated from quiet areas.
- Limit visual distractions and reduce problems caused by lighting.
- Stick to a rigid schedule and alter only when absolutely necessary.
- Try to find the best time of day for each activity.
- Plan for transitions and become creative.
- Use songs, animal noises, picture boards, etc.
- Make the passage of time as concrete as possible (try egg timer or hourglass).
- Pair children for better behavior.
- Teach sharing through role plays or use of puppets.
- When children have trouble staying on task, they may really be bored or lacking necessary skills.
- Keep activities at appropriate level and be creative.
- Limit responses to inappropriate behavior and make a big deal out of good behavior.
- Constantly remind students of the rules.

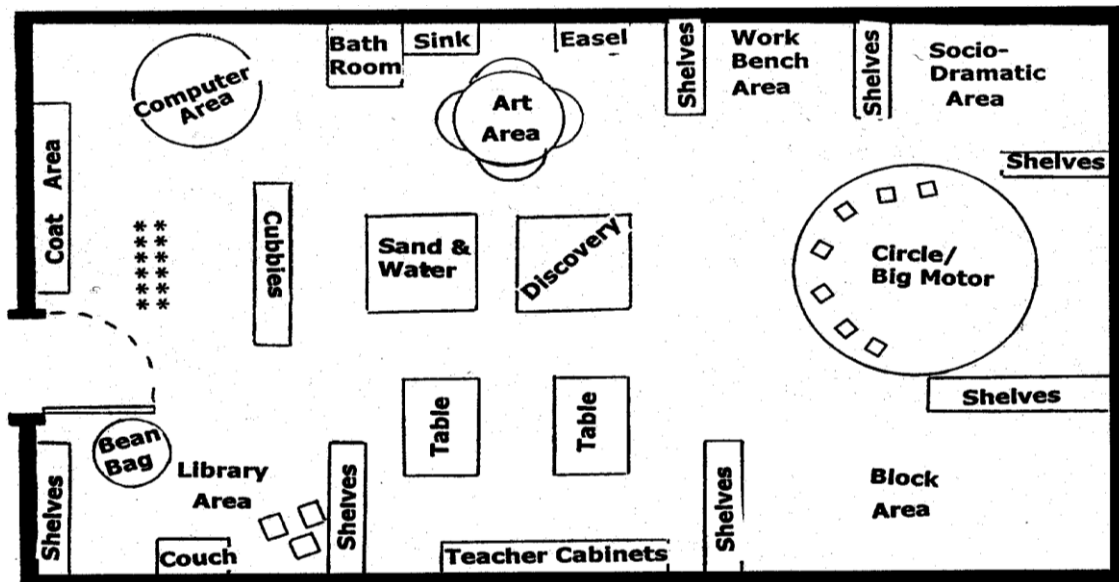
Classroom A: Environmentally Inappropriate



- Art area not near water source
- Toys too close to circle time area
- Quiet centers neighboring noisy areas
- No visual boundaries for play areas
- Unlabeled shelving

- Undefined personal space in circle area
- Snack tables far from each other, limiting social interactions
- Space conducive to running
- Cluttered walls

Classroom B: Environmentally Appropriate



- Visual cues for lining up near door
- Communication pictures pertinent to play area posted for nonverbal children
- Cubbies labeled with photos and names of each child to promote independence
- Shelving labeled to promote independent clean up
- Poster of classroom rules on the wall

- Hooks limiting the number of children in each area.
- Limited visual stimuli on walls
- Personal visual schedules posted
- Picture of play area at entrance to play area
- Classroom schedule posted
- All shelving/cabinetry low to ground (3 ft high) for staff to see into all areas

ATTENTION DEFICIT VS FETAL ALCOHOL
How can you tell the difference?

ADHD

- ◆ very impulsive/act without forethought
- ◆ jump into situation without thinking
- ◆ after the fact, able to process what went wrong, what the problem was & why it developed

Example:

Jane has ADHD & her mind runs at double speed. She drives fast & is impatient with slower drivers. Jane is able to recognize the potential danger being created by her impatience.

Jane is impulsive but she has the developmental thought process of an adult.

FASD

- ◆ very impulsive/act without forethought
- ◆ unable to go back & rethink the situation on their own
- ◆ process information very slowly or not at all
- ◆ can't figure out what the problem was or how to correct it

Example:

John has FASD & caused a bus/telephone truck accident. Even though arrested by the police for reckless endangerment, John was incapable of reasoning out the situation.

John is an adult but does not have the capacity to reason & take responsibility for his behavior.

*Making a determination between ADHD and FASD is critical in order to establish appropriate expectations and treatment directions.

(From F.A.S. TIMES, Summer, 1997)

SEXUALITY ISSUES

Physical Effects

Individuals with FASD can have precocious puberty or delayed puberty, caused by organic damage from alcohol use during glandular development in the 2nd trimester. Anomalies to the genital organs can also occur if the mother drinks during month 5, 6, or 7 of her pregnancy. For example, a male might have undescended or missing testicles and a female might have no ovaries or uterus.

Behavioral Effects

Because people with FASD lack an internal value system, they will participate in professions or activities that society outlaws or demeans. For example, prostitution, stripping, X-rated filmmaking. They see nothing wrong with their actions and are not bound by societal values, church doctrine, etc. In addition, the pay is instant and so is the ratification.

As with issues mentioned earlier, problems associated with the inability to predict or understand abstract processes play a role in sexuality and health for the individual with FASD. The need to protect oneself or others from pregnancy, HIV or other STD's is an abstract concept.

Inappropriate sexual behavior can also result from maternal alcohol use during pregnancy. Children with FASD may demonstrate sexual behavior "beyond their knowledge" and this can easily be confused with concerns that the child has been sexually abused. Again, the individual's lack of internal controls can be a problem. A child with FASD often does not understand "delayed gratification" and will do what feels good whenever and wherever they feel the urge.

Lacking internal values and wanting instant gratification, teens and adults with Fetal Alcohol may be very impulsive in their sexual behaviors, sometimes resulting in sexual assault. As they also lack the understanding of socially appropriate dating behavior, they may see no reason to wait beyond the first date (or the first hour of the date) to expect sex.

External Factors

Pornography, X-rated (and even R-rated) movies, sex channels on the Internet can fuel the fires that lead people with FASD to act inappropriately and become sexual predators. If they see violence or aggressiveness or rape, they may well model that behavior.

Suggestions from a Sex Therapist

There may be an appropriate use for auto erotica with people who have Fetal Alcohol damage. If they can be taught to see gratification through masturbation (in acceptable private places), it is possible to reduce their need to seek sex elsewhere.

Tips

When Males are depressed, their sex drive goes down.

When females are depressed, their high-risk behaviors go up.

Once a person becomes a sexual predator, he or she is unlikely to change if they feel no sympathy for their victim/s.

According to therapist Natalie Novak, to teach boundaries (sexual or otherwise) one must start early and she offers certain questions that may help. The teaching **MUST** begin before the child starts to explore his/her own sexuality.

To teach the concept of boundaries, ask these questions,

- Who can touch you and whom can you touch?
- When is it okay for you to touch someone or for him/her to touch you?
- How close do you sit or stand to people?
- When do you make eye contact?
- How close do you get to people in elevators?
- How close do you get to people while waiting in lines?

To teach the concept that sexual touching is only allowed between grownups, use these questions,

- Whom do you let touch you in a sexual way?
- Who is it okay for you to touch in a sexual way?
- Who can see you with your clothes off?
- When is it okay to touch somebody's private places?
- What do you do if you want to touch someone's private places?

To protect the child from being victimized ask these questions;

- Who is it okay to talk to?
- Is it okay to talk to strangers?
- What do you do when a stranger starts talking to you?
- What do you do if a stranger touches you in a private place?
- When is it okay to play or do things with?

To teach the child to talk about feelings with respect to sexual issues ask these questions,

- Who controls your feelings?
- How do you control your feelings?
- Do you have a right to talk about your feelings?
- When is it okay and not okay to talk about your feelings?
- Who should you talk to about your feelings?

ONCE THE CHILD UNDERSTANDS THE KEY WORDS AND THE CONCEPTS, BEGIN TO APPLY THESE IDEAS WITH VIGNETTES AND EXAMPLES RELEVANT TO THE CHILD'S EXPERIENCE.

TEEN & YOUNG ADULT ISSUES

Teen & young adults with FASD have a particularly difficult time, especially when they have normal intelligence & seem very high functioning. They will seem more able than they are & will have a tough time understanding their limitations. In actuality, those who have mental retardation have an easier time getting through this period. The higher a person functions, the more troubled his/her life may become.

Promoting Optimal Independence:

- Give as much freedom as the person can really cope with SUCCESSFULLY.
- Be observant & discreetly intervene when individual is not handling Independence well.
- Once a problem has occurred, you must spend a great deal of teaching time before giving that person another opportunity. Simple discipline will not initiate change.

Teens Are Likely To Be Extremely Impulsive & Want Immediate Gratification.

- They don't think. People with FASD simply respond to stimuli.
- When things go wrong, they are likely to run away.
- This population will say the first thing that occurs to him/her. They will buy things or give money to others when they can't afford it. They are vulnerable to the pitches of phone solicitors, credit card scams, etc.
- Remove temptations for impulsive behavior.
 - Adult supervision is constantly needed. (After school, evenings, weekends, etc.)
 - Put car keys away; lock up liquor & guns, etc.

Don't feed unrealistic expectations:

- If the teen won't be able to date or drive, don't bring it up.
- If college is not in the future, don't pretend it is.
- Let them know it's not realistic to move to California & become a rock star.

Ensure Appropriate Relationships

- Common age should not be the only factor in developing friendships.
- Activities should be **maturity** appropriate, not age appropriate.
- Teen parties should be avoided unless well chaperoned/supervised.
- Unstructured activities can be a problem.
- Teen may need to be with a responsible adult at all times.
- Consider hiring a "friend" or socialization coach.
- Won't ask for help because they don't want anyone to know that anything is wrong.
- Highly vulnerable & easily victimized.
- Giving expensive gifts to try & buy friends.
- Putting up with an abusive relationship just to be with someone.
- Taking the fall for what others have done just to keep "friends".

Forgetfulness & Lack of Time Awareness

- Make & post a written list of things to do.
- Show how to do things & work some with the teen to get them started.
- Ask the person what would help them do the job better, faster, more often, etc.
- Use a wristwatch alarm for important times.
- Get a pager.
- Fill out large calendar (a month at a time).
- Do weekly schedule.
- If he/she has the responsibility of a pet, get an automatic feeding/watering machine & have a back up plan.

Arguments & Accidental Incidents

- Be philosophical (if possible) & pick your battles carefully.
- Overlook minor infractions.
- Walk away from conflict & give angry teen space
- “I know you’re upset but swearing is not acceptable around me. I
- Won’t stay & listen. We’ll talk when you calm down.”
- Treat a teen as you would an adult
- If he/she spills something, have them clean up the mess
- If something is broken, make it an opportunity to discuss his/her physical strength & problem solve how to replace the item
- Also discuss physical strength in relation to hurting other people
- Put expensive or breakable possessions away
- Avoid testing his/her honesty (if you already know the answer, don’t ask the question). Truth & untruth are abstract concepts & will not be understood.
- Don’t preach or lecture

Money Issues

- People with FASD are very unreliable when it comes to money.
- They don’t understand the buying power of money.
- Strategies for limiting financial problems include:
 - Establish a protective payee or guardian for the person.
 - Require two signatures on a checking account.
 - No ATM or credit cards.
 - Ask the bank for an alert on the checking account.
- Set up a self-reporting budget system. Divide up monthly spending money into envelopes or boxes & the person only has access to one envelope per day.
- Inherited money must be in a trust & only a limited amount is available monthly, no matter what.
- Get a phone number that blocks solicitors.
- If there are numbers in the phone book you don’t want the person to call block or cut them out.

Dealing With Negativity:

- A negative outlook is very common in teens with FASD. Nothing good ever happens to them. Their lives are all misery. What can you do? Travel with a camera constantly. Take pictures of shopping trips, special events, completed tasks, etc. & keep a scrapbook of the “good” times. This provides a visual reminder of how many good things really do happen.

Mental Health Issues for Teens With FASD

- Depression is common.
- Suicide attempts may occur.
- Without intervention, they can become less & less stable.
- Problems may accelerate to conduct disorder, psychosis, etc.
- Traditional (cognitively based) psychotherapy will not work for this population.
- Behavior modification plans based upon the individual understanding that his/her behavior is wrong will also not work.

Growing Up With Fetal Alcohol

Life can be a roller coaster for any teen or young adult. When that person has Fetal Alcohol brain damage, the ride can get very rough. Awareness, understanding & a willingness to work **with** the disability instead of against it are key factors in improving the situation.

Routines can be extremely important. For example, the person with FASD may not be able to decide which clothes are in need of laundering. A possible solution would be to develop a routine of washing **all** clothes **every** Sunday.

Money management may always be a problem. The value of money is abstract. The value of objects is also abstract. Sometimes, individuals with FASD will refuse to spend \$3.00 on something they really need but will spend \$300.00 on something frivolous. Possible solutions:

- Two signature checking accounts.
- Direct payment of important bills (rent, utilities, etc.).
- In person savings withdrawal only or 2 signature withdrawal.
- Call bank to check balance before writing checks.
- Daily or weekly allowance.
- Assignment of a financial conservator.

People with FASD can be very rigid. They may be able to do only one thing at a time. For example, if he/she is scrubbing the kitchen floor, that task must be completed before they can answer the phone. So, scrubbing the floor at 11 PM might be better than at 10 AM.

Time is another abstract. Consider making a linear clock to help the individual understand the passage of time. You can even “color” time to help individuals understand what should go on during the day/night. For example, 6 AM to 6 PM could be light in color, representing daytime. 6 PM to 10 PM could be Twilight color & 10 PM to 6 AM could be dark, representing sleep hours. Egg timers & hourglasses can also help make the passage of time concrete & visible.

Poor short-term memory can be a habitual problem. Write things down! Make grocery lists, schedules, important dates, etc. Written directions can help avoid getting lost & panicking. Use pictures & other prompts. You may need to call & remind the person it is time to leave for work or start dinner. They may also need reminders about returning borrowed items, etc.

Sometimes, individuals with FASD will think “out loud”. This random audible thinking can be very irritating to others. A reminder such as “Mary, you’re thinking out loud again,” can help stop the behavior.

Sex, Dating & Marriage for the Person With Fetal Alcohol

Sex...

- The individual will **WANT** independence but will **NEED** the supervision of a younger child.
- All teens fantasize. This is normal. But, to act on unrealistic fantasies is dangerous & traumatic.
- You must believe that the teen may be **UNABLE** to control impulses, **NOT** unwilling.
- Social naiveté combined with explosive sexual feelings can easily lead to molestation. You may need to consider medication to lower testosterone levels for example.
- Teach the difference between friends & boy or girls friends. A smile or a handshake does not mean the person wants to date or kiss you.
- The world operates on social cues. How one dresses, talks, gestures send a message. Teach directly & control externally is necessary.
- Social & sexual behaviors are complex & very difficult for many with FASD to understand.
- Try a curriculum such as "Circles" which is concrete & visual. It teaches about different types of relationships & the specific, appropriate behaviors in each category.
- Teens with FASD may use "magical thinking". "I'll be elected Homecoming Queen." "I'll marry Brad Pitt."
- They may have trouble understanding concepts that cannot be seen such as the sperm fertilizing the egg or the risk of unprotected sex.

Dating...

- Get to know the date. Ask them to coffee or dinner & find out what kind of person he/she is. Ask why they want to date the person with FASD. Find out their hobbies or interests. Make them welcome in your home.
- Make the date a friend, not an enemy even if you can't stand them. Explain the disability & make the rules very clear. Ask the date to help ensure that the individual with FASD follows the rules.
- Don't alienate the date. You may need to count on him/her in a crisis.
- Teach the script of romance. Role-play correct dating behavior. Have the couple double date with a sibling or mentor several times before going out alone.
- Often the relationships don't last long.

Marriage...

- For a young adult with FASD, marriage to a stable person with a normal brain can be a solution to the problems of the teen years.
- Marriage can provide affection, structure & guidance but the spouse **MUST** understand the disability & what their role will be.
- Marriage to another person with FASD or someone unstable for other reasons can be a disaster.
- Decisions about having children should be made with a good understanding of the possible outcomes.

Puberty & Fetal Alcohol

When dealing with precocious puberty:

- Consider seeing a Pediatric Endocrinologist about using medication (oral Provera) to slow the symptoms.
- Talk casually & repetitively about body changes & what may happen next.
- Use pictures, models & other visual materials to make learning concrete. Check in specialty catalogs, check with the local Arc or talk with special educators about resources.
- Protect from victimization. Without stranger anxiety & proper boundaries, this population is highly vulnerable.

Hygiene during puberty:

- With girls, establish a set schedule for changing tampons or pads. They may not be able to judge when a change is needed so it is best make changes routine.
- Keep hygiene products such as soap, toothpaste, etc. in a special place for use only by the 1 person. Decorate the container, color code the products, anything to increase enjoyment & use.
- There are some wonderful products in different colors & flavors, with sparkles, etc. Let the young person pick out his/her own items.
- Establish a routine early. Wash hair everyday. Shower everyday. Make it habitual from a very young age.
- Keep a checklist (with pictures if necessary) & go over procedures often.
- Let boys practice shaving from a young age. They can use a play razor from an early age & establish the routine.
- Include hygiene in the child's IEP if necessary.
- Bathroom use after each meal. Routine of washing hands/face, brushing teeth, putting on lipstick, combing hair, etc. This is also a time to check clothing for spills or tears.

Modesty:

- This is an abstract concept. If it's OK for a two year old to be nude in front of parents & siblings, then why is it wrong for a sixteen year old to do the same thing?
- Establish "modesty" routine early. One always wears clothing into & out of the bathroom. One always shuts the door when in the bathroom, even if it is just to put on lipstick or get a tissue.
- Have posted rules (with pictures if necessary) in the bathroom. One always flushes the toilet or always hangs up the towel, etc.
- Role model the routine & have everyone in the household follow it.
- Repeat, repeat, repeat & practice, practice, practice.

Vocational Issues and People With Fetal Alcohol

With the person who has Fetal Alcohol, the I.Q. not necessarily impaired. According to Streissguth, Barr, Kogan and Bookstein (1996), people with Fetal Alcohol Syndrome can have I.Q.'s anywhere from 29 to 120 and those with Fetal Alcohol Spectrum Disorders can have I.Q.'s from 42 to 152. Therefore the question is not how smart a person is but how well they are able to use their intelligence.

So, on average, when a person with Fetal Alcohol damage is 17 years old, his/her adaptive functioning is about 7 years. For example, the affected person may test out with the Vineland to have the daily living skills of a 9 year old, the social skills of a 6 year old and significant communication defects. This compounded with inconsistent learning patterns, spotty memory and organizational processing defects affecting input, output, integration and memory means that individuals with FASD have a significant barrier to obtaining and maintaining employment. This must be taken into account when seeking vocational placement.

Vocational testing can also be inaccurate when the person has FASD. Performance in this population is spotty. Testing only measures performance for that particular day or moment. Scores cannot be used to assess past or future ability. Therefore, vocational testing is of limited value at best. Vocational placement must be based upon the individual's particular ability and disability.

Vocational Planning Issues

- Environment MUST be highly structured and slower paced.
- Limit distractions and need for transitions.
- Inappropriate behaviors are likely to continue unless dealt with immediately.
- Good role models as co-workers (people with good brain function).
- "Work buddy" to keep person on task, model good social behavior, etc.
- Build plan on strengths and interests but be realistic.
- Pay attention to the past and the person's functional patterns.
- One-to-one, apprentice programs very helpful.
- Co-workers and bosses NEED to know what to expect.
- Job supports must be long-term.
- If a situation is NOT working, don't try harder, try different.
- Vocational counselors knowledge of FAS/ARND as it affects the individual is critical to success.

*Arc Northland, 424 W. Superior Street, Suite 201, Duluth, MN 55802
(218)726-4725, 1-800-317-6475, lfrigaard@arcnorthland.org*

STRATEGIES FOR MAXIMISING SUCCESSFUL VOCATIONAL REHABILITATION

Robert Schacht, Ph.D.

People with FASD often benefit from repetition, a very structured environment and from visual cueing rather than verbal cueing. Some specific suggestions to illustrate these general principles:

- Use well defined areas. Things are put away in a certain place. Perhaps with a masking tape border to outline the area.
- Remove extraneous materials. Limit the number of objects and displays in the room at one time. Use visual displays, then remove them. Keep work areas cleared off except for material in use.
- Keep worksheets uncluttered, with lots of white space on the page. Use fewer pictures or problems so the page is not so busy or filled with data.
- Use pictorial cues as reminders of routines. Use pictorial signs for subject areas, special room areas and location signs such as parking area.
- Use Brain Maps. Draw a one-page visualization of a task. It gets the client thinking in terms of graphic relationships instead of verbal connections. In the process of creating visuals for their memory map, they are drawing pictures in their brain that will last much longer than words.
- Adapt tasks and materials in terms of frustration tolerance. Shorten the time, number of examples or trials. Simplify material and concepts. When the task is shortened, the client is rewarded with a sense of completion.
- Give direct instruction in thinking skills. Ask the client "How did you figure that out?" "What did you do first?" Instructor can model this by thinking out loud so that the student or client hears the instructor's thinking strategies.
- Use the "broken record" technique by repeating the same words over and over again to strengthen the memory. For example, at the end of each session, "What is the last thing we always do?" Reply: "Turn off the lights." People with FASD often need more repetitions to learn something than other people do.
- Anticipate-learn danger signs and situations. Build relaxation time into the program. For example, when a client who has FASD starts tapping his/her feet and drumming his/her fingers, that person needs to discharge that energy or they can erupt into aggressive behavior. Let the person "take a little break now" and speed walk around the building until they feel calmed down.
- Teach appropriate ways to respond to overwhelming stimuli. They could move to another part of the room, ask others to be quiet or ask permission to leave the group temporarily.
- Encouragement works better than praise. Say, "I know you can do that...You did that part right! Let's try it again."
- Chunk work. Break the work into small pieces. This reduces anxiety and decreases the tendency to think "I'll never get this all done."
- Repeat and restructure continually. Express it in different ways, show them through different modalities, including visual, kinesthetic and haptic.
- Teach them to ask for repetition of instructions or materials in a form other than the one you just used. (Would you write down for me please? Can we make a diagram?)
- Stop at key points in order to determine the client's understanding.
- Focus on the generalization of skills and behaviors. When a task is taught, don't assume that a person with FASD will automatically know how to generalize the information to new situations. We have to point out other situations and get them to actively think about it. When else would you do this? Do you think it would work here? How is that situation similar to this one?
- It also helps to link new learning to prior experience. Fitting information together is the key to successful generalization of knowledge.
- Teach social skills such as:
 - Negotiating to get what you want
 - Disagreeing with someone else in an appropriate way
 - Showing someone you like them (appropriately)
 - Accepting criticism or negative feedback

- Asking for something in a way that will increase the odds of getting it
 - Getting someone's attention in a positive way
 - Giving and taking compliments
 - Starting a conversation
 - Saying no to peer pressure
 - Behavior while riding public transportation
 - What to do when you feel scared
- Call and confirm appointments in a timely fashion. Difficulty with keeping appointments seems to be a direct manifestation of FASD. (Devries & Waller, 1999)
 - Position the client directly across from the employer when speaking, looking directly at the speaker so that eye contact can be maintained. If the client comes from a traditional American Indian or Alaska Native background, make sure they understand that maintaining eye contact with a non-Indian employer is expected and not a sign of disrespect.
 - Alert the client in advance of activity changes: people with FASD often have difficulties with transitions. "We have ten more minutes before lunch...We have five more minutes!...You should be finishing up."
 - Train the client to get ready for work the night before, getting clothes, get lunch money ready and so on.
 - Use calendars and assignment books. Teach them how to use them and review their use of them every day for the first two weeks, then once a week.
 - Assign short tasks and give explicit, concrete and carefully defined directions. Instructions or directions like "Go to the fork in the road...Does that ring a bell? Give her the brush off...Let's talk turkey! Why don't you just throw in the towel!" are very confusing because people with FASD often translate language in a very concrete fashion.
 - Avoid giving multi-part instructions. People with FASD often find it difficult to remember complicated verbal instructions.
 - Increase the client's attention by shutting out all unnecessary auditory stimulation that they don't need to hear. Use earphones (or sound-blockers) with no auditory stimuli to screen out extraneous noise.
 - Use a "study carrel" type of office space to shut out visual stimulation, reducing distractions.
 - Ask the client to repeat back directions in their own words, paraphrasing what was said so that you are sure that the information was processed.
 - After the first several items are completed, check back to make sure they understand the next steps of the task, have not gotten distracted and have not forgotten how to do the next task.
 - People with FASD often have significant difficulty dealing with public transportation. Help the client learn how to deal with problems in this area.
 - Finally, people with FASD often benefit significantly from an advocate. The advocate can be a family member, a job coach or a friend who can educate the employer about core disability issues such as those enumerated above and can help determine when problems are occurring so that troubleshooting and remediation can prevent termination of employment.

Adapting “Talk” Therapy for Those With FASD

Therapy must be linked to concrete, physical representations of the issues.

Techniques that can work:

- Role playing
- Practicing dialogs
- Play therapy (works with the “dramatic” teens & is multi-sensory)
- Art Therapy

Use the individual’s baby book to help individual understand family relationships. This may help with attachment issues.

Try drawing friendship maps with lines & circles. This may improve the understanding of different social relationships.

Try to make abstract concepts visual.

Usually, you will have to deal with the teen attitude that “I’m just fine, everyone else is messed up”.

Generally, there are four goals for therapy & the person with FASD:

- Use words to label & understand emotions.
- Practice talking about feelings to help the client increase his/her awareness of them. Identify circumstances that evoke feelings & work on problem solving. Require the use of practice dialogs & role plays.
- Help build trust between individual & parents/family. They need to believe they can solve problems together. Occasional joint therapy session can help.
- Work on crisis plan. What should happen when the person feels suicidal or explosive? There will likely be need for a physical release of tension as verbal ability may fail at a certain agitation level. Work with the disability. When you have a “runner”, find them a track to run on. When you have a “hitter” get them a punching bag.

Insight therapy adaptations:

- Draw diagrams of friend & family relationships/roles.
- Use pictures to represent feelings & teach concrete ways to express feelings.
- Videotape client behaving correctly or role-playing appropriately.
- Make problem solving concrete.

Cautions:

Avoid using group therapy for problems. For those who can’t separate fantasy from reality, the stories told by others in the group may become their own.

Traditional psychotherapy works when individuals grasp the underlying reasons for responsible behavior & its meaning. Many individuals with FASD cannot do this.

There is logic to their thinking, it’s just not our logic.

HEALTH/MEDICAL CONCERNS

Potential Physical Problems

- * low birth weight or prematurity
- * poor weight gain & possible "failure to thrive"
- * upper respiratory infections/problems
- * ear/eye/mouth problems
- * gross and/or fine motor problems
- * sensory integration problems
- * cleft lip/palate

Organ Defects

- * heart (murmurs, valve/chamber malformations, etc.)
- * skin (tumors, birthmarks, excessive hair)
- * genital defects
- * liver (cirrhosis, biliary system)
- * hernia
- * kidney (cysts, missing pieces)
- * bones (bent digits, joint malformation, scoliosis)
- * brain (abnormal size, malformations, microscopic holes)

Tips for Better Health Care

Keep a notebook regarding illnesses

- * date & duration
- * observations
- * treatment

Medical/dental appointments

- * schedule doctor/dentist appointments for "off" hours (early AM/late PM)
- * call before leaving to check on wait time
- * bring a snack in case you have to wait
- * request flexibility from office staff (wait outside, in cafeteria)
- * bring "comfort" item

Anticipate and plan well in advance

- * make a list of questions
- * refill prescriptions before you run out
- * have a well stocked first aid kit

PARENTS WHO HAVE FETAL ALCOHOL SPECTRUM DISORDERS

People with FASD often have children and have few of the skills needed to parent well. They appear to purposefully neglect their children and don't seem to benefit from the traditional social service programs like counseling and parenting classes. Often, the children are taken out of the home for their own welfare and the parent will try hard to do whatever they must to get the kids back but he/she never quite gets their act together. People with FASD are going to have problems parenting for several different reasons.

Lack of Bonding

- Organic brain damage can result in an inability to bond or to recognize any relationship being more important than another.
- It may be generational in that the affected individual perhaps never bonded to his or her parents and cannot bond to the children either.
- As parents, they may know that they are supposed care but really don't have the internal feeling.

Poor Memory

- Parents with FASD will intend to get to appointments, finish paper work, etc. but will often fail to do so because of their bad memory.
- They may appear to neglect their children by taking them outside to play, returning to the house to answer the phone and remaining inside because they have forgotten that the children are outside.
- They may forget to feed, clothe and bath their children.
- Poor memory can mean that children don't get basic medical care, don't get to school, etc.

Compartment Thinking

- Parenting requires being able to do many things at the same time. People with FASD tend to be limited in this area. For example, a mother trying to feed the baby and make dinner at the same time may be completely overwhelmed when the phone rings.
- Typical people see life as a string of beads. If you move one bead, the other beads also move. People with FASD have trouble understanding that things don't happen in a vacuum, that every action has a consequence.

Poor Problem Solving and Anger Issues

- Parents with FASD can easily become abusive.
- Anger tends to be a common response to many problems.
- Because there is a disconnect between actions and consequences, nothing is ever their fault.
- Anger management programs tend to be cognitively based and unsuccessful for those with FASD.
- Frustration is increased because many parents with FASD recognize that they are not doing what need to be done but can't seem to resolve their problems.

So, What Can Be Done For Parents With FASD?

1. Obtain a clinical evaluation for a FASD diagnosis parents and their children. Everyone working with the family needs to understand that brain damage is not fixable.
2. Help clients follow-up on referrals and make linkages with community service providers.
3. Assist with paperwork and transportation to appointments.
4. Help evaluate birth control and assist in obtaining reliable long-term methods.
5. Obtain a developmental disability status as appropriate.

6. If the client with FASD is using drugs or alcohol, try to find a treatment program that is concrete rather than abstract.
7. Find safe, stable housing in a supervised setting if possible. People with FASD use the brains around them. If they are with good people, they will be good. If they are with bad people, they will be bad.
8. Teach and role model basic life skills such as bill paying, food shopping, cooking, hygiene, etc. If the person with FASD continually fails at this, provide them with external supports. Someone else pays the bill or buys the food.
9. Find a solid network of community service providers who can work with the parents for the long run.
10. Educate the providers in relation to FASD and the individual family needs.
11. Try to locate long-term mentors for these families because family members may have burnt out from dealing with the parents and need a respite from them.
12. Eventually, you may need to make difficult decisions for the sake of the children. Because the damage cannot be repaired, it may be necessary for the children to be raised elsewhere. Unless there is enough support to ensure their safety, removal from the home may be necessary. Work with the courts and foster care to determine visitation versus cutting all parental ties.
13. Try not to judge. The parents with FASD did not cause their own damage. Someone else made that decision.
14. Be kind to yourself. Even the best professional cannot fix the damage in the brains of parents with FASD.

(Adapted from Grant, Ernst, Streissguth & Porter)

*Arc Northland, 424 W. Superior Street, Suite 201, Duluth, MN 55802
218-726-4725, 1-800-317-6475, lfrigaard@arcnorthland.org*

CAREGIVING & FAMILY ISSUES

Basic Issues

- * understand the realities of this disability
- * prepare for possible negative situations/outcomes
- * realize this person may not fulfill your dreams for them
- * this may be a life long commitment
- * recognize the importance of routine, consistency & family

Emotional Issues

common feelings

- * anger
- * hopelessness
- * guilt
- * "why me"
- * frustration
- * isolation/withdrawal
- * stress

possible coping skills

- * acknowledge & validate feelings
- * network with others
- * find healthy releases
- * make personal time a priority
- * find new interests
- * have some fun

Emotional strength will be needed for the long run.

From the start, establish a family operating system.

- * everyone is entitled to safety, privacy & respect
- * the "rules" apply to everyone though consequences may vary
- * have regular family meetings
- * distribute responsibilities & tasks fairly

Siblings have issues & rights

- * help them understand that FASD is brain damage, not willfulness
- * need one-on-one time with parent/s
- * may resent time & energy required
- * need to have their privacy & belongings protected
- * deserve to be physically safe
- * deserve to be emotionally secure

RESPONSIBILITIES

Teaching

"First Knowledge" is extremely important when a person has FASD or cognitive difficulty from some other cause. The way something is learned the first time will always have more impact than any second or third effort. For example, if you teach a child with mental retardation that the grass is blue, he or she may have a great deal of trouble relearning that the grass is really green. Teaching & learning things the correct way the first time can save hours of re-teaching, and sometimes, years of frustration.

People with FASD need to be specifically taught values & feelings. These are not things they can learn by osmosis. If a person is unable to "internalize" feelings or values, they can still be taught to behave as if they understand & do or say the appropriate thing.

Appropriate behavior must also be taught. How do we act in church? How do we act while shopping? These things must be learned by rote & constantly reinforced. Tools for teaching could include role-playing, video, pictures, discussion, prompting & transitioning.

Basic concepts like "how to be a friend", "how to share", "how to date" are not automatic & should be specifically taught. Typical children & teens learn by watching & listening to peers or family. Individuals with FASD will need a more direct approach and, because they have trouble generalizing information, these skills must be taught again & again.

Teach to the appropriate developmental/emotional level, not to the chronological age of the person with FASD. Commonly, these people operate socially & emotionally at least 5 years behind their "age". When a person is 18, they may behave like a 12 year old. When that person reaches 30, he/she may act like a 21 year old. Expectations & teachings must be adjusted accordingly.

Methods

- * Post all rules (house, kitchen, bath) & schedules. Use charts, pictures, drawings, symbols, whatever seems most effective at getting the message across. It is also important to go verbally over the rules (and what they mean) at least once a day.
- * Prompting & transitioning are important. Again, visual or tactile cues should be used with verbal ones. Discuss & demonstrate what behavior is expected in what setting, etc.
- * Always say the person's name & have direct eye contact with them while talking to them. Use short sentences, simple words. Less is more.
- * Model tenderness, respect & patience. Demonstrate love to the individual & to other family members.
- * Positive reinforcement is always better than negative. Praise appropriate behavior, attitude, etc.
- * Identify the person's strengths & abilities and also know his/her needs.

SLEEPING & EATING ISSUES

SLEEPING

- poor sleep cycle
- difficulty in getting to sleep & staying asleep
- may sleep only every-other night, etc.

In Infancy

- use crib for sleeping only, not as a play pen
- no mobiles
- plain bumper pads & safety net over top
- dark room best
- if using night light, keep it high for safety
- sleeping habits have nothing to do with whether the baby is eating solid food or not

In Child & Adulthood

- best to have a room to him/herself
- room darkening shades
- white noise
- use bed for sleeping only
- no napping during the day
- post list of acceptable solutions to sleeplessness
 - ⇒ must remain in the room
 - ⇒ activity must be quiet

TIPS

- establish & maintain a bedtime routine
- transition from wake to sleep
 - put pajamas on
 - reading
 - snack
 - “good nights”
- keep it consistent
- ease into quiet/bed time
- no excitement/limit stimulation
- limit noise (TV radio, stereo, phone)
- quilt or sleeping bag to wrap in

EATING

Generally Poor Eaters

- picky or painful due to missing enamel on teeth
- abnormal oral sensitivity & gag reflex
- not interested in food
- sometimes physically unable to eat solid food
- may need food & liquid the consistency of honey to avoid aspiration
- may be impulsive eater or binge one day & then not eat again for 3 days

Mealtime is a socialization & relationship experience. It helps set the tone for bonding & relationship patterns. A positive mealtime experience is critical & should be a priority.

TIPS FOR HAPPIER MEAL TIME

- fixed plate method better than family style
- limit choices
- remove distractions (salt/pepper, napkin rings, center piece)
- serve food warm (not hot or cold)
- finger foods helpful
- no TV, radio, telephone, etc.
- don't discuss stressful subjects
- be realistic regarding food portions
- allow plenty of time
- chairs with arms are preferred
- smaller, frequent, high calorie meals (4-6 in a day)
- preferential seating (not facing a window, busy bulletin board)
- allow the person to stand & eat if necessary (limit standing area by requiring the person to stay on a rug or mat)
- learn hunger signs & serve meal when the signs are first displayed
- quick, easy to prepare foods are helpful
- food texture can cause problems (adapt from apple chunks to apple sauce, chunk meat to ground, cooked carrots instead of raw, etc.)
- be cautious of foods that are too spicy
- structure is key during mealtime; lack of structure results in chaos
- beware of "trendy" vitamin therapies, etc. Supplements may be needed but check with your physician or nutritionist first.

REMEMBER: People with disabilities have less tolerance for lack of sleep, cold temperatures, hunger & poor nutrition than typical people. Response to these situations can negatively affect all facets of their lives.

COMPETENCY/CAPACITY ISSUES AND FETAL ALCOHOL BRAIN DAMAGE

Competency

- Is the person able to understand the charges against him/her?
- Can this individual understand the legal process?
- Can this person aid his/her attorney in his/her defense in a reasonable fashion?
- To make a determination, it will be important to:
- Ask open ended questions:
 - “What are the charges against you?”
 - “What do these charges mean?”
 - “What is your attorney’s job?”
 - “What does the prosecutor do?”
 - “What does the judge do?”
 - “Why are you in court?”
- Avoid close-ended, single answer questions.
 - “Who is the judge?”
 - “Who is the attorney?”
 - “Do you understand that you are on trial?”

People with Fetal Alcohol are able to answer the close-ended questions and may appear more able than they really are. Questions must be phrased in a way to elicit as much information as possible, particularly in relation to the individuals real understanding of his/her situation.

A competency evaluation should include:

- An intelligence test.
- Measure of social interaction style and competency.
- Projective tests looking at emotional functioning.
- Screening for possible organic brain damage.

Capacity

Generally based on chronological age.

Those under the age of 12 are often considered unable to understand right from wrong.

Diminished Capacity

Refers to an individual over the age of 12 who “lacks the specific intent to commit a crime” due to his/her mental disorder.

PROBLEMS IN THE CURRENT SYSTEM

Punishment is delayed

Individuals with FASD have trouble connecting action and consequence, even when consequences are immediate. Delayed punishment is even more difficult for them to comprehend.

Community Service as a punishment

This sentence is often used with youthful offenders and is unstructured. An individual with FASD is likely to fail to meet expectations for community services and is sent back to court for more punishment.

Incarceration is seen as deterrent

Based on middle class values, incarceration is a deterrent, for folks with FASD, time spent in jail is just a holding pattern. They don’t learn from previous experience and are unlikely to change behavior just because they have been locked up.

Prison/jail environments and procedures.

People with FASD are overly impacted by external stimulation. Constant sound, light, smells, etc. overwhelm them and can increase negative behaviors. Involved people can’t control responses to

overstimulation and often end up in trouble. The physical management of prisoners can also be a problem. Many with FASD have tactile hypersensitivity so that touching, holding, restraining, etc. will send the person over the edge.

Individuals with Fetal Alcohol are highly vulnerable.

Folks with FASD can be easy prey for other prisoners. Poor judgment, inability to predict, desire to please and “belong” put the person at risk of use and abuse by others. People with Fetal Alcohol are also prone to model the behavior they see and hear. They are likely to believe what other prisoners tell them and are not able to realistically separate truth from B.S.

Jail time is only a holding pattern and discharge planning is not proactive.

People with Fetal Alcohol will not learn to change their behavior simply by being locked up for a period of time. Incarceration will protect society from the individual but will not teach a lesson or keep the person from committing another (or the SAME) crime. Jail time should be used to plan a comprehensive program to support the individual after release, Where will this person live? Who will be responsible for him/her? What kind of job training will be provided? Who is going to provide social/emotional support? If this planning is not done and if the needed supports are not available, the individual is likely to return to the behavior that landed him/her in jail in the first place.

Parole system.

Often results in failure for people with FASD. They are unable to remember and show up for appointment. Parole doesn't provide enough structure and assumes the individual is capable of monitoring his/her own behavior. They need assistance in all areas and, without it, they are prone to reoffend.

WHAT WILL HELP?

- Improved evaluation/identification system.
- Diversion track for special populations.
- Case management.
- More effective alcohol/drug treatment.
- Vocational and living skill training.
- Better training for staff.
- Appropriate alternative placement options.
- Early FASD identification.
- Primary prevention of FASD.
- Prevention of secondary disabilities for those with FASD. \

FETAL ALCOHOL SPECTRUM DISORDERS RESOURCES

BOOKS

Fantastic Antone Succeeds: Experiences in Educating Children with FAS (1993)

Fantastic Antone Grows Up: Experiences with Adolescents and Adults with FAS (2000)

Kleinfeld, J. & Wescott, S.

Anchorage, AK: University of Alaska Press. These readable books give poignant, instructive and often positive experiences of parents, educators, therapists and researchers with children, adolescents and adults who have Fetal Alcohol Spectrum Disorders.

A Practical Guide for Caregivers of Children, Adolescents and Adults
With Fetal Alcohol Syndrome and Fetal Alcohol Related Conditions

LaDue, Robin (2000)

Available through Indian Health Service Agencies

The Difficult Child

Turecki, S. (1989)

A useful book for caregivers raising children impacted by parental substance abuse and for children with difficult behaviors and unsuccessful coping strategies.

Fetal Alcohol Syndrome: A Guide for Families and Communities

The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities

Streissguth, A. (1997)

These books are suggested for all services providers working with this population, including mental health, education, corrections, health care and so on.

Trying Differently Rather Than Harder

Malbin, D. (2001)

This booklet was written to provide useful information, increase understanding of FASD, reduce frustration and develop appropriate intervention and prevention strategies.

Order at 1-503-621-1271 or www.fascets.org

The Out-of-Sync Child

Recognizing and Coping with Sensory Integration Dysfunction

Kranowitz, Carol Stock (1998)

This first accessible, clearly written guide to Sensory Integration Dysfunction offers a drug-free approach to problem solving and offers new hope for parents.

Building Bridges Through Sensory Integration

Yack, Ellen; Sutton, Shirley; Aquilla, Paula (1998)

A wonderfully organized and easily understood book on Sensory Integration Dysfunction
With great ideas and interventions.

FASD RESOURCES

Arc Northland
424 W. Superior Street, Suite 201
Duluth, MN 55802
218-726-4746
1-800-317-6475
lfrigaard@arcnorthland.org

FASD prevention and intervention training.
Advocacy and family support.
Respite care.

Minnesota Organization on Fetal Alcohol Syndrome (MOFAS)
1885 University Avenue W., Suite 395
St. Paul, MN 55104
1-651-917-2370
1-866-906-6327
info@mofas.org

Multiple FASD services.

Hayskids
63370 County Road 557
Cook, MN 55723
218-376-4501
<http://www.hayskids.com>

FASD intervention consultation and training.
Residential and therapy services.

Westbrook
9549 McCamus Road
Brookston, MN 55711
218-453-5021

Residential option for those with FASD.

Northland AFC
6580 Arrowhead Road
Cloquet, MN 55720
218-729-4857
northla2@aol.com

Residential option for those with FASD.

Pi-Nian Chang, Ph.D.
P.O. Box 44, U of M
420 Delaware Street SE
Minneapolis, MN 55455
612-624-9134

FASD diagnostic option.

Elizabeth Reeve, M.D.
Regions Hospital
Department of Psychiatry
640 Jackson
St. Paul, MN 55101
651-254-3456

FASD diagnostic option.

**FASD IN-SERVICE
Participant Feedback Form**

City: _____ Date: _____

Occupation: _____

Check all that apply (optional)

- American Indian/Alaskan Native
 Asian/Pacific Islander
 White
 African American
 Hispanic
 Other _____

We are very interested in understanding how this in-service has met your needs. Please take a moment to share your thoughts. This information will help improve our work.

How satisfied were you?	1. Very Satisfied	2. Satisfied	3. Neutral	4. Dissatisfied	5. Very Dissatisfied	6. Not Applicable
INFORMATION						
1. The information on how FASD occurs.....	1	2	3	4	5	6
2. The information about FASD characteristics.....	1	2	3	4	5	6
3. The information about FASD behaviors.....	1	2	3	4	5	6
4. The information about setting up environments.....	1	2	3	4	5	6
5. The information about discipline strategies.....	1	2	3	4	5	6
6. The information about sexuality issues.....	1	2	3	4	5	6
7. The presenter's knowledge of the material.....	1	2	3	4	5	6
PRESENTATION AND MATERIALS						
8. The length of the presentation.....	1	2	3	4	5	6
9. The quality of the program materials.....	1	2	3	4	5	6
10. The number of program materials.....	1	2	3	4	5	6

OUTCOMES

What influence, if any. Do you foresee this program having on your professional or personal life?

If a friend asked you about this program, what would you say?

What specific suggestions do you have for improving this program?
