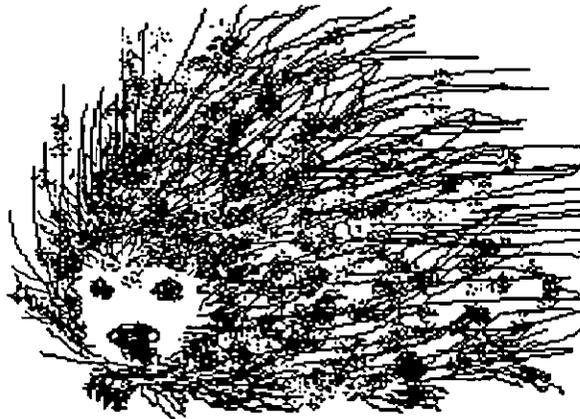


FAS / Special Needs Parent Training  
& Support Group Curriculum:  
"Parenting Your Porcupine" Series



Developed by  
Antonia Rathbun, M.A., A.T.R., LMHC

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## FOREWORD

This curriculum is dedicated to my daughters and my friends' children, young and grown alike, and to all the families and parents (adoptive, foster, birth, permanent guardian and kinship care), the children and adults with alcohol related disorders, and the caring professionals I've met as all our paths have crossed in the field of FAS over the past 15 years. I am thankful for everything you've taught me. I appreciate every one of you.

You make my day, each day at a time.

It has been a true honor to work with dedicated and inspiring people on this project. For research, clinical, administrative and technical support, I am extremely grateful to:

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*Antonia Rathbun  
Vancouver, Washington*

*September 27, 2002*

## FACILITATOR'S GUIDE TO USING THIS CURRICULUM

This curriculum is the basis for holding a psycho-educational course to teach families effective strategies for raising adoptive children with fetal alcohol syndrome (FAS) and similar disorders. It is not a typical support group, but rather a teaching tool that follows a structured group treatment framework. The overall goal is for parents to enhance positive attachment dynamics that support resilience in the parent-child relationship so that parents are better equipped to assist their child's adaptive coping. Recognition of the "culture" of cognitive diversity serves as the basis for expansion of anticipatory coping skills, symptom management and proactive communication patterns that can improve the family's ability to develop unique solutions to their own particular challenges and their child's specific symptoms.

Some parents will attend this group only; others will participate with respite providers , extended family members, or additional mental health supports for themselves and their families. This guide is intended to provide both general guidelines as well as specific suggestions for facilitating a successful group, based on over 12 years of experience.

The course contains four components, which are designed to be covered in 12 weeks (three weeks per theme). A list of supplemental readings are provided. A certain amount of homework, in the form of parent observations, is required. This is a vital part of the curriculum, and families need to be engaged to complete these assignments. It helps to be aware of possible learning differences among parents so that accommodations can be used where needed, ie. to tape record their observations vs. writing them out, etc. Modelling sensitivity to learning styles helps parents integrate such accommodations at home and is a powerful form of learning.

Please review all of the materials carefully, including this guide, before beginning the process of facilitating a group. And, if at any time you have questions regarding this curriculum, please contact: Antonia Rathbun at Childrens Center in Vancouver, Washington, 360-699-2244 (fax 360-699-1900).

### *Initiating a Group*

**Choosing facilitators** – Facilitators should be clinicians, such as a Master's level social worker or therapist, a psychiatric nurse or a psychologist. However, it is recommended that the clinician pair with a parent mentor, who has at least one year of adjustment after diagnosis to living with a child with FAS or other alcohol related condition. The facilitator may be a case manager with a minimum of five years experience with families of children with disabilities, and educational background with rehabilitation medicine or behavioral symptoms in children receiving special education. Experience working with children who have traumatic brain injury or other developmental disabilities may be more important than mental health training.

Advertising a new group – Group members may be referred from a number of sources, including schools, counselors, child development specialists, general education or special education teachers and administrators, the

mental health community, pediatricians and maternal-child health workers, and the larger public health community. Group announcements about the time, location, and purpose of the group can also be sent to Court Appointed special Advocates (CASA), state Social Service agencies, adoption permanency units, local parenting and adoption organizations, the Department of Developmental Disabilities, the Arc, the March of Dimes, Easter Seals and local Headstart or Early Childhood Education and Intervention centers, and the juvenile justice system. Information about the group can be placed in local newspapers and newsletters, and posted in public places such as libraries, grocery stores and childcare facilities.

**Referrals** – Participating families may be legal foster-adopt parents (after a completed termination of parental rights) with adoption pending finalization, permanent guardians, kinship care families, relative adoptions or post adoptive families. In concurrent planning situations where it is yet unclear if the child will be returned to the care of the biological parent, it is best not to have biological parents in the same group with the placement foster parents, to avoid ethical conflicts of interest. In the case of an open adoption, where the biological parents actively maintain an ongoing relationship with the child and the adoptive family, it is recommended that biological parents have at least 1 to 3 years of continuous recovery to enable them to benefit most from this course. Emotionally charged topics such as grief are confronted, exposing families to one another's varied emotional reactions which ebb and flow over the 12 weeks. Biological parents need support to maintain relapse prevention when facing their own and others' grief and anger in group. However, as parents ally to face these difficult and healthy reactions with honesty and compassion, the child's circle of support can strengthen, improving prevention and intervention options, and reducing risk of subsequent of prenatal substance exposure to the next generations.

**Create a waiting list** – As families call to register for the group, create a list until the group is full. Ideally, families should have to wait no more than 6 weeks before there is a group they can join. Reminder calls one week ahead, then two to three days before the beginning of group, help to ensure good attendance.

### *Logistics – Planning and setting up for a group*

**Location** – Ideally, choose a location that is central to the community and held in either a secure public or private space. Hospitals will often donate the use of conference or Community Education rooms. If your own agency has a conference room, that may also be appropriate.

**Room arrangement** – Chairs around a table offer the most convenience, enabling people to write easily or put things down. Offer simple beverages, such as coffee and tea.

**Materials/handouts** – Each section of the curriculum comes with supplemental reading. For additional materials, please see the appendices, and the bibliography.

**Time** – Evenings (6:30 – 8:00 p.m.) seem to work best for most families, with Mondays through Thursdays the best days.

**Confidentiality** – All members need to understand and respect the need for confidentiality of the meetings and the discussions/disclosures which take place. This concept is introduced in the curriculum and discussed the first session to emphasize its importance. The meeting room is kept closed and private while group is in session, so that participants are free to speak openly. The smaller the community, the more vital that all participants appreciate and practice respect for one another's privacy.

**Accessible space** – It is important the meeting space be physically accessible, as many caretakers may be grandparents who have physical limitations.

**Childcare** – In our experience, it is not advisable to offer on-site childcare. Children who have the types of disabilities represented by FAS rely heavily on a consistent routine, which cannot be maintained in a childcare situation. For families who were unable to obtain at-home childcare, their parents would often participate in the groups in succession, one parent taking it for 12 weeks followed by the other parent taking it the next time. When two different groups were offered during the same 12 week period, parents often came on different evenings.

### *Putting together a group that works.*

**Intake from the agency** – It is important to have an initial phone call with each potential group member to ensure that the group they wish to attend is appropriate for them. For example, if the intake determines that either a parent or child is in an acute situation at the time, then you would want to defer their participation until the crisis has been resolved. (See appendix for examples of intake forms.) Once you have cleared a family to participate, apprised them of informed consent and secured consent to treatment, obtain the necessary legal releases and coordinate with any other therapists or concurrent providers of care. It is best to be aware of your regional administrative codes as well as federal regulations, such as HIPPA (Healthcare Information Privacy and Protection Act) in order to honor confidentiality requirements of participants. It is not unusual that group members might seek your assistance with advocacy or collaboration with existing providers, necessitating completion of person-specific legal consents to permit release of private information (pertaining to either the child's if under age 11, or the parent)..

**Size** – Groups work best with a minimum of 5 participants and a maximum of 12.

**Time use** – Groups benefit from a 3 minute check-in from all members, which enables the facilitator a glimpse of emerging concerns that may be a priority for therapeutic intervention, and provides parents who may have particular urgent issues to ask for extra discussion time from the group. Check-in should be brief, a few sentences at best, to allow all group members to be acknowledged and still maintain a focus on the curriculum

as the course is psycho-educational, and functions differently than a process group. At the end of group, ask each participant to check-out by describing one positive characteristic of their child. The idea is that parents get used to airing concerns over problems, yet practice focusing on the child's strengths and positive qualities to help parents engage in cognitive restructuring. Burnout and compassion fatigue involve depression, with attendant black and white thinking, stimulus augmentation, and affective constriction. Listening only to the disappointment will not help parents back towards balance, though considerable venting is needed. After venting, focusing them towards gratitude and strengths actually helps them regain resilience and perspective on their situation. Ending each group on a positive note is of crucial importance for these families. Many comment later how this skill was internalized from the group, and proves so useful it is internalized into their maintenance habits over time.

### *Using the curriculum –*

Reading though the text – It is helpful to read aloud select handouts. Group members often read a paragraph and pass to the next person to keep everyone involved. Comments amidst the reading may deepen the group process, however, it is wise to keep some members from monopolizing by maintaining focus to the topic at hand. There is time in check in for parents to indicate need for process time, and group members need to respect one another's time by reducing tangential monologues. Group members who tend to monopolize or think out loud after every comment may benefit from getting together with another parent separately for coffee during the week, or initiate a phone buddy to have deeper conversations with, or use an FAS Parent Mentor's help to download grief or other reactions wherein more support might be needed for a period of time.

Choosing additional materials to prepare – Many texts from the bibliography have proved helpful. The Select Bibliography in the appendices lists some of past group members' favorite picks.

Audio visuals – Videos can be helpful when parents need real-life examples.

Video segments can help where parents have learning disabilities, ADHD, and other conditions that interfere with processing the written curriculum. Also, parents range of learning styles and need of information in various channels can be acknowledged, discussed, and provides more practice in applying accommodation logic that can be modelled and shaped in their parenting. What parents are used to is professionals dictating to them what is right, and it is less common that parents will have self-advocacy skills for expressing their needs and preferences – thus, by learning more and getting more from accommodations to help them practice the principles in the course, they are actually rehearsing skills sets to pass on

to their children as needed. Parents found these videos so helpful, they often checked out the films to share with extended family, their child's teachers and other school staff:

Videos for parents and professionals accompany this curriculum, Also the first person "Interview with Beka McConnell" video.

"Worth The Trip" by Vida Health Communications.

"Journey Through the Healing Circle" Video series from the State of Washington DSHS Resources Division.

Parent log – This a vital part of the curriculum which asks parents to make their own observations of their child. It is intended to help them organize and validate what they already know about their child's behavior, and enables them to put it to work. This decreases a parent's sense of learned helplessness, that there is nothing they can do to help their child. It rebuilds resilience and parental confidence, and reframes complaints about a child into a parent's knowledge base. As Dorothy Beckwith eloquently describes in her poem about parents and professionals, the difference in power and role can have a negative impact on parents: "I see, they *observe*". The log elevates parent perspectives into organized "observations", which helps concerns register with people less familiar over time with the **differences in intensity, frequency and/or duration** of symptoms that appear as behavior.

The following are some of the questions which are often asked by parents during the course of a 12-week group, and suggestions on how to answer them.

**Why don't verbal explanations work (or what part of the brain does that)?** Logic and reasoning are the work of the frontal lobes. Alarm, arousal, calm and emotional regulation involve the mid-brain area, where emotion and response may be coordinated and responded to via two separate pathways involving different brain systems. One of the pathways involves the prefrontal cortices where reasoning still occurs. The other pathway activates reflexive responses run by the mid-brain's systems that handle alarm and fight or flight reactions.

Learning disabilities, gaps in processing across various linked systems, are not all found in one area of the brain. When a child experiences a "bristle attack" it is as though the logical part of the brain (frontal cortex) stops responding for a while. It cannot respond. Instead of persisting to try and get that part of the brain to respond, just try to calm the mid-brain instead. When reasoning returns, pace your interaction with your child more slowly than usual.

(Neuroscientist Joseph LeDoux uses the analogy of a person walking through a forest as dusk turns to dark. Walking along, the person sees a black line across the dim path, and before he knows it, jumps back three feet. Why? His brain is "wired up" to make a "quick and dirty" assessment: stick or snake? If it's a stick, jumping won't hurt or help him, except he may not trip over it. However, if it's a snake, the reflex just saved his life

because the snake might have struck and bit him. Therefore it is adaptive that his brain performed a rapid, course assessment and defaulted to the reflex pattern of jumping away, rather than using a more detailed search and comparison involving the frontal cortex's judgement and reasoning systems which would have taken 4 times longer. Did he have the extra time to spare? Again, when it's a stick, yes; but with a snake, probably not. This example shows a main difference in the brain's 2 routes of processing, which are really there to provide the proper route under the proper circumstances.)

Though research has not yet identified what exactly may be happening for children with alcohol related disorders when regulatory and information processing capacities are compromised to varying degrees, the analogy above is useful in that small things seem to set off some large reactions in the children. Routine stressors are not read as routine, and their stress threshold for stimuli can become exceeded. Adding language adds stress because logical problem solving centers are offline during stress episodes.

**Where do I go for a diagnosis?** (Have a list of local practitioners available, using positive comments from other parents as a guide.)

**Why does the school say my child doesn't qualify for an IEP?** Traditional psychological assessments are a one-shot deal; many of your child's most troublesome symptoms wax and wane over the course of a day or a week. The school can't see what you see. The parent log is your documentation of your child's needs.

**How do I get my child to take personal responsibility?** To take responsibility assumes an ability to respond. Most children with these problems lack the consistent ability to respond. It's not that they won't (or don't want to), it's often that they cannot respond as evenly, consistently and proportionally as adults expect, especially where insightful action, judgement, social and self-help skills are involved. Parents may find it helpful to focus on improving the child's help-seeking (self-advocacy) skills, so that as problems occur over time, they become comfortable with seeking out auxiliary assistance.

**His teacher says he has ADHD and that we should take him to the doctor for medication. Is that common in children who were exposed to alcohol or drugs during pregnancy?**

Yes, however medication and/or a diagnosis of ADHD may not be Parents can get caught in a crossfire of opinions because:

Each field uses a different approach to a set of concerns, though other aspects of the diagnosis need to be taken into consideration. Plus, each field uses distinct terminology, categories of classification or descriptions of concerns and what improvement would mean.

Parents feel responsible to make decisions on treatment direction based on new information, still being unsure of various terms, their own goals, and/or how such an approach might work with their child or family. If unfamiliar with the concepts and practices in a certain field, for example, beginning a trial of medication, or taking their

child to occupational therapy, they may gain a general idea but still not have a clear picture of how this relates to their child's struggles at home or school.

Professionals with short appointment times due to managed care have to keep things brief, and may miss what is different about the intensity, frequency or duration the parent is trying to explain. They are used to seeing many conditions and may miss more subtle details suggesting a different starting point in medication regimen, i.e. is the target of the medicine to reduce hyperactivity, or anxiety that drives restlessness and sleep disorder, or other tough choices.

**I don't want to hear other parents complain. It's hard enough for me to keep going...do I really need to come to group?**

Voicing and comparing experiences with others facing similar symptoms normalizes frustration of effort, loss of confidence, and increased defensive coping styles, which are common sequelae to the demands of exceptional parenting. Validation of these responses carries the immediate therapeutic benefit of decreased emotional isolation and improved reality testing to help offset compassion fatigue. Likewise, the facilitator will want to keep in mind that:

Parents benefit when professionals describe what happens, or what a child's behavior looks like, sounds like, etc., in clear common language. Parents see the child around the clock and have the most time-span information. They aren't used to seeing this as 'data' or asking others for theirs in plain language. When a professional sees something different, they can feel dismissed or discounted. Often parents ARE being dismissed or discounted. However, even when this occurs, the solution involves comparing actual simple information in plain terms to find out what kind of response a child is having to varied environments. Parents may try to use common behavioral interpretations such as "oppositional", "passive aggressive" or other descriptors, not wanting to seem unfamiliar with common theories about child behavior, motivation, etc. The problem comes when the terms may capture one part of the actual data, but omit others, such as the blank looks, headaches, tactile defensive reactions, or confusional states that may co-occur with episodes of aggressive or regressive reactions.

**My child's counselor told me "all children do that". Is this true? I never did that when I was a child...**

Professionals may comment, "all children do that" or "that is pretty normal for his age". Parents are struggling to describe that **over time**, the **frequency, intensity or duration** of the child's symptoms may be what sets it apart. **There is no better source for 'data'.** **No test measures fatigue, confusion, and behavioral deterioration or disorganization quite as accurately as what is seen during a routine day or routine weekly period – a time span view.**

## **SUMMARY OF CURRICULUM TOPICS**

### **Topic 1 – Introduction: “My child has... and I’m ready to... !”**

Normalizing experiences of raising children with prenatal exposure: participants share stories about parenting. Introduce concept of diathesis and stress sensitivity; behavior as key to seeing brain function at work. Discuss group rules, parent expectations of the curriculum materials, and begin group process.

### **Topic 2 – Parenting “Porcupines”: Patterns Over Time**

Parents share examples of good days and bad days at home and in school. Common symptoms in routine conditions show “hidden” stress threshold leading to behavioral deterioration, irritability, non-compliance, fatigue, “blow-ups” and “shut-down”. Parents discuss typical recommendations and interventions, idiosyncratic responses to medication, ongoing struggles with prolonged poor regulation, tantrums, broken belongings, head banging, and other extreme reactions. Parents identify challenges to child’s “stress threshold at home and school.

### **Topic 3 – Diagnosis: FAS Spectrum Disorders & Drug Effects**

FAS Spectrum disorders with a range of neurodevelopmental symptoms may be “hidden” or and overlap other childhood psychiatric or developmental disabilities. Common differential diagnoses and co-existing conditions are discussed. Parents are introduced to professional terms they may encounter trying to communicate about their child’s abilities over time, with doctors, psychiatrists, counselors, educators, and special education staff. Parents discuss child’s history and characteristics.

### **Topic 4– Diathesis: Relief, Grief & Resolution**

Common reactions and stages of adjustment involve cyclic relief, grief, and resolution. Case examples of living with alcohol-related disorders are explored to show how diagnosis guides coping strategies that help children and their families compensate and enhance capacities. Emotional reactions accompany recognition of diathesis over time. Patterns of chronicity and “anticipatory coping” tools offer perspective on raising a child with symptoms that wax and wane, changing with the life span.

### **Topic 5 – The Stress Map: 3 Key Signs & Strategies**

The Stress Map is used to identify child stress indicators when internal and external factors converge resulting in patterns of behavioral deterioration. Parents build a Stress Map to track the flow of stress signs: they “see” stress and start to shift approach to the intensity, frequency, or duration of episodes. Homework logs provide real examples from everyday life across different ages and ability levels. Brainstorming solutions to match stress levels helps parents choose their battles. Focus is on crisis de-escalation, restoring equilibrium from fatigue, headache, and other physiological symptoms prior to problem solving (staged approach to restoring equilibrium, then verbal or non-verbal communication, followed by reasoning).

### **Topic 6 – Family Support: Talking with Your Children**

Children with alcohol-related disorders struggle with a health condition, not of the lungs, but involving the brain and its tasks: FAS is not “who they are” it is what they have, and it isn’t everything about them. Parents explore supporting the child through recognition of FAS using verbal and non-verbal

communication tools for addressing feelings, grief and resolution, and focusing on strengths. Parent review patterns of stress with their children that may need adjustment, accommodation or more structure in light of children's comments, sharing ways to rebuild rapport with the child.

### **Topic 7 – FAS Accommodations and Environments**

Adjusting various aspects of the environment begins with understanding how these can impose or reduce stress, especially for children with brain disorders. Parents assess their own initial reactions as children experience stress, in order to simplify and revise their own stress reduction tools. Examples of how diathesis stress technique is applied in other learning environments helps parents participate actively in the continuum of intervention, sharing with others what has been successful at home. Observation, preparation and patience can help parents collaborate with others in their child's circle of care.

### **Topic 8 – Parenting for Resilience: Anger to Awareness, Roles, Rules and Expectations**

Parenting doesn't come with a manual, especially when raising a child with special needs. Caregivers are at higher risk for burnout. This state of physical and emotional depletion signals depression, is also known as "compassion fatigue" and is treatable! Excessive demands of round-the-clock care eventually wear out the primary caregiver (not related to weakness or lack of character). Parents assess themselves for warning signs and learn tips for restoring resilience. Healing burnout and restoring resilience involves building a tool kit of various cathartic and self-care activities. Parents pick and choose what is most compatible with their own wellness beliefs and practices. Parent actions "speak louder than words". Discovering how past roles, rules and expectations shape values and actions helps parents sort out what to build on, and what to let go of in parenting children with special needs. Exploring the role of anger in parenting allows modification of beliefs about how to provide, nurture, and protect with regard to developmental expectations. Parents discuss solutions to over- or under-reacting.

### **Topic 9 – Advocacy: Reaction to Action!**

Parents find themselves translating between the world of their child's stress sensitivity and the demands of learning and vocational environments. Systems negotiation requires more than parental conviction, as the varied systems each have inherently different structures, purposes, procedures and personnel. Informed advocacy involves identifying missing information, hidden blame or defensiveness, and creating alliances out of support for the child's success rather than personal vindication. This is especially challenging while still healing from grief and compassion fatigue, and involves patience, assertiveness, and concrete information that is easily understood across varied systems languages.

## INTRODUCTION for PARENTS: WELCOME!

*Welcome to the FAS/Special Needs Parent Training & Support Group curriculum. Following this curriculum is like learning how to “parent your porcupine”. In the wake of adopting a child with prenatal alcohol or other drug exposure, you may have figured that some of the stuck or extreme behavior would ease once he or she felt more at home with your family. That what you were seeing might finally resolve with time and a consistent home life, with choices and opportunities to grow and understand healthy family roles and rules. Yet despite your patience and good enough parenting, you’ve noticed that your child gets upset over things others just take in stride, or that certain things seem to “set them off” or cause them to “go ballistic”, just “loose it” or “shut down”. If the child were a porcupine, it’s like watching a “bristle attack” – when bristles go up, you can’t reach in with words or explanations, or even touch, because when you do, they ball up tighter and it gets worse! How do you soothe someone having a “bristle attack”?... how can daily life go smoothly when bristles go up over every other thing, especially when such minor changes are known, familiar, ordinary or routine adjustments? What makes them swell into dramatic catastrophes!? How do you handle the child when typical efforts to ease upset, confusion, or misunderstanding set them off even more? What is happening? What will help?*

*If this seems familiar, take heart. You are not alone. You are not a bad parent. It is NOT your fault. Nor is the child to blame. What comes at you may “get your goat” but it is not necessarily aimed at doing so. The behavioral disruption may leave you feeling ragged and empty, or stuck full of bristles for no clear reason. What for? Though it is natural to dissect the issues, or wish to reason things out with your child, bristle attacks are simply not a “fault” or “blame” kind of problem. Bristle attacks can be part of a hidden physiological mechanism related to brain development that was destined to surface once you and your child started down the road of becoming a family. Feeling lost, you may not have realized the parenting terrain changed into parenting in “porcupine country”. If you were looking for the family resort with all those typical tourist pictures, you may want to turn in your tanning coupons and get your thick leather gloves. Or maybe you did that long ago and now need some other new gear for the rough back roads. This curriculum works like a catalog of concepts from which to select key ideas, use what helps, and leave the rest to review and consider over time. Regardless of any books or advice, you do know a lot about what helps you and your child. However many parents hit a point where they feel so confused and exhausted they lose their parenting bearings completely.*

*This curriculum cannot give you an exact route to where you and your unique child will go – BUT, it will give you tools to define your location, read the terrain you’re in, refuel your supplies for the journey, and provide you a compass to help you remain able to navigate towards a destination you and your child can both benefit from. As research on intervention with FAS is still only beginning, some 25 years after this syndromal condition was formally defined in the medical literature, there is not a cookbook on “what to do with kids with FAS”. Some of us believe there never will be, as each child’s brain is unique as a fingerprint, and remains plastic (changeable to some degree), a mix of compromise and capacity. Compensatory functioning can be encouraged or clouded by how we relate to the basic systems and how they are working.*

*For now, the curriculum is simply “one way” that has proven initially promising. Comparisons are not yet possible without considerably more prospective study in clinical populations.*

*This curriculum reflects 10 years of dialogue with adoptive, foster, biological, relative or kinship care and permanent guardianship families, as well as a variety of professionals from medicine to counseling and education who have experience with these children. We find so many children with alcohol / drug exposure have similar problems: inability to consistently regulate behavior despite routine or familiar circumstances, sleep problems, poor grasp of cause and effect, learning differences and other familiar symptoms that discouraging to parents and children alike. This is a challenging parenting landscape. Some of the stories and examples may seem so familiar you'll wonder if these people were living at your house, with you and your child. Though each child is unique, there are many common experiences shared by families when they come to the curriculum group for alcohol-related disorders. There are things that help, and ways to handle what can't be helped. Parents may feel worse, at times, because there are no quick fixes, yet ultimately better as time goes on, because this information will change how to work with what you know about your child. It's a little like waiting to get a puppy, then a lonely porcupine arrives. You bring them in.... but what to do with all these quills? It's just...so different! A big part of the adjustment is recognizing a porcupine when you see one (despite how much you've held out for a puppy).*

*This method is designed to help you develop specific skills matched to your child's symptoms, to help you parent differently, not harder. This is not about "the right way" or even "the best way", because there is no one scientifically proven method that "works" with alcohol related disorders or other drug effects due to the many ways the symptoms show and how severe or mild they are over time and growth. What research tells us about children with Fetal Alcohol Syndrome and the spectrum of alcohol related disorders is that though children may have some similar challenges, there is also a wide range of variation in their neurodevelopmental and neurobehavioral symptoms that are constitutional, in addition to maturation and environmental factors that can either help, or further hinder their course into adulthood.*

*Each child is a child first, with various symptoms to be managed, which vary in intensity, duration, and frequency when compared with their age mates. If typical methods resolved the greater intensity, duration, and frequency of problems, families would not have sought out this course. Most have tried time-tested approaches that work for most children. Unfortunately, the behavioral strategies often suggested, such as star charts, natural consequences, and other methods based on insight and reflection, though very useful with typically developing children, may have limited effect, at the least, or at the worst, actually exacerbate problems for children with FAS. Increasing expectations for uniform performance or consistent competence is inherently stressful for people with an organ that functions off and on, in a variable way. It happens that the organ we're talking about is the brain, and the brain is "traffic central" for the vast signal load between the inner personality and the external reality of life in a human body. Symptoms like somatization (showing one's upset through physical distress) are common in children with brain damage or neurological disorders. Parents report initially feeling hopeful about "making this troublesome behavior go away", soon followed by grief and loss over what to do to control behavior through typical means. It is very demoralizing to parent confidence when good methods appear to make things worse....what could be happening?*

*What works for one child with alcohol related disorders could be completely different from what helps another, even in siblings with the same disorder, because of individual differences in neurobehavioral functioning. A number of factors have impact on the severity and expression of prenatal alcohol or drug exposure symptoms, and outcome. That is why this course focuses on a basic method for sleuthing out key signals shown by each child, as a predictable pattern of "hot spots", stress signs that signal need for adjustments beyond those that seem sufficient for other's their age. This stress mapping system helps in*

*developing a better match of interventions to adapted and upgrade as the child grows up. . Professionals may be able to help, but parents are the only ones with the close up and personal view, the daily data, to sheds light on a child's vulnerability to stress-related episodes of deterioration in basic skills. Though there is no "cookbook" for parenting these children, certain key signals become main ingredients for stress mapping and accommodation as your child grows up.*

*Families have different lifestyles, customs, traditions, other values, and beliefs that shape their lives accordingly. Cultural models about "healthy" vs. "dysfunctional" families have tended to overlook the adaptive nature of some interaction patterns, unnecessarily pathologizing fairly typical adjustment reactions to the stressors of coming to terms with a loved one's chronic condition, whether the condition is medical, developmental, or psychiatric. Without cultural images of resilient families coping compassionately, though not easily, with chronicity in a child or loved one, parents feel isolated as well as scrutinized, and even blamed for various manifestations of their child's "invisible" disability. They are inadvertently shamed or dismissed for trying to help their child with a subtle brain disorder remain able to cooperate and participate. For example, compassion and anxious questions about the future are typically misinterpreted as overcontrol or overanxious parenting (pathology), while the real risk of increased burnout (signaled by increasing symptoms of clinical depression, confusion, irritability, diminished self-worth, catastrophic expectation for the future)) is overlooked and untreated in parents.*

*Parents don't say, "I have compassion fatigue from providing exceptional care" when showing symptoms of depletion brought on by appropriate concern and response to loved ones with sleep, mood and/or behavioral abnormalities. Until our culture values compassion as highly as assertiveness and self-interest, those who do the work of caring will also be subject to snap judgments, dismissals, and negative stereotypes that make demands for exceptional care feel even heavier. For this reason, parents are urged to notice how much has already been accomplished despite setbacks, well-intended but misguided advice, or lack of access to information that might have helped them. Parents deserve credit for having hung on where others did not, would not, or could not. Being present in their child's life despite the many barriers has often been a constant uphill row -- no small thing!*

*These materials help parents organize existing information that may have slipped by or accumulated, unrecognized. The goal is to help parents meet children with Alcohol Related Disorders where they are, instead of where parents (or teachers) think they should be. The goal is to improve the fit between the child's adaptive capacity and parental (teaching) opportunities to expand it. Parents of porcupines know that the standard "30 days to a perfect pet" book has to go. Time-tested methods work for a great many people...just not that well for these people.*

*Parents will learn about handling a form of chronic condition that "waxes and wanes", changing as the child develops. Parents already have a wealth of knowledge about the good days and bad days with their child, the bristle attacks, and the sweet days when parents say to themselves--  
"...he's really just like any other child, he's not THAT bad...maybe he really doesn't have an alcohol-related disorder after all", only to say exactly the opposite later: "What if he's STILL doing this when he's sixteen! He MUST have FAS, because nothing works! He's destroyed his whole bedroom and says I'm to blame!"*

*That said, parents are urged to use this information like a buffet: take only what is needed, and leave the rest. Each family's pace is what guides use of the material. Parents know their children best, because they live with them 24 hours a day, seven days a week, 52 weeks a year, day in day out. If the parent were a nurse or doctor working this shift around the clock, no weekends, vacations, sick leave or paycheck, would loved ones, friends or people out in public be as likely to cast the critical eye or make comments?*

*Parenting a child with FAS or alcohol-related disorders is something many people, even close family and friends, may not fully understand because they have not lived it OVER TIME. Parents need to rebuild trust in themselves, make the changes that improve their own and the child's quality of life regardless of others' opinions (whether personal or professional). If something doesn't work, parents may have to adjust it, adapt it, or drop it, according to what best fits their own family culture.*

*A last word: mistakes are truly the main way of finding what to let go of or what seems to work. This applies to parents, and the professionals they may work with, as well as the children. So far:*

- ⇒ Every parent wishes at some point that they would have understood sooner about what prenatal exposure had meant, in terms of the brain and behavior (so do ethical professionals).*
- ⇒ Every parent goes through an adjustment period, with regrets and grief, wishing they'd known what couldn't be known until it is known (so do ethical professionals). That seem to be the way life works.*
- ⇒ Every parent recycles that energy into advocacy on the child's behalf at some level, home, with extended family, friends, school, church, etc. So do ethical professionals.*
- ⇒ Every parent experiences eventual return to a family life larger than FAS. The focus will shift back towards being a family, like any other and will not always have it's related issues on the front burner at all times.*

*Acceptance is learned a piece at a time. Compassion is needed at every turn when navigating forward in dialogue with others as the child's advocate. Gracious interpretation is encouraged: for another's heart to hear, their mind needs to be still and listen. This may take a long time, and parents, even the best parents, who want to provide for, nurture, and protect these children, may feel intense need for others to "get this" when they do. The course also speaks to this reality and ways to improve collaboration as advocacy extends to such a broad range of systems, each with different perspectives, terms, and procedures. These children are a call to the everyday practice of deep listening (to the meaning, not the words) and compassion (acceptance without control). Because they live, we all learn. Some parents wake up one day realizing that they've fallen back in love with their lives, and shifted out of humiliation or regret over adoption, to seeing the child with FAS as a special gift – someone who they could only truly meet by making changes that brought deeper meaning to the rest of life.*

## GROUP RULES

**Please plan to attend all sessions.** Each group covers lots of material, generally in sequence. Call the group leader if you can't come.

**Confidentiality:** *"What you see here, what you hear here - when you leave here, let it stay here!"* Respect the privacy of others, as you wish them to respect yours. This is a place to let down; if you have concerns about your own or others' participation, please discuss them privately with the group leader.

**Allow room for differences and disagreement.** Imagine an invisible basket in the center of the room. Everyone is free to put ideas in. Take with you only what you need, and leave the rest. Others are free to do the same. It is not necessary to have consensus on discussion topics.

**Please abstain from all use of any mind or mood altering substances (unless prescribed by a doctor) throughout the 12 weeks.** If there is any difficulty with this, please talk with group leader after session. (See Appendix for further explanation).

**If you are a "talker", practice leaving room for other's sharing.** When sharing, respect the group's time. If you have trouble over talking, use 3-5 min. then stop for feedback.

**If you are a "listener", stretch into your discomfort by talking more.** Strengthen advocacy skills by practicing talking in group. Even if you think you "don't know what to say", open your mouth. Something will come out, as most people, even shy ones, haven't been known to sit long with their mouths hanging open like that. It's just a natural thing.

**There is no one right way to raise children with Fetal Alcohol Syndrome or other alcohol-related conditions, or drug effects.** *Everyone grows at their own rate.* Be patient with your self and others. Mistakes are not the end of the world, they are just mistakes: something we now know we prefer not to repeat if possible. Again, *be patient* with yourself and others. We all know this is harder parenting than most!

## GLOSSARY OF TERMS

**Alcohol-related neuro-developmental disorder (ARND)** – a term used to describe the central nervous system problems resulting from alcohol exposure during pregnancy.

**Alexithymia** - loss of ability to identify specific emotions to serve as a guide for taking appropriate actions can occur with a variety of brain disorders, and with brain changes from trauma. Inability to link language to specific physical states is related to aggression against self and others (Krystal, 1978).

**Alzheimer's** – a disease in which the brain loses memory and other abilities it once had, usually occurring in people over age 60.

**Anosognosia** – a condition in which the patient literally does not know the obvious deficit exists despite evidence of it. This is often associated with lesions in the non-dominant hemisphere.

**Anxiety disorder** – *fear or concern about events or activities that would not ordinarily cause concern, sufficient to interrupt a person's ability to function normally day to day.*

**Aphasia** – an acquired inability to use certain aspects of language. Aphasia can be either an expressive or receptive language disorder that impedes understanding of the spoken or written word.

Example: A child with *fluent aphasia* may “talk all around the word” (circumlocution) or speak in pictures, saying “the pull-over man”, unable to access the noun “policeman”.

**Apraxia** - when seen in children, the lack of motor planning that interferes with imagining and sequencing motor movements to carry out a physical task. This may impede either the fine motor (hands & fingers) or gross motor systems (arms, shoulders, neck, torso, hips, legs). Thus, they can picture something done, but not necessarily, the steps needed to accomplish the task, or the action sequence to follow.

**Dyspraxia** – poor motor planning and coordination of motor activity.

**Attention Deficit (hyperactivity) disorder (ADD or ADHD)** – A condition in which a person has difficulty keeping themselves focused on a activity for any length of time. Some people also have difficulty keeping their body quiet, which in turn, interferes with the ability to focus.

**Auditory** - pertaining to the sense of hearing.

**Auditory defensiveness** - oversensitivity to sound; also termed *hyperacusis*.

Example: "He interrupts constantly asking, 'What was that?', over the littlest noises none of the rest of us can hear. Some really bother him."

**Autism** – a family of developmental disorders in which a person has difficulty making appropriate social connections to others. (Also known as Autistic Spectrum Disorders)

**Autonomic Nervous System** - Also called the involuntary, or visceral nervous system, it has two branches: the sympathetic and parasympathetic nerve fibers. These branches work opposite one another to “automatically” adjust activity between the brainstem (spinal cord) and internal organs through chemical signals read by muscle, gland, or brain cells. Each branch uses different chemical messengers signaling and balancing one another as the body shifts through changing states of activity from resting states to high

exertion. Our ability to adjust to our surroundings is usually not conscious. We take notice only if we are unable to coordinate bodily responses with actions to master environmental demands around us. For example, when stepping forward to walk, think of having to consciously work at how to keep your head from falling backwards as you picked up one leg and moved it.

**Blood alcohol level (BAC)** – A measurement of how much alcohol is in the blood stream, as a way of determining how much alcohol someone has consumed. For example, a 130 lb. woman who has 1 drink (consumed quickly) (1 beer, 1 glass of wine, or 1 shot of hard liquor) would have a blood alcohol level of .40 or 40 milligrams percent about one half hour after she drinks it.

**Body image** (body schema or percept) - a person's mental perception of his/her own body. It consists of sensory pictures or "maps" of the body stored in the brain. The map is continually being updated by real-time information from the Autonomic Nervous System to the Central Nervous System.

**Brain stem** - the lowest and innermost portion of the brain (top of the spinal cord), it regulates internal organ functions, arousal of the whole nervous system, and elementary sensory-motor processing through communication from branches of the autonomic nervous system.

**Cerebellar hypoplasia** – referring to underdevelopment of the cerebellum in the brain.

**Central nervous system** – the brain, spinal cord, and nerves of the body, and all of the interconnections between these parts

**Cerebellum** – the region just above the brainstem, which controls coordination and movement, behavior and memory.

**Basal Ganglia** - affects spatial memory and behaviors including perseveration, rigid cognitive set (the inability to switch modes), ability to work toward goals, ability to predict behavioral outcomes, and the perception of time.

**Frontal Lobes** - control impulses and judgment. Individuals with Fetal Alcohol Syndrome (FAS) and related disorders often have symptoms or behavior issues that are a direct result of damage to the prefrontal cortex, the part of the brain which controls "executive functions": organizing, prioritizing, and applying complex information in varied combinations, or alternating, sequential, or parallel patterns over time.

**Cerebral cortex** - the outer layer of the cerebral hemispheres, also known as the neocortex; its lobes or regions are involved with precise sensory processing: visual and auditory details, sensations from the body, fine movements, voluntary body movements and speech, thoughts, and mental evaluations and goals.

**Cerebral hemispheres** – are the left and right sides of the cortex, in which four lobes govern specialized functions. The **frontal lobes** make up the "command center", that oversees decision making and other executive tasks; the **occipital lobes** process vision; the **parietal lobes** analyze sensation; and the **temporal lobes** orchestrate hearing, understanding speech and forming an integrated sense of self.

**Corpus callosum** – a band of fibers that connects and allows for communication between the hemispheres (halves) of the brain. Agenesis of the corpus callosum is a term used to mean that this structure is missing, or greatly reduced in size.

**Environmental control** - a neurobehavioral approach that focuses on reducing or removing external factors that may cause inappropriate behavior, such as noise level, number of people, length and timing of demands that stress the functional threshold.

**Ethanol** – the chemical name for alcohol.

**Executive functioning** – functions that come from the frontal lobe of the brain, and control a person's ability to reason and plan their behavior

**Fetal alcohol effects** – 1 or 2 of the signs seen in fetal alcohol syndrome, most commonly central nervous system abnormalities.

**Fetal alcohol syndrome** – a specific cluster of birth defects (changes in the facial structure, slower and smaller than average growth patterns and central nervous system abnormalities such as behavioral disorders and learning disabilities) that result from a mother's alcohol use during pregnancy

*Functional skills ability* – *The ability to take information or knowledge (assessment) and apply it to daily life.*

**Gestation** – the length of pregnancy. A typical pregnancy is 38-42 weeks long.

**Gestational age** – the number of weeks of pregnancy at the time of birth. A baby can be appropriate size for gestational age (AGA) or small for gestational age (SGA). A baby who is smaller than expected for the length of pregnancy is considered at risk.

**Head circumference** – a measurement of the outside of the head, used to determine how the brain is growing.

**Hippocampus** – an area of the midbrain, which plays a fundamental role in memory.

**Hypothalamus** – also in the midbrain, this region controls appetite, emotions, temperature, and pain sensation.

**In utero** – Latin for “in the uterus”, or during pregnancy.

**Information processing** – the brain's ability to intake information from the world, store it for future use, combine it with other information, and apply it in the right situations.

**Inhibition** - a neural process that reduces excess neural activity. Inhibition performs the important function of reducing the conductivity of certain synapses so that some impulses are blocked.

**IQ** – short for intelligence quotient, a method of measuring how much a person knows and understands.

**Learning** - a change in neural function, which etches synaptic activity (circuitry) into the brain as a result of experience. Information is stored as neuroelectrical patterns that fire together linking activity across different regions.

**Lesion** – a general term for any defined area of the body that is changed or damaged from the way it should be, as in a cut or wound.

**Microcephaly** – head circumference in the lowest 3% of all babies born. This measurement is used to describe smaller brain growth than is typical for the person's age.

**Modulation** - the brain's regulation of its own activity. It involves letting some neural messages through to produce more of a perception or response, and reducing other messages to reduce excess activity.

**MRI – Magnetic Resonance Imaging** – a test which magnetic energy in the body is used to provide an image of various internal organs, such as the heart or brain.

**Musculo-skeletal** – Referring to the system of muscles and bones in the body.

**Neurobehavioral** – Behaviors that originate from brain structure, as opposed to behavior that is chosen or willful.

**Neurochemical** – involving chemical activity of the brain.

**Neuroelectrical** – involving electrical activity of the brain.

**Neurological** – having to do with functions of the brain and its connections in the body.

**Neuron or neuronal** – referring to nerve cells; the cells in the central nervous system which conduct electrical impulses and allow information to be communicated in the brain and spinal cord.

**Neurotoxin** – any substance that can affect brain development and function if it is ingested.

**Oppositional Defiant Disorder** – a psychiatric disorder characterized by opposition towards input in the form of arguments (even when agreement would be sought), refusal, and stubborn behavior, even when the child can describe, and tries to follow, appropriate behavior and wants to please adults.

**Palpebral fissures** – the eye openings in the face.

**Parkinson's Disease** – a brain condition in which the muscles of the body become weak and rigid, i.e. though a person has a limb and looks physically able to reach out and pick up a glass, signals to the limb aren't properly causing it to move and carry out the brain's orders (uncoupled initiative).

**Perseveration** - repetitive action that is not goal directed or planned. Persons experiencing perseveration persist in the "fixed" activity despite attempts to redirect, interrupt, or inhibit it.

Example: A child runs hands through faucet water beyond washing up or filling a glass; staring but not looking, as if disconnected to everything else but the physical sensations. Or, a child keeps repeating

the same question or phrase over and over, despite answers or explanations. Child appears unable to disengage motivation and shift attention (cognitive set): child's thinking and actions is locked into in a mental "rut".

**Philtrum** – the two ridges and groove found between the bottom of the nose and the upper lip.

**Plasticity** – In the brain, this refers to the ability of one part of the brain to take over for another part, which has been destroyed or injured.

**Prenatal** – Before birth.

**Reactive Attachment Disorder** – a deeply ingrained set of responses to having experienced unstable caregivers who neglected or maltreated the child. Child copes by shutting down the inability to trust appropriate emotional connections to other people, especially family members, and shows a range of inappropriate behaviors (that may have been survival adaptations to early loss or danger, but which are not proportionate or suitable to general life in relationships with others).

**Resilience** – the ability to bounce back from difficult or from unexpected events in life.

Sources: Ayres (1991), Morse (1993), DSM-III-R, Taylor (1990), van der Kolk, McFarlane & Weisaeth (1996); Krystal (1998).

**State regulation** - the brain's work of coordinating changes and adjustments in response to the environment, i.e. manage mood, alertness, or relaxation states, handle sudden events, etc., to ensure survival. This work is done by the autonomic nervous system, with input from the central nervous system.

**Stimulus control** - a neurobehavioral technique of teaching the child how to recognize what behaviors are appropriate in different situations (like learning a script for how to respond or interact).

**Synapse** – the electrochemical connection between one nerve cell and another which is necessary for relaying information along a path of synapses in the central nervous system.

**Tactile** - pertaining to the sense of touch.

**Tactile defensiveness** - when tactile sensations cause excessive emotional reactions, hyperactivity, avoidance, or other behavior problems.

Example: Child cries when hair is brushed because scalp is over-sensitive, wants water tepid or it "hurts", mouth is over sensitive to certain food textures so that child cries or spits food out or toothpaste "burns".

Note: Some children are extremely *under* or *over* sensitive to stimulation.

**Visual** - pertaining to the sense of sight.

**Visual defensiveness** - when visual sensations cause excessive emotional reactions, irregular reactions to the seen environment.

Example: Child has problems with visual discrimination, gets "disorganized and overwhelmed" amidst her toys, or patterns on surfaces of walls or bedding and clothing, can't find objects in plain sight when visual field overloaded and gets emotionally.

## Section 1: Parenting Porcupines

### Topic 1 – “My child has...and I’m ready to...!”

A diathesis, or vulnerability inherent to the body, can change significantly how a child functions in relation to routine environments. For children with significant prenatal exposure to alcohol, the organ most vulnerable to structural, neuroelectrical and neurochemical damage throughout fetal development is the central nervous system: the child’s brain. Daily demands considered “routine stress” to most people, can translate into “exceptional stress” for those with damage to the central nervous system – the vulnerable brain is their “diathesis”. Unless we can see the brain itself, however, we look at the work the brain does, how it manages behavior and regulates the body’s responses under different conditions. We see stamina vs. fatigue, energy vs. lethargy, typical vs. abnormal sleep patterns, clarity of thought vs. confusion, perception of reality vs. disorientation or distorted thinking, organization vs. disorganization, comfort vs. headaches, differences in registering sensory information or pain signals, and other areas of function.

If your family has been in counseling, you may already have concerns about your child’s learning and behavior. Your child may have received diagnoses of Attention Deficit Disorder, Oppositional Defiant Disorder, Reactive Attachment, Anxiety Disorder, or other mental health conditions that overlap prenatal exposure. Tried and true methods for handling problem behavior may have been ineffective, or made this worse. Though we wouldn’t dream of disciplining a child with a visual impairment for not being able to read the blackboard (Clarren, 1994), we routinely impose consequences and other punishments when a seeing child with visual processing disorders fails to comprehend written instructions. The problem may be he can see but doesn’t know what to do with what he sees. Such gaps are common with FAS.

The group is designed to help you develop an individualized and comprehensive approach your child’s unique symptoms and strengths. It’s taken time to get stuck, and it will take some time to get unstuck.

If you are working with a counselor or other professionals, it is suggested that you sign a legal release to permit sharing of information in support of your child and family. Ask the group leader for releases as needed for you or other members of your family (if your children are older than 13, they must give consent in writing just like adults).

This curriculum offers specific materials & tools to help you make changes, and teaches a proactive approach for integrating parenting, educational, medical and counseling interventions to help your child over time.

*It is helpful to get familiar with the Glossary full of terms for common symptoms because:*

- 1) renaming helps parents detach and “see” symptoms differently*
- 2) this validates involuntary symptoms so parent and child get credit for efforts despite the ongoing struggles*
- 3) This helps others recognize what may be different than previous assumptions about the child’s behavior and abilities*
- 4) Resulting in broader access to the range of specialties and skills that may work together to support abilities and ease stuck points for the child at home or school.*

Others can also have a hard time “seeing” your child in neurobehavioral terms. Phrases about behavior imply different assumptions to what causes it. For example, “perseveration”, a symptom of getting mentally “stuck” in purposeless activity or repetitious phrases despite attempted redirection (common to autistic disorders), as opposed to “she just refuses to listen and obey, keeps pouring and pouring even though it’s time to clean up or another’s turn and it’s been 45 minutes”. We look for what we know, and in a child with superficial chatter and some eye contact, this symptom is easily misread. How it is read guides what others might do to help when they see it. It will be worth your time to explore the glossary to add new terms to your tool kit for describing what you see in discussion with others.

The materials supply a framework for group discussion to expand sharing of practical experiences and strategies from which parents can pick out what is best suited for their own child and family. Give yourself at least 4 times in group to check out whether it’s for you. If you hear only one thing each session that helps, it may turn out to be the very thing you need one day down the road, to help you weather a rough passage as your child grows and changes. A group can serve as a resource for many solutions to questions, as well as a springboard to local advocacy efforts, skill exchanges, and other mutual supports. Refrain from judgment, and learn from one another. If something doesn’t fit for you, leave it alone.

You are the expert on your own children. We hope this curriculum helps you organize and apply your observations over time, as know one else has quite the vantage point that you do, or the dedication you have shown, even before you found any help. We hope these tools will help you get more mileage from your parenting efforts so that you can “choose your battles”, sustain your stamina and renew your resilience for raising your unique children.

**WELCOME!**

## Topic 2: Parenting "Porcupines": Patterns Over Time

Though children are children first, if their biological mother used alcohol and other drugs during pregnancy, they may have some symptoms that seem to get better with time, and some that remain as they grow up. Some symptoms wax and wane, better on some days, while worse on others. Learning may be practiced today, only to be "erased" three days later, and need to be repeated. Many parents have run across good methods for trying to overcome difficulties with the child's behavior or motivation, but find that no matter how "consistently" such principles are applied, their child's performance gets "better for awhile" then ultimately lapses back into the "good days / bad days" pattern. Parents get very frustrated trying to "force solutions", trying harder and harder to make performance rise to a consistent, uniform level:

"I know he can do it. We practiced his math skills over and over. He GOT it! Now three days later, it's like he just spaced it out...like we never spent all that time, did all that work! It seems to go like this. We get things down. But then, what if he can't do it at school? They think I'm just letting him slide. It's just like he loses it again or something."

Parents may be told to count and measure behavior, to be consistent about trying to "extinguish" the undesirable actions. Behavioral theorists have shown that if a behavior is not reinforced, either positively with a reward or negatively with a punishment (as this still gives attention), behavior gets stronger first, then sharply drops away: "extinguished" as it's called. Problem solved. However, this assumes the behavior is not a reflex or a physiological symptom (like a limp). Reflexes are involuntary. So is mental "limping". Think of something coming in fast and close to your eye: you squint! Was this chosen? Rather, it was "automatic". For someone with a limp, that IS their gait pattern – uneven! Despite all the natural consequences they may face for it, they cannot by act of will or any other means cure it.

Many behaviors that occur in children with prenatal exposure may reveal delayed primitive reflexes, or delays in learning a basic repertoire of preparatory sequences, "readiness" states that can be called "neurodevelopmental delays". Some children may have the equivalent of cognitive "limps", processing abnormalities in the brain, such that they have ongoing, permanent gaps or variable ability to perform specific cognitive, motor, psychosocial, and emotional tasks. Exploration and mastery are basic to later combination efforts, reassembly and innovative integration of new input allows even broader creative use of ideas and actions. Children learn, file away the learning, and retrieve it as needed. Gaps in a child's grasp of daily operations hamper smooth performance of self-care and social skills, much less academic information, such that what is obvious to them one hour can become completely missed or spotty later in the day, or week, and without repeated step by step hands-on coaching. It can slip through their mental cracks -- even when they *want* to remember something! The good days, the bad days, again. Despite all the consequences, the loss of learned material is involuntary for many children with prenatal damage from alcohol. The patchiness of performance remains:

"The worst thing is, I try just as hard on an 'A' day as I do on a 'D' day! That's why I hate grades. Grades don't show my trying; they just show when my brain **happens** to work. This makes someone else feel like I've learned something, I guess. But for me, it's all the same. People have to understand that I'm trying just as hard either day. That's why it's so hard for me to keep going. ... But you know that forgetting thing? I guess I also forget how awful it was last Thursday, so by Tuesday I'm trying again cause I don't remember yesterday or last week. I'm just always trying for right NOW."

All people need to make sense to themselves. Pain is unpleasant, but "meaningless" pain is worse. It builds into a sense of punishment or defeat. The ups and downs, good days and bad days may have a flow or pattern that begins to emerge through use of the materials in this curriculum. Information about chronic conditions can help make sense of what may have felt at times like futile struggle.

It is not futile. There is a flow to it, and a way to find one's parenting "legs", to no longer feel blindsided when things fall apart in your child's weekly ability to handle routine life. Many refer to it as "trying differently, instead of harder", or "choosing one's battles".

What do parents see?

When a child can't count on the body to work the same way one day to the next, when little things get stuck and snowball into larger problems, the child may act like a porcupine in a "bristle attack". Irritability or explosions swell out of nowhere, often in disproportion to surrounding events. In 1994, some children with FAS originated the porcupine image in counseling, elaborating on it, showing what seems to set them off, trying to describe to others how their differences work: they played and drew about where, when and what happens when they get "bristly", or "spike" over things, how words can "make it worse" and the bristles get bigger, and they can end up "exploding and poking at everyone!" or getting "all balled up". Out of the mouths of babes (actually the bodies and hands first and approximately 20 minutes later the mouths, as they "spoke" through their art, showing how life works with FAS.

This simple, practical metaphor is rather elegant. Parents can see how their reflexive, defensive system gets tripped, and explore without assigning a particular motive to the actions. Interpretations or assumptions about intention or motive can be checked.

Porcupine thinking helps parents see how often atypical stress is set off in routine settings or circumstances the rest of their peers don't find stressful, or may even find enjoyable or desirable. Where most children who overreact can calm down once a helping adult talks them through the situation, these children already have a "full" tank and talking makes for even more to process and keep track of! For children with alcohol related disorders, talking almost always makes the bristle attack worse! And few have ever known how to signal others that words added fuel to their mental fires of confusion.

When parents follow porcupine pictures and logic, out comes information of how uncomfortable the child is from someone standing too close, about to touch them, or how routine sounds of traffic, school bells, car horns, etc. set off migraine-like pain, and other common discomforts. Children don't bring these up easily as problems in clinical practice because they may not know how, or that adults are not aware of their discomfort.

When children can look at us, hear, and speak back when spoken to, we assume a meeting of the minds. We rely on language to link actions in mental pictures (symbols of the action). We assume if a child can vocalize, then gain speech and vocabulary, that they will talk and use verbal communication as we do. However, decoding language and its implications can be complex. Thinking in pictures can occur without the auditory patterns that go with them being brought "on board" at the same time. Or when busy noting the sound patterns, the pictures they represent may not pop up into the mental "slide show" in a child's mind. Poor ability to forecast, to create various mental pictures to compare, contrast and select from, exaggerates the sense of being always a little lost, feeling around in the dark, then Wham! Things can get all balled up. The porcupine gets a "bristle attack" and balls up, overwhelmed when others are merely

surprised. It may take much longer for that child to reorient and regroup. The work of calming may take extra time or special accommodations or techniques, before any problem solving is safe. Discussion of solutions again rests on the verbal exchange of mental pictures...once again through language or visual signals.

This course emphasizes a new tool kit, a way of rethinking the connections between brain, behavior, and language. With the analogy of a porcupine getting "bristle attacks", for example, the key problem is difficulty with regulating one's state of being, something we can describe in words only if sensations are then coupled with thoughts.

The term "state regulation" in our discussion doesn't mean a law imposed by the state, but instead points to the "state" of a person's attention or concentration, how the brain "adjusts" or regulates that "state of being".

This includes the range of how excited (good or bad), alert, calm, or drowsy a person is, their emotional tone, the pace of their thought processes and other brain activities inside the body. We usually see external signals of "states" in someone's face, bearing, manner, gestures, tone or speed of gesture or vocal communication and other signs (called "paralanguage"). These cues broadcast information about what "state" someone is in. These cues can tell us what states we are in, if we can recognize and use the cue as a signal about what we need. The idea is that as a child grows, states may become "traits", a background tone to the personality, which gets 'hardwired' into the brain's actual structure, after that structure or hardware was already altered by exposure to alcohol and other drugs.

The same way a porcupine gets bristly when sensing danger, many children with prenatal substance exposure are often poor at matching their state to the surrounding conditions, i.e. a baby "molds" to the body of the nurturing adult when feeding vs. stiffening and arching or completely falling asleep unable to successfully feed. This can progress into difficulty discerning states of discomfort from actual danger. They may function at a low level of constant alarm as their background way of being. They may register intense "states" beyond their control, especially over reactions such as alarmed agitation when others would simply "get ready" or be curiously alert. Or, though awake and wide eyed, they lack alert attention, concentration, or comprehension of the cues despite how obvious these seem to others; they may miss cues to follow through when others are still tracking information and acting on what it means. They may have no way to refer to these states of experience or shades of internal sensation, either to make sense of them in reference to external conditions, or to convey to others what is happening.

Children with alcohol related disorders and other drug effects can have poor calming skills, inability to settle themselves into quiet, restful attention, and poor ability to wind down to go to sleep, despite being fatigued and genuinely weary. When they say, "I'm NOT sleepy..." they may actually mean, they aren't able to feel relaxation physically, that their bodies and brains can't find the "OFF switch" to shift gears. They may not register, physically, the 'wearing down' sensations others would begin to yield to when tired out, for example: i.e. may not begin to breathe deeply, or mold their bodies to the bed as is part of yielding into progressive relaxation.

Prospective and post-adoptive parents often find that their children with prenatal substance exposure struggle sometimes with daily life in a way that is harder than for the other children in the family,

not because they are cold, indifferent people, but because the shades of their physical and emotional experience are a few settings “off” of typical childhood responses. These subtle, but pervasive differences with “regulating state” over the demands of a typical day can wear out children and parents alike.

Who would expect a youngster might suffer the fatigue, disorientation, confusional states or mental disorganization, impaired concentration or focus, or emotional disconnection or ‘flatness’ someone might from Parkinson’s Disease, a stroke, or from Alzheimer’s Disease, or dementia. Those characteristics are not what we associate with childhood, that bouncy, curious, energetic, charming, playful time of life. Can a child be fraught with symptoms such as trouble shifting cognitive set (mental and emotional rigidity), irritable depression, fatigue, disorientation or confusional states despite familiar people, routines, and known surroundings. In the elderly, perhaps, but in children?

Parents wear down when they meet with more bristles than hugs...and get discouraged that they are “just not good parents”...when there is so much more going on than parenting.

Tantrums may be sharp, more intense, prolonged, or more frequent than typical. The child “slips the clutch” from discomfort to anger that can escalate into an agitated, confused, and disoriented state in which unusual aggression or shutting down completely into sleep occurs. The episodes occur despite promises, punishment, or remorse, and seem unavoidable. When the parent tries to talk the problem through, the child’s behavior gets worse, not better. It’s as if the brain’s ability to handle the problem through talking it over collapses! Language skills just “go offline”. Communication can bring about a full-blown mood storm; breaking toys, pounding down doors, biting hard enough to bleed, etc. Parents often report their child implodes or explodes, swaddles in the dark, wadded up with blankets and pillows, or smashes up their favorite toys or belongings, totaling the room. The reality is that the child is literally **unable** to work out the problems until equilibrium is back. Then after an hour or more, the child picks up and goes on “as if nothing happened” – while the parent is still rattled by the chaos that took place. It is rare that the children apologize when these episodes happen, though many respond to diathesis stress treatment and can acquire this social skill with lots of rehearsal and extended time.

How can things be good, almost like any other child, then fall apart and be so bad? Parents think:

“What do I have to do to get him to keep doing it the way I showed him? I showed it over and over. We practiced. He did it. Now he can’t? But he knew how!”

The good-days/bad-days pattern is as baffling, as it is ever present.

When parents seek help, professionals may attribute the behavior to adjustment reactions over transitions at home or in school, or to attachment problems or other trauma in the early years after the child was born. It is a fact that post-natal losses and traumas produce changes in the way the brain works, literally, what pathways are myelinated (strengthened) or pruned at critical periods. But, nature holds the trump card.

When alcohol in the pregnant woman interrupts neuronal cell migration in the growing fetus, the actual structure of the brain and its delicate network of neuroelectrical and neurochemical systems is altered. Variations may include thinning of the corpus callosum, actual lesions, and changes to the synaptic circuitry that allows the brain to move information around from area to area to achieve thought,

feeling, senses, and actions within and outside of the body and its extremities. Cocaine and other drugs can change intercranial blood flow while producing a flooding out of the body's neurohormones that regulate pleasure and calm. Then, withdrawal follows with release of stress hormones. Stress hormones have a negative effect on brain development. Even certain medications, Depakote, Dilantan, and anti-nausea medicines, are neurotoxic to fetal development. Myelination of pathways depends on the availability of those pathways or others to compensate. What was done to the neuronal growth by neurotoxin exposure in the first 9 months, is then further sculpted over the next 2 years of a child's interaction with the surrounding world. Many adoptive children have faced such invisible neurodevelopmental challenges without extra intervention to the most basic developmental underpinnings, such as how to deeply breathe, enter into calm attention, drowsiness, and rest. It is no wonder so many run around the world seeming permanently grumpy, edgy, sleep deprived, frantic or "always on". It is as if their mental body-clutch is out.

This curriculum explains another way to approach the management of episodes. Parents and children want to understand what's getting stuck and create a successful way to handle these areas over time so that family relationships can be more fun.

## THE WISH LIST

Every parent who starts a group wants something to show for all the time and effort it takes to attend every week. Select the phrases that best fit what you wish you could get from FAS Parent Support Group (or add your own statements to the list below).

**"What I most want from this group is...."**

- \_\_\_\_\_ To educate myself so that we can be as successful as possible as a family.
- \_\_\_\_\_ A magic wand to let my child be normal.
- \_\_\_\_\_ To know how other families cope with children like ours: what do they do (or not do) when their child acts this way?
- \_\_\_\_\_ To become more resilient...and help my child improve resilience.
- \_\_\_\_\_ To know how we will face the future...what do we do with them as they grow up?
- \_\_\_\_\_ To be able to sort out typical development from behaviors related to alcohol exposure, so as not to be too hard or too lenient as a parent.
- \_\_\_\_\_ To gather ideas on how to address my anger over my child's problems.
- \_\_\_\_\_ To learn to overcome my fear of my child.
- \_\_\_\_\_ To know how to protect myself from my child.
- \_\_\_\_\_ How to deal with difficult behaviors like my child's anger or rage without yelling or becoming enraged myself.
- \_\_\_\_\_ What to do besides "behavior modification"? How do others intervene or coach their child when "natural consequences" don't seem to connect to deter the behavior next time?
- \_\_\_\_\_ To better understand and handle the more difficult behavior my child shows.
- \_\_\_\_\_ Ideas on how to deal with mood swings?
- \_\_\_\_\_ How can I get a break from caring for my child once in awhile?
- \_\_\_\_\_ What others have experienced with schooling and the school system.
- \_\_\_\_\_ To understand the idea of anticipatory coping.
- \_\_\_\_\_ How to stop taking my child's behavior personally.
- \_\_\_\_\_ How to deal with "NO", defiance, rebuttals...how to manage feeling disrespected or dismissed.

## FAS/ ARND IN DAILY ENVIRONMENTS

Some or all of these common classroom symptoms may happen to children with Fetal Alcohol Syndrome or Alcohol-Related Neurodevelopmental Disorder:

- ⇒ Often described as having "low motivation", "not paying attention", or "daydreaming" (distractibility). "Soft" neurological signs frequently mistaken for lack of effort, laziness, defiance, or low self-esteem.
- ⇒ May be ultra sensitive to noise, light, texture {auditory, visual, or tactile defensiveness}; and over/ or under sensitive to pain. May ask "What was that?" make off-the-wall comments about "little things", seem picky, or avoid eye contact (gaze aversion).
- ⇒ Need more re-teaching, or seem to be starting from scratch (memory deficits). They tend to hide this, not wanting to look different from other kids or be teased as "stupid".
- ⇒ May master tasks one day, be unable to retrieve same skills a few days later (sporadic mastery): "I KNOW I know it, but I just can't DO it". It distresses them not to be rely on their minds to recall what they learned when they need to {memory deficits}.
- ⇒ Unexpected schedule changes may disorient them (sequencing problems). Rearranging seating or decorations may precipitate anxiety & distress, increase loss of belongings & disorganization (strongly visually/kinesthetically cued).
- ⇒ Difficulty with verbal instructions, though they hear them and can even repeat them back (auditory processing deficits). May appear to have understood, only to miss inferential aspects necessary to task completion (information processing deficits, trouble generalizing).
- ⇒ Discouraged, de-motivated by incentives that work for many other children with same intelligence level, i.e. grades, sticker charts. Variability of performance related to their central nervous system impairments (poor state regulation, overstimulation), rather than their level of desire to achieve: "I work just as hard on a 'D' test, as I do on the days I get an 'A', so the grades don't help me."
- ⇒ May have trouble changing activities, resist redirection (disregulation, state rigidity), show irritability, "stubbornness", or repetitive speech or behavior (perseveration) as signs of distress.
- ⇒ Though interested in a project, may not know how to start in (problems with differentiating, prioritizing information).
- ⇒ Difficulty seeing patterns, trouble understanding cause and effect, i.e. can make verbal contract about schoolwork, without understanding actions that support it (information processing deficits). Note: The "obvious" is not necessarily obvious to them!
- ⇒ Require external prompts and cues longer than peers (memory deficits), despite efforts to be self-sufficient and show competence. Keep directives simple; use as few words as possible. Give instructions one at a time. They may need some visual cues as prompts.

Rathbun, A. (1991). Reprinted with permission.

## "A Tribute to My Daughter"

by Hillary O'Loughlin of Donnelly, Idaho

"But she's so bright! Not Misty. There's nothing wrong with her — she's just spoiled. It's 'only child' stuff. She's spacey. Sometime she's not motivated at all. Her classmates are friendly to her, but she's not friendly back. Misty is just immature, she gets all upset about such LITTLE things."

*Misty was diagnosed with Fetal Alcohol Effects (FAE) in the spring of 1992, when she was ten years old. As a birth mother and chemical dependency counselor, I naturally kicked myself severely for lots of reasons. The hardest kicks were probably administered for not having figured out sooner that Misty's differences were organically based. Factoring organicity into our parenting and our lives has allowed miracles to happen for our daughter.*

*For ten years, Misty was dealt with based on mistaken beliefs. We thought that she was willfully resistant, uncooperative, and so sloppy that it was no wonder she could never find anything. We wondered how a child could get A's in school and not have the sense to understand that when she is rude to her friends they might get mad at her. We were convinced that our fourth-grader with her ninth grade reading level should remember to wear clean clothes to school and wear her boots in the snow. We didn't understand that certain connections were just not being made.*

*It didn't make sense. She didn't make sense. Being a parent didn't make sense. It was TOO HARD. I had to be the worlds' most incompetent mother — my charming, intelligent daughter was driving me crazy! Could I be doing EVERYTHING wrong? My husband had children from a previous marriage, and HE didn't think I was a bad mom. "Misty," he said, "is different from other kids." "Sure," I thought, "because I'm such a bad mom."*

*When our daughter was diagnosed with FAE, WE changed. We changed our perception, our parenting styles, and even our unstructured lifestyle. We began learning and working towards*

*realistically meeting Misty's needs...she didn't change, things around her did.*

*She was happy to know that when she drew a blank on the multiplication tables, it wasn't because of stupidity. Relieved that when she was standing in the hallway because she forgot where she was supposed to go, it wasn't because of being an idiot.*

*I hear people say, "Why diagnose? There's nothing you can do about it." For our daughter, a diagnosis was pivotal in that it gave us a solid place to begin. In order to deal with any problem, it must first be identified. Strategies do work, and interventions can make the difference.*

*One morning Misty accidentally put on two different earrings. Several children in the local stores pointed this out, laughed, and Misty's "reaction process" began. The first sign is a look of total panic in her eyes. Then the sagging body language, tears, self-deprecation, and finally utter defeat.*

*I happened to be standing nearby, and having just finished an article on reframing, I chose to intervene. "Wow, how incredibly cool! What a great idea! Who made that silly rule that we're supposed to wear the same boring earrings in both ears?" Misty relaxed and the other kids quit chuckling. Reframing. It works. One less blow to the self-esteem.*

*I've not worn matching earrings since that day...a tribute to my daughter and to others with FAS/E.*

*Last year Misty's fifth grade teacher wrote: "Social skills are developmentally delayed. Misty has severe anxiety attacks, nervousness, crying, and lack of ability to identify and voice gears and concerns before they become overwhelming."*

*This year Misty is in the sixth grade. She remains high functioning, bright and charming. This year her teacher does not believe there is anything wrong with her. Her anxiety and depression have improved. Armed with knowledge, we were able to request a teacher whose classroom has a calm, relaxed emotional environment and to provide information and strategies. Reading the teacher's face and body language to interpret the world, Misty is significantly more calm and relaxed as well. Perhaps my child's successes are the reason why I react so strongly when I hear, "Why bother to diagnose? There's nothing we can do about it." There's LOTS we can do.*

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KOW-ISH-KAH-NEE-XLA  
(She Who Digs Fast While Traveling)  
*A mother's reflections on her daughter who lives with Fetal Alcohol  
Syndrome*

By Suzie Kuershener

She is beautiful and bright and generous in her love, beyond usual, gift those around her with an energetic spirit that magnetizes and "re-stimulates" all, including herself. Sometimes her energy seems boundless and way beyond your own. Sometimes, her energy seems *heyoka* or contrary to everything you are trying to do. And sometimes, her energy is so quiet, in a sad self-image of failure.

Somewhere between the boundless energy and the sad self-image, there is a time of watchfulness, of observation of "how to be good." She has a genuine desire to please. My daughter, Kow-ish-kah-nee-xla (She who digs fast while traveling) has worked hard to learn to be good. She watches, she tries, she asks and she is broken-hearted when she sees herself as having "failed." The strength of her trying and asking tug at my heart; her perception of failure breaks it.

She has been lucky in her life because many have come forward to show her how to be. Elders, grandmas show her how to be who she is and in the showing have offered her a structure of skills in watchfulness, respect and gratitude through ceremony and action, that have honored and become the foundation of her being.

Aunties and uncles and two devoted nun-nah, sister, have loved her unconditionally. A Montessori preschool guide and a warm and responsive kindergarten teacher have intended and reinforced, rather than detracted from the traditional values of observation and respect.

All of these teachers have valued my daughter and have used her strengths to heal her weaknesses. They have honored her life with a structure of functional skills in concrete learning.

Together my daughter and I have learned many things. Some of them are:

Her need to give and get love is real and almost insatiable, but I love the process of meeting this need.

Her difficulty in understanding and behaving in the midst of chaos and confusion is at least as upsetting to her as to me, and we should avoid noisy overly active environments because as hard as she tries, it is just too much to process; and as hard as I try, my strategies for handling the stress may not work.

Her knowledge of what is going to happen a while before it does, makes pre-planning extremely helpful in terms of both her cooperation and her understanding. Such pre-planning and foreknowledge also diminishes her impulsivity.

Her response to calm, single, or one-part directions is immediate and cooperative.

Her response to loud, hyper-, many-part directions is one of trying, then becoming frustrated and irritated and then finally tuning out (or it used to be tantrums).

Her appreciation of praise and all forms of positive reinforcement is obvious by her immediate repetition of those actions or behaviors that received praise.

Her visual memory is keen and incredible in its ability to observe. This means that curriculum materials, behavior, language patterns and values that are "shown" and visually modeled will be the ones most remembered for later use. Their use will be almost exact and she will say what she has seen.

Her need to know who she is, spiritually and culturally, is critical to building the resilient self-esteem that she will need to work her way through life.

My daughter and I are still learning, but with the learning, we continue to be grateful that there are so many who have come forward to love her and show her how to be. We have needed, and she deserved, that honor that will reflect Kow-ish-kah-nee-xla's beauty and brightness, so that she can see it for herself, even when the letters, numbers, and colors don't match.

*This article is reprinted with permission & grateful acknowledgement to the author, Kowishkaneexla & the Northwest Indian Child Welfare Association.*

## FAS & Alcohol Related Disorders:

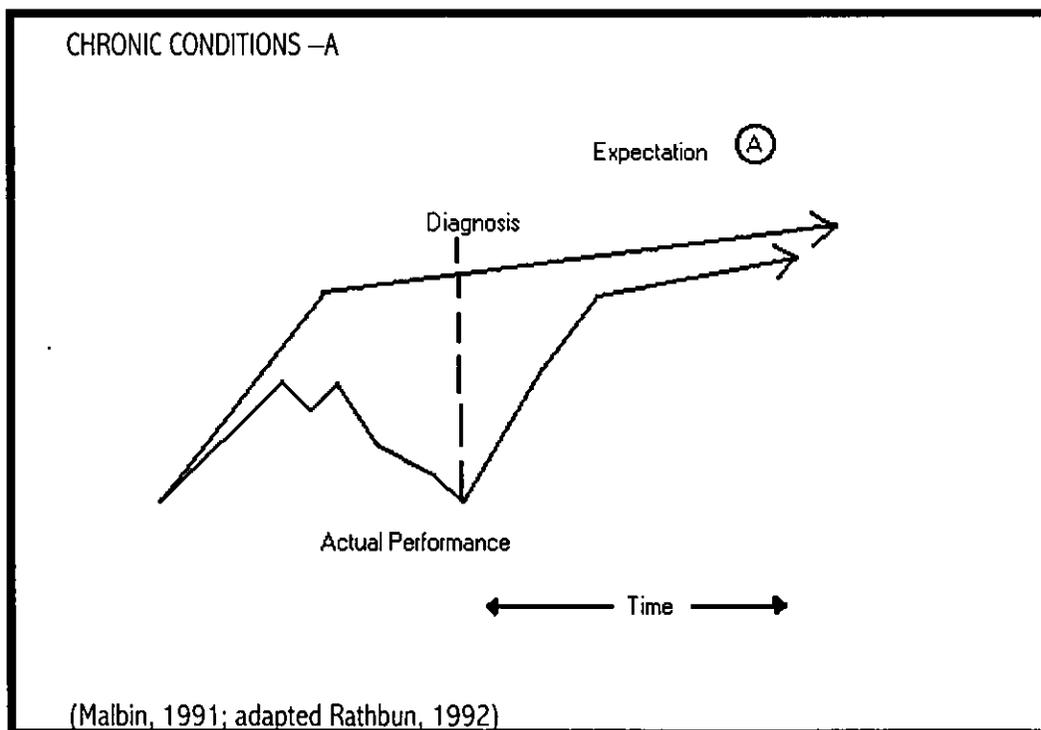
### COPING WITH VARIABILITY

The following ideas provide a framework for thinking about interaction between parents and children with alcohol related disorders, compared to other chronic childhood conditions. As with all concepts, parents need to take only what is useful to compare with their own experiences.

Psychiatric and behavioral science research have yielded concepts, data and practical guidelines for enhancing the development and well-being of children diagnosed with a variety of medical conditions (Hamburg et al., 1980; Magrab, 1978).

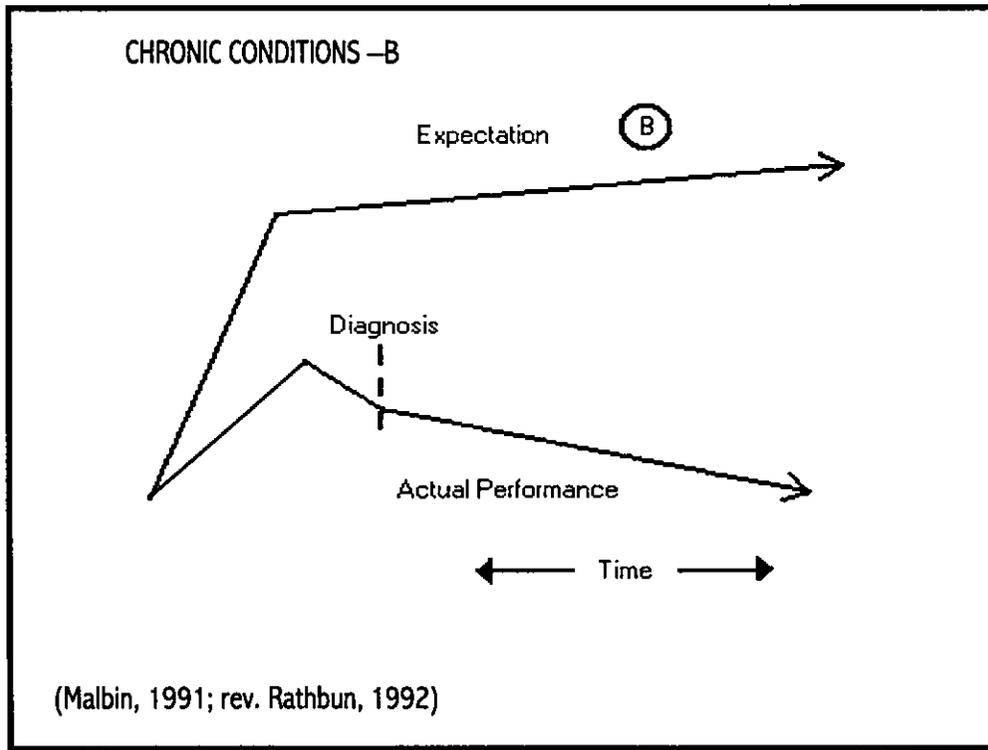
Patterns of chronic conditions in children can include:

A. Conditions for which reasonable control can be provided throughout most of the course of the disorder.



For example, children with diabetes can learn to take insulin and modify their nutrition and activity patterns to help them prevent risk and lead full lives. As long as the medical regimen is in place, adults have reasonable control in managing the condition and helping the child achieve expectations for development.

B. Conditions showing a progressive downhill course.



Some conditions compromise the child's development by progressive deterioration. Once a diagnosis has been made, families and significant adults in the child's support system (extended family and friends, teachers, counselors) cope with helping their child's optimal development on a daily basis, while adjusting to the reality of loss through progressive impairment, deterioration, and eventual premature death.

Though pattern A and pattern B represent different hardships for the child and significant adults in the child's life, there is some degree of predictability involved in each of them.

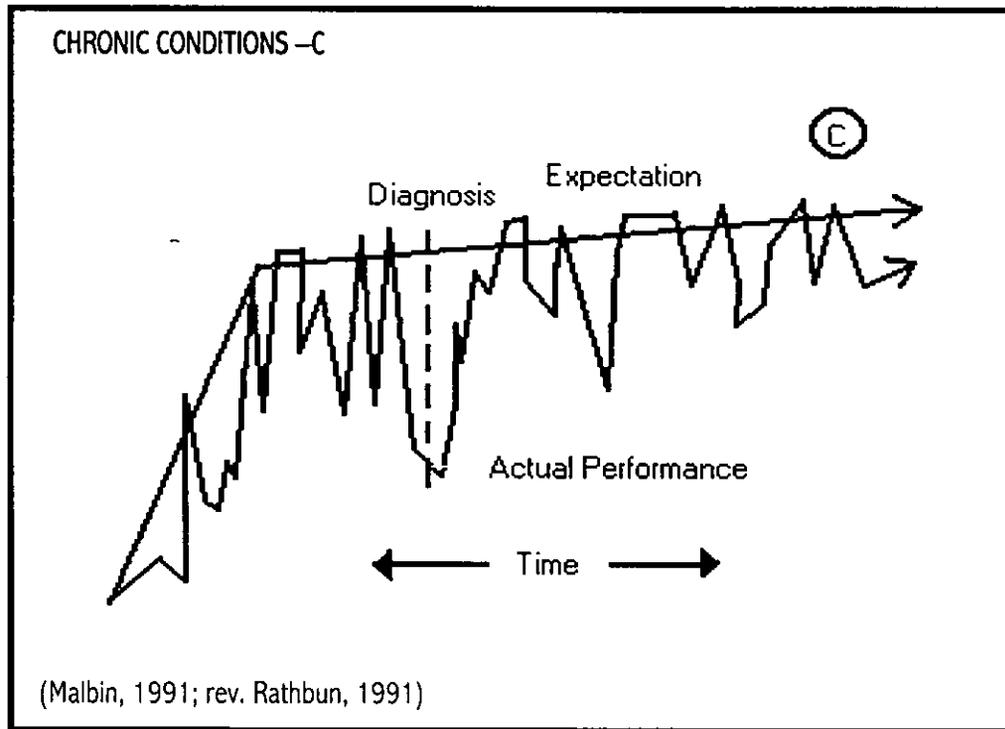
Families dealing with pattern A conditions count on the medication regimen to allow their child to meet expectations for overall development (cognitive, social, emotional, physical, academic, etc.) As long as the medicine is in place, things proceed fairly evenly and expectations tend to stay high.

Predictability is also part of pattern B. In this case, what is predictable is progressive loss, and eventual death of the loved child, as difficult as it is. All significant persons learn what is ahead, change their expectations over time, and resolve unmet hopes for the future.

In the above cases, adults providing care or education to the person with the condition develop "anticipatory coping". They learn to accept what the condition means for daily life, and begin to anticipate or prepare for how to support the best possible outcome. Even if the condition cannot be cured, predictability allows them some sense of control.

In contrast, a third category of chronic condition can occur in children.

C. Conditions characterized by exacerbations and remissions.



There are conditions, such as asthma, which have a waxing and waning course; i.e. symptoms vary from active to inactive, requiring differing degrees of intervention, though the underlying condition remains present. Alcohol related disorders may resemble this pattern of ups and downs: some symptoms remain present but vary in severity and manifestation dependent upon the age of the person and his/her fit with the environment (variable performance characteristic of brain damage means that inconsistency may persist throughout development into maturity). What is consistent about pattern C conditions is predictable inconsistency (variability).

Literature on medical conditions in childhood suggests that the more predictable the course of a condition, the more feasible it is to take appropriate steps. Coping varies by condition:

**PATTERN A** – Parent expectations may remain fairly high. As long as the child continues on medication, the condition is “controlled” and developmental expectations remain typical.

**PATTERN B** -Expectations are reduced by premature decline. Coping means accepting catastrophic loss. The family and child prepare for and experience loss over time. Expectations progressively decline.

**PATTERN C** -Expectations must accommodate highs and lows. Coping means expecting “good days” and “bad days”. Uneven performance is predictable and typical for the condition. Progress is on target in some ways, while not in others. Though effort is continued, stamina, performance, and resilience may wax and wane. Think back to the diagram of pattern C: Where would you draw your line of expectation? What kind of line would it be? Draw it!

## ACCEPTANCE IN ACTION = "Anticipatory Coping"

Dealing with predictable stress through preparation is called "anticipatory coping"; put simply, acceptance in action.

Parents and children learn skills for living with ongoing and variable challenges, the consistent inconsistency of FAS, and the range of alcohol related disorders. Predictable unpredictability is met with a flexible, preventive, and innovative attitude. Three main coping tasks include:

Becoming familiar with the child's symptoms and how these are manifested in daily life;  
*becoming a student of the condition,*

Identifying patterns of interaction;  
*recognizing the fit between the child's condition and the environment, and*

Finding ways to modify the environment and build strengths in areas of capacity, improve the match or fit;  
*creating options, instead of waiting for them!*

It is natural for parents to want to "fix" symptoms by seeking out professional help. Yet fewer professionals go into practice with chronic conditions, than those who practice in specialties where they can cure or see quicker results. Some professionals may have an underlying belief that if a condition cannot be "fixed" or cured then "nothing can be done". This misperception can be overcome.

Research in medical family therapy suggests that families can learn to build on strengths and help children face their challenges by learning about the condition, gaining support throughout the stages of grief and adjustment, and by becoming active participants in developing solutions based on family and individual strengths.

Source: Adapted from Schowalter (1979); McDaniel, Hepworth & Doherty (1992).

## PARENTING: Seeing Differently

Being a parent of a child with special needs is a complicated thing. We seek a "roadmap" for parenting chemically effected children. We want to know what the problem behaviors are about so we can read these "signals" and decode them. When we think of providing structure, instead of trying to exert control, we get lost. "Forcing control" often makes problem behaviors escalate. Still, we have to do *something*. What will work??

Many of us have had less than pleasant experiences as children ourselves. We may have had abuse that left us worried over "not knowing how to parent *the right way*" (meaning we don't want them to get what we got). Even if our past went fairly well, we might be confused about what is typical at certain ages. We have questions about many common situations. We can get hooked by our children's' symptoms, like power struggles for example, mistaking their "help" or "ouch" signals for personal attacks. We get tired of being the brunt of their resistance. They may be rigid despite our attempts to "make" them flexible. Desperate for order and reasonable control over the constant struggles, we may feel guilty, cheated, and inadequate in the face of not knowing how to "make them stop" or "finally please them". We hate things feeling out of control. (Notice, they may FEEL out of control, but not actually BE out of control.) In our frustration, we may feel victimized by the child with effects, as if she or he has the ability (to satisfy our demands) but is denying us out of spite.

In short, parenting pushes our own buttons. We know what gets to us, and we find out this is where the struggles heat up. We say, "They know how to get to me." This is harder parenting than most, true. Slowly, we begin to see a larger picture, not just of who the child is and what she can't do or can do, but also, where our own strengths and vulnerabilities are, and how we can do this hard work, while taking care of our own hearts gently. It is never too late to stop trying harder, and try GENTLER. Begin with yourself.

The biggest rule is: **THERE IS NO PERFECT: there is just "right now"**.

Question: What is the worst thing she/he does that I feel *has to stop*? Pick something that really "gets to you". (Now, use your log).

## FAS /DRUG EFFECTS PARENT SUPPORT GROUP

### HOMEWORK LOG

Please plan on spending 10 - 15 minutes each day with this exercise.

The key to the log is to observe behaviors, reactions, patterns of getting "stuck" that seem to happen a lot. Refrain from interpreting, judging, or guessing motivations underlying what you see. For example:

Observation: "He *looked away* when...."

Judgment: "He got very angry when...."

Describe one thing your child did:

What was your first reaction: (name the feeling if you can)

What did you do next?

I saw my child (describe the behaviors, words, actions that occurred)

What did you notice in this example, either about you or about your child?

Source: Adapted from materials by Malbin and Rathbun (1992).

## Section 2: Diagnosis and Diathesis

### Topic 3: "Getting A Diagnosis": FAS Spectrum Disorders

When parents take a child to counseling, a formal diagnosis from a mental health professional will address 5 areas that work together like a puzzle. This puzzle forms a working picture of what is going on for a child who seems to be having problems *beyond* what most children the same age might experience. Each area is called an "axis", with a different specialist offering information on the focus of a particular axis. For example:

Axis I	Emotional, social, learning, functional or behavior problems	Mental Health Counselor
Axis II	Intelligence, mental capacity & personality disorders	Psychologist
Axis III	Medical conditions, i.e. physical conditions including brain damage	Physician or Psychiatrist
Axis IV	Environmental stressors, i.e. moves, divorce, death, family issues	Parent, Child, Counselor
Axis V	Rating of child's overall functional level at time of assessment	Counselor or Psychiatrist

We've been told that "you can't get a diagnosis of FAS because it's not in the DSM"! Why can't we get a diagnosis?

In fact, FAS *is* listed in the Diagnostic and Statistical Manual of Mental Disorders, Revisions III, IV, and V. It is found under medical disorders, 760.71, Fetal Alcohol Syndrome, because it is a physical condition. A pediatrician, child psychiatrist, geneticist, dysmorphologist, or other physician may diagnose medical conditions on Axis III. Mental health counselors diagnose only on Axis I, II, IV, and V. Counselors refer the child to child psychiatry or pediatrics asking the doctor for a "rule out of FAS on Axis III". The counselor reports symptoms and history consistent with diagnostic criteria, and asks the doctor for a final determination (called "their diagnostic impression"). FAS is then differentiated from a host of other developmental or genetic conditions that could explain the child's symptoms. The doctor gives an opinion on the severity of the condition, and if co-existing conditions are present. Overlapping mental health conditions are the rule, and there are medical conditions, which may overlap as well. It is more common to find a child with several diagnoses listed, than solely FAS as an isolated medical diagnosis. The brain-related behaviors are commonly described by one or more mental health diagnoses of childhood.

Children with prenatal drug exposure can also receive diagnosis, or "rule out" of various drug effects upon the fetus, listed with FAS under medical conditions. These include Toxic Effects from Cocaine (tremors, shrill cry, abnormal sleep and regulation), Toxic Effects from Hallucinogens, or others on the list in the DSM. Physicians can specify Polyneuropathy Due to Drugs when structural neurological deficits or abnormalities to balance, coordination, hearing, speech, or vision occur secondary to severe drug exposure.

Static Encephalopathy, 348.3, non-progressive brain damage, is diagnosed when:

- Physicians find only some but not the full presentation of symptoms consistent with an FAS spectrum disorder,
- Evidence of organicity in neurological examination for “soft signs”, and
- Alcohol or other drug exposure history of unknown quantity (“Unknown quantity” simply means that though the mother drank or used, exactly how much and how often, or in what combination with other substances, remains unclear specifically during the pregnancy),
- Additional genetic history of DD or chronic mental illness, multiple drug exposures, and post-natal trauma such as anoxia at birth, multiple placements prior to age 6, or other maltreatment or neglect.

Compiling the portrait of a comprehensive diagnosis involves parents working systematically with different specialties, each contributing a piece of the diagnostic puzzle. It is rarely a “one time visit to the doctor” situation. Like pearls on a necklace, each part is added to form the whole pattern. It can take weeks or months to receive a diagnosis, depending on access to specialists, insurance approval of referrals, adoption support, and regional resources.

In group discussion, parents explore the five axes describing experiences of how this process has worked in different families. We discuss how this “comprehensive multi-axial diagnosis” or functional picture, translates to services from medicine, education, mental health, occupational therapy, speech and language, etc. In general:

In general, each field has an approach to the problem, though the other aspects of the diagnosis need to be taken into consideration. Each field uses distinct terminology and techniques. Each kind of expertise may apply, but the parent has the whole view of how the pattern plays out on a daily, weekly, or monthly basis, and how life is working using the new tools.

Parents benefit when professionals describe what happens, or what the child’s behavior looks like, sounds like, etc., in clear common language. **Parents see the child around the clock and have the most time-span information.** Parents need to learn to use this ‘data’ and ask others for theirs in plain language. Comparing what is seen; the child may function differently in different environments.

Professionals may comment, “all children do that” or “that is pretty normal for his age”, and when the difficulty is that simple, parents are more than pleased. However, it often is not. Parents can show **over time** that the **frequency, intensity, or duration** of the child’s symptoms may be what sets their behavior apart. There is no better source for ‘data’.

No test measures fatigue, confusion, and behavioral deterioration or disorganization quite as accurately as what is seen during a routine day or routine weekly period – a time span view. Stress is “dosed” over time. It builds or decreases over time. This makes it hard to “see” as compared to other factors professionals usually encounter.

Research has explained some of what alcohol exposure can do to change fetal development and therefore, later behavior. When a mother drinks, her blood alcohol level goes up sharply. As her mature liver and kidneys slowly metabolize out the byproducts of the alcohol, her blood alcohol level goes back down. While the alcohol is present in the bloodstream of the mother, it also enters the fetus, where it slows or stops normal activity of cell development in the child's growing brain for the duration of that exposure (until the mother's organs clear the alcohol from their shared bloodstream). This translates into structural, physical changes to brain development, which may occur from exposure to alcohol. The fetal brain is generating cells continually, and then encounters a recognized poison to cell development— this defines alcohol as a “neuro-toxin”.

In a typically developing fetus, glial cell migration builds the layers of brain tissue, which become the cortex – the “command center” of the brain. The cortex is the rich mass of neurons (nerve cells) that communicate with each other through synaptic activity that underlies thinking, feeling, sensing, and learning. Cells have sites (terminals) for synapses that fire chemical signals back and forth. This is the processing work of the brain. Alcohol in the fetal bloodstream disrupts glial cell migration. The cells fail to migrate properly, changing the actual structure of the cortical cell layers. Synapses fire from billions of cell terminals in these layers. Where cell layers are changed, terminals and synaptic activity are also.

Cell growth “catch up” after alcohol leaves the system, occurs to compensate for missing activity. This is called “fetal plasticity” and can result in overgrowth; cell migration clustering upward like ‘tangles’. Gaps can occur, where there is no tissue at all (lesions, discussed above), interspersed with areas of tangled-looking cell overgrowth. When considerable damage is done this way, the cortical tissue, which usually has orderly layers rich with connections, instead looks disorganized, with dense cell clusters, gaps, and tangles.

Even when no gross abnormalities in the child's brain structure can be seen on the MRI, electron spectroscopy can show problems with how different regions are working together (or, not working together as would be typical). The brain's synapses and linked networks of specialization govern assorted functions: this allows the body to do fundamental tasks over various conditions and in different combinations of accommodation, habituation, and modulation – the regulatory work of constantly upgrading capacity of the body-mind to successfully master changing conditions.

We hear about ADHD, Attachment Disorder, Learning Disabilities, and other names for patterns of atypical development, behavior, learning, emotional functioning, and social interaction in children. When a physical difference underlies a pattern, outside factors further shape it for better or worse. Damage to the brain sets up increased vulnerability to behavioral, learning, and social problems.

Meningitis, encephalitis and other diseases can also cause brain impairment, as can shaken baby syndrome or other traumas; closed head injury; neurotoxin exposure (including anti-nauseants and other medications, dilantin, depakote, etc.), and environmental toxins (lead, mercury, certain pesticides, etc.). These things change brain development in ways that cannot be “undone”. Alcohol is the most socially accepted, commonly used and abused neurotoxin known to pose risk of damage to an unborn fetus. Sadly, women in their childbearing years are also in the stage where there is greatest likelihood of increased alcohol use. It is a common “way to unwind” and creates a feeling of easy comradeship. In the earliest

weeks of pregnancy a woman may still be unaware she conceived. Many children may see some alcohol exposure, but have no measurable adverse effects. They are the fortunate ones.

Knowing what harm can be done, how can women drink when they are pregnant?

This question implies two answers. First, the emotional reality of being angry and upset over how this continues to happen to children is a legitimate expression of the natural desire to provide, nurture, and protect children and future generations (even after the fact!) Anger and grief towards the birth parent is completely normal and understandable. Sometime a parent's sense of frustration with the children shifts quickly to impatience and indignation with what harmed (or harms) them. Anger and grief are the markers of rethinking how to provide, nurture, and protect these children, according to their unique challenges and compensating strengths.

The second point is the alarming fact that though, on some level, a woman may know instinctively that alcohol and pregnancy don't mix, yet somehow keeps drinking. What accounts for this? How is it that she earnestly promises to abstain one moment, yet at another time (perhaps even the same day, a different hour) any deterrence she felt is simply overcome, she drinks again, with the denial, displaced anger and inner despair increasing in a vicious cycle? It's irrational!

Nothing could be truer! The rational part of the brain, the frontal lobe, is not the part of the brain making the decision. It recognizes compulsion from another brain region, and powerless to shut off those urgent signals, makes "mini" deals trying to quell the mismatch of information, i.e. "I'll just have one quick drink", or "It IS my vacation after all" or "I had a bad day", etc. Internal chemistry changes are at work which she doesn't understand; reduced neurotransmitter activity occurs when the body is craving the next use, there is neurochemical flooding when high, followed by even further depletion and poor rebuild of neurotransmitters, causing a state of slow "starvation" of the "feel good" chemical signals in the brain between using episodes. What we actually see is what appears to be a loss of the ability to choose, to take a drink or leave it (or continue to leave it). Loss of choice over the compulsion is termed "loss of control", the signature of alcohol dependence. Binge drinking is not choosing either, because sooner or later in the binging process, another high volume use will inevitably occur (though verbal rationalizations may try to explain this away). Abnormal metabolism of byproducts of the alcohol cause a neurochemical chain reaction which signals "time for another dose" to the abnormal body chemistry of people with this particular brain-body chemistry problem (a genetic component for which runs in certain families).

Alcohol use varies among women. Many drink completely unaware they are pregnant. Some consider beer and wine benign and only "hard liquor" a risk, though the absolute alcohol content is the same (1 can of beer = 4-5 ounces of wine = 1.2 ounces of spirits or liquor). Binge drinking is defined as 5 or more drinks per occasion, typically 1-2 times per week. Binge drinking was found to produce measurable damage, and is found to be as hazardous to fetal development as chronic, daily drinking. The variability and complexity of these issues suggests why it has taken over twenty years of research to define these effects as distinct from other malformation patterns in childhood and causally link a particular syndrome with exposure to alcohol.

A standardized diagnostic set has been in existence since 1980 (Rosett, et al). A comprehensive diagnostic protocol developed for pediatricians was introduced in 1997 as part of the CDC's FAS surveillance efforts. The 4 digit code procedure developed by researchers at Seattle's Fetal Alcohol

Syndrome Diagnostic and Prevention Network helps physicians evaluate for FAS spectrum disorders using a standardized method for assessing level of alcohol exposure, plus changes to growth, facial characteristics and brain function. It is more complicated than a blood or skin test that reads positive or negative, and involves several disciplines working together with parent and child. This curriculum was developed in conjunction with trial use of that protocol in a typical outpatient mental health center.

How does all of this play out in real life for most families?

When a child suffers a head trauma, doctors can see and measure the location and extent of the damage. They can compare how the child does after the injury to how the child did before it happened. With damage to the central nervous system from alcohol, no "pre-injury" baseline measurement is possible. No one will ever know how the child would have functioned before the brain was exposed to alcohol. A doctor compares the child to age mates, and to what is known of typical development. Without a standardized test for the condition, i.e. a blood test, or medical procedure that is standardized and accepted for use, physicians are often ambivalent about the worth of a diagnosis. Would it help or not? Does it change anything for the child, either favorably or unfavorably? Could it harm by increasing stigma associated with alcohol? Would it change people's perception of a child's potential? Would someone still want to parent this child?

Discussion of possible disability is often delayed as long as possible, to prevent limiting positive expectations for a child and safeguard the child's acceptance by society as a whole. Few are willing to diagnose or suggest a condition for which there is thought to be no cure, or where the scientific literature has not yet indicated a course of action to take in response so as to have a way to manage the condition. Though Rossett, et al. described procedures for diagnosing Fetal Alcohol in children back in the 1980's, the pediatric diagnostic guide now in use by the Centers for Disease Control for surveillance data on Fetal Alcohol Spectrum Disorders now was not available when most physicians were medical students. No specialty field of medicine has chosen this population, i.e. genetics, teratology, environmental medicine, behavioral pediatrics, developmental pediatrics, psychiatry, neurology, etc. In addition, the professional's role is to treat disease; **chronic conditions in children are hard on the natural desire to offer a remedy.** Referring out for a specialist consult would happen only if gross abnormality of the brain (serious hard signs) are suspected, and the rounds of specialists may include one or several of the above distinct specialties in medicine, not to mention psychology or counseling. Doctors wish to match the needs with actions that will bring as much relief to the child and family as possible. Reduced emphasis on these conditions is thought to help the family not be problem-focused, however, actually adds to family stress. It is not unlike the emotional motivation of an adoptive parent, who wants to love and restore opportunities to a child who was initially hurt or disadvantaged by another, and avoid any terms or labels on his experiences that could "stick with him" and induce negative perceptions by others. **All loving adults want to do something that might help, while at the very least, doing no further harm:**

Doctor: "Any harm to a child can be hard to talk about because no one would ever wish a child brain impairment, knowing the grief and challenges that then must be faced. It can be hard to tell... Is this from the alcohol or from early losses?" The literature documents abnormal regulation, problems with shrill cry (acoustic properties), sleep abnormalities, difficulties coordinating feeding sequence (suck, swallow, breathe) and hypo- and hypertonia (neurologic tone in musculoskeletal system) occurring from the alcohol and other drug exposure giving rise to persisting difficulties in early childhood and beyond which occurred despite placement from birth into stable, loving adoptive homes.

Professionals worry "...if I diagnose the child, I'm essentially accusing the mother of damaging her child. I can't tell her that. Besides, children grow...maybe she'll grow out of it..." As FAS is only diagnosed in childhood, some think it simply 'disappears' by adulthood. The vast majority of adults with FAS who may warrant diagnosis of Organic Brain Disorders based more on how they continue to function, are served under other mental health conditions or developmental disability, if they are ever recognized has have organic brain damage at all. . Long-term issues for adults are still being studied (see literature by Streissguth and colleagues on secondary disabilities).

What can I say to a drinking mother? When the alcohol damages the mother (*causes any inebriation at all, even mild*), it can damage the child. When a mom knows alcohol can hurt her baby and still drinks, that is not social drinking...that's when alcoholism screening is warranted. Empathy, honesty, and timing are important; most chemical dependency treatment centers have staff that can assist when intervening with someone who has a problem with alcohol or drugs.

What is worse than having an addiction is not getting the facts. How can another alcohol-related birth be prevented? Facts permit the opportunity to face what is real and learn to handle it. With diabetes, for example, there is no question of referral to supports for improving management of the condition. With a mother's alcohol abuse, discussing the condition and risk to the child is simple and sad: when alcohol hurts her body, it also hurt her baby's body inside her. Provided with reassurance that, clearly, no one ever *intends* to have this happen, a woman can face this medical issue as with any other; gaining an evaluation of the problem and degree of symptoms the condition is creating in her life, and gathering social or family support to aide in rehabilitation once treatment has stabilized her. Referrals and calls need to happen immediately, with help from the professional and hand-to-hand, face-to-face support.

Professionals and families can begin outreach to treatment by normalizing losses to quality of life and relationship the drinker never *meant* to have happen. "Loss of control" IS the fingerprint of addiction. Abnormal brain responses of craving, protecting supply and access to the next use, and other symptoms show that alcohol is "driving the bus", while the woman and her best intentions bump along for the ride. Her frontal lobe can "see" how her behavior (at the midbrain level) begins to violate her own values (which are held in the frontal lobe). This is why denial, a protective defense, arises: to rationalize or make sense after the fact of insensible action. She denies use, minimizes negative consequences, promises not to use, attempts to stop or cut down, believing she can, then runs into the brainstem-driven cycle with alcohol again! She can see what is happening, but cannot reconcile the war between her frontal lobe (concepts) and midbrain and reflex level behavior (reactions). When met with empathy, plus honesty, the above can be explained, i.e. most people can have drinks, but do not experience improved performance in early use, crave drinks, gulp their drinks (a late middle stage sign in women) or get blackouts. Imagine what it's like to promise then find oneself acting "on autopilot" doing exactly what was not supposed to happen again, etc. Something physical, beyond her understanding is wrong with her physiology. Naturally, she can't fix that without tools, and even so has to harness the help of the very organ experiencing the worst symptoms – her brain. Not all recovering people can go through rehabilitation retaining their children or remain consistently abstinent over time in order to make amends and raise their children adequately. Carefully specialized programs are needed for persons with dual disorders of chemical dependency plus either mental health, or additional developmental disorders, and pregnancy.

In screening for childhood disorders, fear of stigmatizing the child and avoiding reference to a mother's drinking are the rule, *even when the facts of alcoholism are known about a child's parents*. Professionals may see a person's discomfort about the subject and distance from the subject so as not to "chase them off" or "shame them" or "risk an angry patient complaining". Or, like anyone else, professionals may discover unresolved feelings or past experiences with an alcoholic family member or friend. Denial may cause gaps in patient care, such as omission of alcohol or drug use or abuse in a child or mother's medical or counseling chart (effort to protect appearances). Professionals also have legitimate concerns about oversimplifying, or attributing what they see to just one cause, even when they know alcohol and drugs can compromise a child's health. Added, damage from alcohol and drugs during pregnancy shows a broad range of outcomes, from little or no effects to severe disability or even death.

*Where we are with FAS intervention as a society:*

Unless the professional was trained in the last 5 years using the latest diagnostic information from the 1996 Institute of Medicine's Report on Fetal Alcohol Syndrome and Effects (see Section 2 handouts), the information they have on FAS may not include current criteria for diagnosis of alcohol related disorders along a spectrum. Past studies familiar to professionals focused on mental retardation often found with alcohol related disorder. However, studies now show a broad range of outcomes: IQ's from 30 up to 130, with median IQ at 74, just slightly higher than that which meets clinical criteria for mild mental retardation. As a general rule, this does not match with legal definitions used in developmental disabilities, requiring an IQ of 63 or lower for retardation. Parents are understandably confused. Professionals may be caught at cross purposes depending on which system they belong to and the criteria used there: they often have to describe the deficits several ways (rather than just by IQ scores) trying to piece the puzzle together to legally secure supports.

Thus even when a child with full FAS walks into a doctor's or psychologist's office, the professional may not *see* it. Seeing it depends on what the professional would *recognize* as FAS from the studies or prior training. If "it" walks in announced by an adoptive parent, the professional may caution parents not to oversimplify or jump on the "newest trend" in disorders. Natural feelings of intense concern and anxiety may be misunderstood as overprotection or controlling.

Fewer physicians go into treatment of chronic health conditions like cancer, than those treating what is curable. Fewer counselors and psychologists have specialized training or experience with both developmental disabilities and mental health conditions, though these so often overlap. Unless they have worked with stroke rehabilitation, i.e. to retrain language or motor functions with Alzheimer's or Parkinson's disease, they may be unfamiliar with distinguishing organic from psychological disorders.<sup>1</sup>The organ most sensitive to damage from alcohol during gestation is the brain, but the damage can be the hardest to measure because we can't "see it" like we would a blow to the head or visible limb malformation. Instead, we have something similar to a chemically caused closed head injury profile without the benefit of any way to measure how the brain would have functioned prior to the repeated exposure to alcohol while it was developing. As stated by Dr. Jay Edwards, a neuropsychologist, "Even with beneficial environments to further a child's potential, once a child's brain has been damaged by neurotoxins, Mother Nature holds the trump card. We can assist further growth in a child's ability to compensate, but we can't change the brain back to where it would have been before."

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<sup>1</sup> Taylor, Robert L. (1990): Distinguishing Psychological from Organic Disorders: Screening for Psychological Masquerade; Springer Publishing.

## Topic 4: Diathesis – Relief, Grief, and Resolution

“One day I was sitting in the cab of our truck with our 16 yr. Old son. And it was like just sitting there, he takes all the air in the cab, without even saying anything. He just sucks all the energy around him. And I realized, *this is who he is*. What he has...he will always be like this. He was this way as a tiny boy and he still is, though he's almost grown now. His condition will always be with him.”

“And in that moment, I thought of sitting some morning at the breakfast table, he and I, drinking coffee and reading the newspaper together, maybe talking a little about what's going on in the world, like a father and a grown son would do on a Sunday morning... and it hit me. We will never do that. It's not going to happen. I won't get that father-son moment I've been waiting for all these years. (With tears) It's such a little thing, but it was all I really wanted. Just to have that kind of quiet understanding together as father and son... to share some interests. That's when the wall of all this grief I've been holding back for years came crashing down. I'll *never* know him like that. It's not in there. I haven't just been waiting until he's grown-up. I was hoping for someone to be *in* there and “he's” not *in* there. What *he is*, my real live son instead of my fantasy of who he would be, is this person I'm sitting here in this truck with. Someone for whom everything is somehow always about him, what he wants, *the endless wanting that pours out of him* even when he's just sitting here restless *taking all the air in the cab. This is my son.*”

Our biggest goal as parents is really about learning how to be present with others where they are; not just where we want them to be. Healing involves becoming emotionally and physically available to reality – our life as it is, on life's terms. Many of the most loving, caring parents find themselves at an unforeseen crossroad: they love their child but can't stand living with them. It is a devastating sensation: as if the heart cannot bear what it knows. Some say, “But I can't *divorce* a child!” They feel trapped by how they are feeling.

Parents who adopt a child with special needs experience this phenomenon and often feel terrible about having such emotions and thoughts: increased irritability, exaggerated negative self-perception, insomnia and appetite changes, catastrophic expectation and overreactions to changes beyond their control, limited awareness of possibilities, displaced anger, tearfulness, sense of futility. These symptoms are all associated with depression, a physical state of depleted brain chemistry, when one's “feel good” and self-calming neurotransmitters in the brain have been used up in the course of being the emotional and cognitive “valve” for another person's damaged mind. The symptoms aren't as simple as true emotions about the child, as a human being, but are interwoven with emotions reflecting the yearning for parent-child relationship. Hopelessness, anger and defeat can reflect utter exhaustion from the stress of what it takes to help the child “read” and “relate” effectively to self and others – to be their auxiliary circuits, translating back and forth, breaking the large into bite sized, do-able pieces.

Parents see that “normal” life is continually swamping the child's mental boat, which then tends to take the rest of the family into the hurricane with them. They expend enormous energy serving as the child's rudder. This literally drains a parent's stamina, and puts the parent into mental and emotional fatigue (beyond what genetic tendencies may already exist in the parent's background).

When they seek out a counselor, that professional may confuse the signs of **burnout** for lack of genuine love, or not know how to ease the friction, inadvertently shaming the parent for getting to this

point when they “knew what they were getting into by adopting”. No one, however, truly “knows what they are getting into” developmentally, as the unique mix of strengths and vulnerabilities can only reveal itself over time. Risk of burnout for special needs adoptive parents is something only recently observed in the literature. It is most often recognized in relation to caring for loved ones with Alzheimer’s or other chronic or deteriorative illnesses. This common experience can be named and treated, because it is part of the walk every family learns as they make the shift into *living well with a chronic condition in someone they love*.

Parents show the physiological changes of depletion, confuse these signals for “negative” emotions or character weaknesses, personalize the cycle of stress dynamics and feel ashamed or different from other parents, unaware that much of what has occurred are normal byproducts of exceptional care.

*Compassion fatigue* describes this wear and tear on caregivers, whose own bodies become the auxiliary brain and physical support for someone who remains inconsistently able to function safely – to think, feel and do for themselves in the course of daily life. We might expect it to produce physical, mental and emotional exhaustion when we consider a caregivers “work shift”, i.e. we wouldn’t dream of expecting nurses or doctors to work a shift that lasted 24 hours a day, 7 days a week with no weekends off, no vacation, no medical leave time and no paycheck – for five years! (Much less 10, eighteen, etc.) That IS the work shift of primary parents of children with special needs. No wonder, then, that we are on empty. So, what helps?

Parents inherently fight feeling grief because it is so at odds with internal images of what it would be like bringing a child into one’s life. Unmet expectations, even owning the ones that were unrealistic and arose from our own unmet childhood needs, are still pictures in our minds and hearts, and with those pictures come many kinds of longing. Many parents want to provide for a child because they didn’t get provided for themselves, as children, and didn’t want another to have to go through it. When this happens, the child’s needs may seem endless and eventually our own needs compete. Parents may want the family to be a certain way out of fear that if it’s not... well, what exactly what is the fear if in real life, things are not as we’d envisioned? What kind of structure is needed? Are we seeking to provide structure, or slipping over into insisting on control? Parents slowly learn to give up trying to control their child’s emotions. To recognize how to begin to accept the “unacceptable” which is defined differently according to each particular family.

However one defines it, the bottom line becomes clear: that no matter how parents try, our ability to provide, nurture and protect is naturally limited, for all growing children, but with particular poignancy for children with alcohol effects. Parents learn how to live out choices, not chain reactions, by accepting differing expectations for different family members, rethinking roles, spoken or unspoken assumptions and beliefs.

Parents step back and regroup, rethinking how to be there for the child. They stop confusing who is there for whom. Any child, but especially the child with special needs, needs immunity from being unconsciously confused with our parents or resented for others who failed to meet our emotional needs. Organic brain impairments and other symptoms are plenty for the child to handle without additional accusations, blame, or emotional blackmail (i.e. “I will love you if...”, “*WHY?* Can you just tell me why you didn’t...?”, “You don’t love me or respect me, or you wouldn’t keep doing...”). We take inventory of what triggers we have and how these get “bumped” when our children with alcohol related disorders are self-occupied. When

reciprocity just works very differently for them – or how caring and sympathy are so concrete, and empathy may or may not be available due to their brain “blindness”.

The old ways to change a child’s behavior perhaps involved attempts to manipulate, cajole, coerce, threaten, or force. These new approaches require that parents detach, break things down, motivate, and provide, while accepting the child’s natural right to reject much of what parents offer. Parents must also learn to accept their child’s cognitive rigidity, concreteness, or reflexive arguments, which show they cannot take in the pictures or meaning of our guidance and then apply it in step-wise fashion. Add in the complex and variable nature of organic brain impairments, and we need extra information to help us differentiate, plan, and interact successfully. What we are after here is restoring balanced parenting (even if on sore feet, and on rocky, uneven terrain of “good days & bad days”).

It is a parent’s job to revise unacknowledged expectations of the child with FAS/E, while taking care to stop role reversals that make the child live “for the parent”. As parents, we need to grow gently, but persistently, into awareness of ways we avoid the effected child’s needs, or rationalize that “we could..., if only they would...” acting out our own unresolved anger or disappointment on them and their disability over which we feel so powerless. We may come to a point of resenting their handicap, repressing the guilt we feel from having taken on a basically impossible goal of trying to “fix them” and make all things right. Much of the effected child’s typical problem behaviors result from their frequently unsuccessful attempts to respond to the environment through the distortion of symptoms they can’t help. We may sink into despair that they “just can’t get it”, as if we didn’t try hard enough. Usually, we need to shift into trying differently, instead of harder. We need some new tools in our parenting tool kit.

**Keeping it simple involves learning some basic facts about neurological vulnerabilities. It helps to get a feel for what it’s like in their skin, so that we can reduce our tendency to overreact or personalize behaviors.**

Several handy tips can enter the picture here.

1. When running into a familiar stuck point, ASSUME THE BEHAVIOR IS TRYING TO ACCOMPLISH SOMETHING. AVOID PRESUMING THAT A) IT IS BAD, AND B) IT IS AIMED AT YOU. It may be convoluted, but not willful. Take the time to ponder what purpose it has for someone for whom things get very “uncoupled” and disconnected. As the saying goes, “Don’t prejudge.”

Sally Caldwell tells a wonderful story about a little boy with FAS who got up at 3:00AM and went down to his friend’s house to play. When asked, he could agree that it was dark outside, that he hadn’t had breakfast, that he was in his pajamas, etc., but the pieces of information didn’t form a pattern for him about social convention for visiting a neighbor’s home to play. He had no mental “set” for the appropriateness of his behavior. The information he was acting on was that he was going to his friend’s house, where his friend lives, and it was the same place he always plays with him. Never mind the rest.

2. If getting hooked, DETACH. Take your eyes off the person; step aside or into another room. Take 4 deep breaths. Feel the effort going back to the child. Stop “wearing” their feelings. Back your own energy off! When they sense others’ build up it adds overstimulation, which makes processing even harder.

3. Comment, don't cross-examine. A gentle phrase to point out what you see putting the subject first helps, i.e. "your jacket – it's on the floor. Hook is here, please" (pointing). Avoid ever asking, "WHY did you DO that?!" because it's actually not a question, as there is no okay answer that would ease the parent's anger. The "Why" question actually communicates: "I'm upset! What on earth was that action for? (or...lack of action for?) and shows that parents are already stuck in personalizing the behavior.

4. Reminders, not reprimands. You can offer information. It is quite possible this information simply didn't *register*. Try to "boost the signal" with a visual image or a gentle touch on the shoulder only when you are not feeling pressured. Example: on memory cuing, you might say, "Let me check something with you. Getting reminders. What will help and not hurt your feelings?"

5. One bite (byte) at a time. Let them finish the first step and come back to you when they are ready for the second. Don't chain a list of directions together, as it guarantees disaster. Stay with one instruction at a time. Take the time, and let them do so, too. Arguing when it all falls apart takes just as much effort without nearly the gains.

6. Keep the environment as simple as possible to reduce things they have to keep track of...think "Zen bedrooms". Less is best. For them, and for you. Simplicity equals freedom from the overstimulation that is relentlessly exhausting to them. Never underestimate how tired they get from what seems a "typical" day of having to order, sequence, track, etc. to get through their routine.

7. Routine! They need external order, because it is constantly falling out of place for them internally. Think of a building that is constantly under construction and needs a sturdy scaffold around the exterior to hold up the walls. They need a daily schedule to be a scaffold so they can hold things together.

8. Cue changes or transitions well ahead of time and at intervals (45, 30, 15, 5 minutes if possible.) It is amazing how much difference this makes. Getting ready to go do something else is an actual task as much as the activity that was scheduled, according to Carol Cole of the Savin School project of the Los Angeles Unified School District.

Taking a different approach doesn't happen overnight, but there are definite rewards from giving up an adversarial relationship with your effected child. Know that anger is not the opposite of love, indifference is. Anger is a normal part of grieving, and it occurs in the face of coming to terms with losses. The level of anger you may feel will give you some sense of the amount of strength you may have for the journey of reconstructing new ways to relate to your effected child (ren). Don't stuff it or be ashamed of it. Talk it out with the group. It is fuel for the journey.

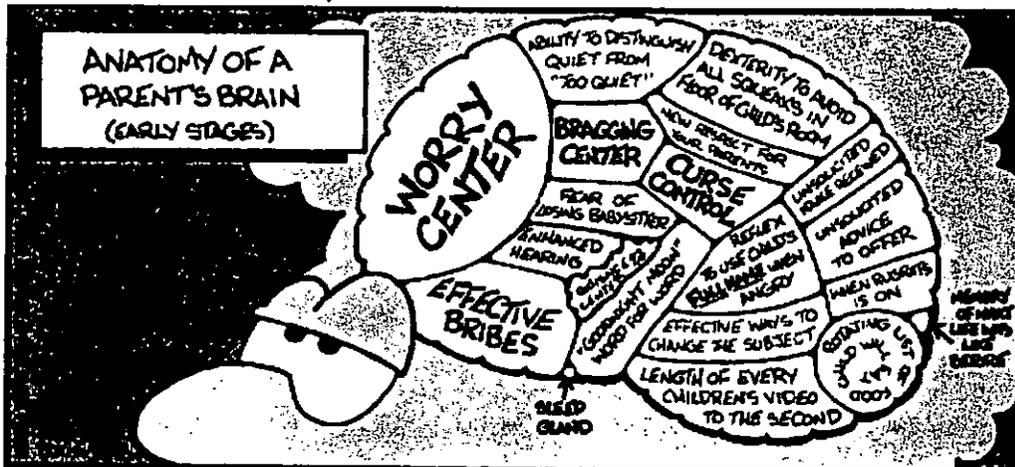
At some point, your children may need as much room as you can give them for dealing with their own anger, loss, and grief over their condition.

# Group 10- Family Support: Talking With Your Children

off the mark

by Mark Parisi

www.offthemark.com



## A DIAGNOSIS = 5 PARTS

FAS is a handicapping condition listed among medical disorders of childhood.

What about when we're told our child has ADHD, then later this or that other diagnosis?  
Let's look at the parts of a diagnosis. It's like a puzzle with 5 pieces (each called an Axis):

<b>Axis I – This axis involves mental health:</b> a counselor describes what a child's problem "looks" like in terms of mood, behavior, thinking, or learning. The child may have Post Traumatic Stress Disorder, ADHD, Oppositional Defiant Disorder, Anxiety Disorder, Depression, Learning Disorders, or other overlapping childhood mental health problems.
Your child's Axis I:
<b>Axis II – This axis involves psychology:</b> a psychologist evaluates intellectual capacity or personality functioning through testing...retardation and personality disorders (considered fixed traits) are listed here. Retardation is often not diagnosable until after age 7. Personality disorders may be emerging, but not formally diagnosed until adulthood.
Your child's Axis II:
<b>Axis III – This axis involves medical conditions:</b> FAS spectrum disorders, brain injuries or organic brain disorders, seizure disorders, asthma and other physical conditions are listed here. The physical condition may underlie or contribute to what is described elsewhere on Axis I, II, IV or V.
Your child's Axis III:
<b>Axis IV – This axis involves life stressors:</b> a counselor explores relational problems for the child related to significant changes, losses, or stressors to a child's family, home, school, peer, occupational and community functioning. Included in this axis are problems related to history of maltreatment or neglect the child experienced or other significant "life events" (i.e. witnessing domestic violence, terminal illness of a sibling, etc.)
Your Child's Axis IV:
<b>Axis V – This axis rates how the child is doing according to a functional scale at the time they are seen.</b>

## Diagnostic Criteria Fetal Alcohol Syndrome (FAS) and Alcohol Related Effects

In the 1996 Institute of Medicine report, Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention and Treatment, edited by Stratton, Howe & Battaglia and published by National Academy Press, Table 4-1 outlines diagnostic criteria for FAS and Alcohol Related Effects as follows:

### FETAL ALCOHOL SYNDROME

#### **FAS with confirmed maternal alcohol exposure (1)**

Confirmed maternal alcohol exposure (1)

Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (i.e. flat upper lip, flattened philtrum, and flat midface)

Evidence of growth retardation as in at least one of the following:

Low birth weight for gestational age

Decelerating weight over time not due to nutrition

Disproportional low weight to height

Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:

Decreased cranial size at birth

Structural brain abnormalities (e.g. microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

Neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, and poor hand-eye coordination

#### **FAS without confirmed maternal alcohol exposure**

B, C, and D as above

#### **Partial FAS with confirmed maternal alcohol exposure (1)**

Confirmed maternal alcohol exposure (1)

Evidence of some components of the pattern of characteristic facial anomalies Either C or D or E

Evidence of growth retardation as in at least one of the following:

Low birth weight for gestational age

Decelerating weight over time not due to nutrition

Disproportional low weight to height

Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:

Decreased cranial size at birth

Structural brain abnormalities (e.g. microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

Neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, and poor hand-eye coordination

Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment.

## ALCOHOL-RELATED EFFECTS

Clinical conditions in which there is a history of maternal alcohol exposure (1)<sup>2</sup> (2), and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome. There are two categories, which may co-occur. If both diagnoses are present, then both diagnoses should be rendered:

### Alcohol-related birth defects (ARBD)

List of congenital anomalies, including malformations and dysplasias:

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Cardiac	Atrial septal defects Ventricular septal defects	Aberrant great vessels Teratology of Fallot
Skeletal	Hypoplastic nails Shortened fifth digits Radioulnar synostosis Flexion contractures Camptodactyly	Clinodactyly Pectus excavatum and carinatum Kippel-Feil Syndrome Hemivertebrae Scoliosis
Renal	Aplastic, dysplastic Hypoplastic kidneys Horseshoe kidneys	Ureteral duplications Hydronephrosis
Ocular	Strabismus	Refractive problems secondary to small globes
Auditory	Conductive hearing loss	Neurosensory hearing loss
Other	Virtually every malformation has been described in some patient with FAS. The etiologic specificity of most of the anomalies to alcohol teratogenesis remains uncertain.	

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<sup>2</sup> A pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking. Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, legal problems related to drinking, engaging in physically hazardous behavior while drinking, or alcohol-related medical problems such as hepatic disease.

<sup>2</sup> As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with ARBD or ARND, these patterns of alcohol use should be incorporated into the diagnostic criteria.

**Alcohol –related neurodevelopmental disorder (ARND)**

Presence of:

Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following:

Decreased cranial size at birth

Structural brain abnormalities (e.g. microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)

Neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, and poor hand-eye coordination

Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment.

Table 2. Effects of Prenatal Drug Exposure during Pregnancy, on the Newborn, and on the Growing Child

Type of Drug	During Pregnancy	On the Newborn	On the Growing Child
Cocaine	Poor weight gain Sexually transmitted diseases Fetal hypoxia Intrauterine strokes Spontaneous abortion Pre-term labor Premature rupture of membranes Precipitous delivery Stillbirths Abruptio placentae	Premature birth Intrauterine growth retardation Meconium staining Smaller head circumference Tremulousness Increased startles Shrill Cry Abdominal muscle tone/ reflexes Restlessness, irritability Rapid state changes Irregular sleep pattern Difficult to console, decreased cuddliness Poor feeding, vomiting, diarrhea Impaired habituation Gaze aversion Facial defects Neural tube defects Visual defects Limb defects Genitourinary defects Congenital heart defects Intestinal impairments CNS lesions Intraventricular hemorrhage Seizures	Disorganized form of attachment Easily frustrated Mood dysfunction Seizures Autism Learning Disability Language processing problems Difficulties with articulation Attention Deficit Hyperactivity Abnormal Oculomotor functioning
Marijuana	Difficulty conceiving Spontaneous abortion Precipitous labor Tachycardia Hypertension	Intrauterine growth retardation Meconium staining Myopia Increased tremors Features compatible with fetal alcohol syndrome Poor habituation to visual stimuli Abnormal oculomotor functioning Abnormal sleep and arousal patterns	Leukemia Myopia Strabismus
Narcotics	Difficulty conceiving Sexually transmitted diseases Hepatitis A, B, C	Premature birth Meconium staining Intrauterine growth retardation	Strabismus Attention Deficit Developmental delay

3. "Infants and Children with Prenatal Alcohol and Drug Exposure: A guide to identification and intervention", by Keeta DeStefano Lewis, R.N., P.H.N., M.S.N., Sunrise River Press, 1995, ISBN #0-96248-24

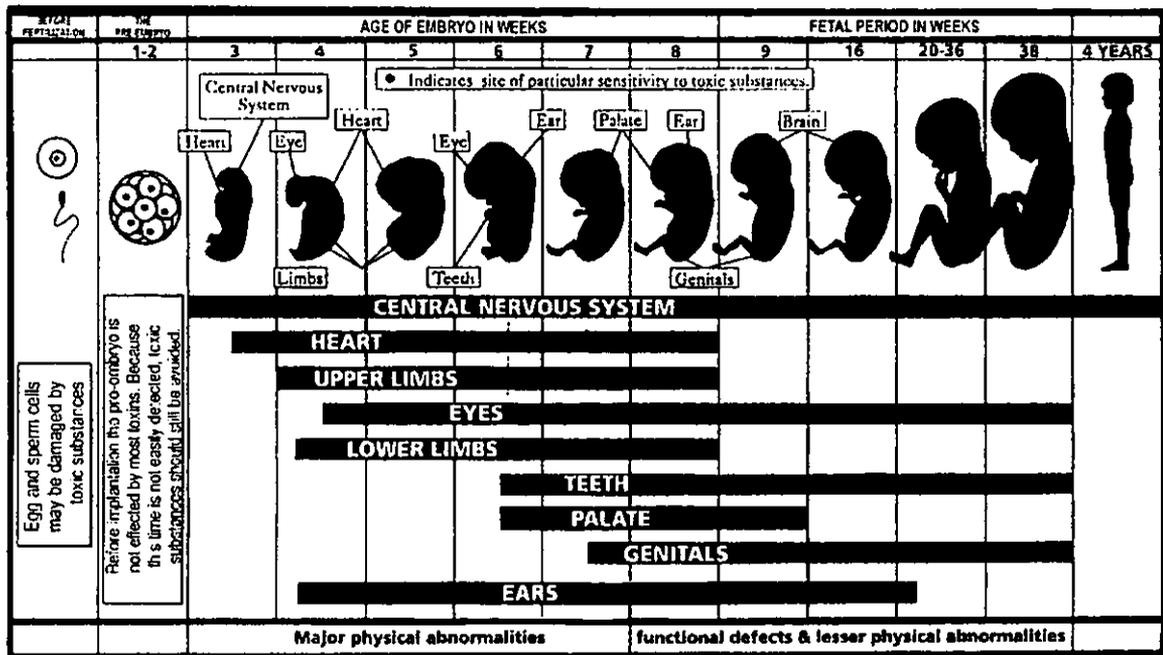
Table 2. Effects of Prenatal Drug Exposure during Pregnancy on the Newborn, and on the Growing Child (continued)

Type of Drug	During Pregnancy	On the Newborn	On the Growing Child
Narcotics (continued)	HIV Bacterial endocarditis Septicemia Cellulitis Toxemia Eclampsia Placental insufficiency Abruptio placentae Pre-term labor Premature rupture of membranes Breech presentation Stillbirths Spontaneous abortion	Smaller head circumference Neonatal abstinence syndrome SIDS Apnea	Learning disability Hyperactivity Slowed psychomotor level Temper tantrums Delayed speech Impaired visual motor functioning
PCP	Tachycardia Hypertension Hypertonia Seizures	Intrauterine growth retardation Tremulousness Irritability Hypertoxicity Meconium staining Diarrhea Vomiting Temperament instability Poor visual tracking Difficulty consoling Rapid state changes Nystagmus	Attention deficit Diminished social interaction Dull with flat affect Poor fine motor coordination Oppositional behavior Delayed speech language
Tobacco	Difficulty conceiving Ectopic and tubal pregnancies Poor weight gain Chronic fetal hypoxia Vaginal bleeding Spontaneous abortion Pre-term labor Premature rupture of membrane Placenta previa Abruptio placentae	Premature birth Intrauterine growth retardation Smaller head circumference Tremulousness Hypertoxicity Poor habituation to sound SIDS Cleft palate/lip Hernias Eye and ear malformations Congenital heart defects Central nervous system abnormalities	Increased respiratory illnesses Diminished lung function Chronic otitis media Childhood cancer Attention deficit Hyperactivity Diminished reading, verbal, and math skills Lower IQ Poorer social skills

See Fetal Development Graph

## The Effect of Toxic Substances\* on Development

\* Such as: Alcohol, tobacco smoke, illegal drug and some over the counter and prescription drugs.



Note: Adapted from: Mare, Keith L., 'The Developing Human, 4th Ed. (W.B. Saunders, Philadelphia, 1988)

## COMMON REACTIONS TO RECEIVING A DIAGNOSIS

The words "Fetal Alcohol Syndrome" or "drug exposed children" typically bring up discomfort, fear, denial, minimizing, avoidance, and other natural reactions. Unresolved feelings about addiction can be triggered by the mention of alcohol and drugs inherent to this disability. Professionals with personal associations to addiction may overtly or covertly communicate conflicting attitudes and beliefs. These can influence how the family's situation is handled: the professional may guide the natural, productive opportunity to support prevention and intervention to reduce risk for the next generation, or inadvertently delay solutions (Morse, 1990; Malbin, 1993). Some families remain hostage to blame and other emotions common to an unresolved grieving process, stuck in helpless outrage that their child could have suffered preventable harm. This is commonly felt by parents over any disability in a child, much less a preventable one. As grief resolves over time, this surge of protective instinct generates increased advocacy and compassion for the children, and the larger community of families facing similar challenges.

Parents hearing about other medical conditions in their children go through a similar process. Parental discomfort when receiving diagnostic information can include:

1. Anxiety about medical outcome.
2. Fears about future complications and risks.
3. Loss of (or change in) valued life goals and aspirations for the child.
4. Feelings of helplessness about how to manage the condition.
5. Anxiety about how to plan for the future.
6. Feelings of intense guilt or anger about the child's condition.
7. Recognition of the need for changes in living patterns due to the condition.

Obtaining information about FAS or FAE and other medical conditions in children involves phases of grief: impact, denial, anger, bargaining, mourning, acceptance, focusing outward. Recognition and support provide a context for the adjustments families face in accepting the reality of an ongoing condition in the life of a loved one.

Source: Adapted from Schowalter (1979)

## PSYCHOSOCIAL TASKS: COPING AFTER DIAGNOSIS

Several tasks are part of successfully coping with FAS and other alcohol related disorders and drug effects. Literature on chronic conditions in children emphasizes:

Maintaining emotional distress within manageable limits –  
(learning how to care while detaching from overreaction).

Understanding medical and developmental needs and how to meet them with new knowledge, skills, and motivation.

Preserving important relationships with others in a support network \_  
(stepping out of isolation).

Regaining hope for the future - (alleviating burnout).

Encouraging adaptive development for the person with FAS or other drug effects in family, peer and school roles and responsibilities;  
(building on inherent potential & characteristics of the condition).

Maintaining stable, equitable family functioning –  
(using solutions-focused, instead of problem-focused coping skills).

### CUMULATIVE FACTORS and FAS/Alcohol Related Disorders:

1. The sense of success or failure from earlier coping efforts can influence later outcomes, and may determine lifelong patterns of adaptation to the condition.
2. Children who learn about their symptoms may develop an increased sense of control and ability to cope from participating in problem solving.
3. Conversely, repeated failures in coping can impede psychosocial development and contribute to maladaptation (increased defensive behavior).
4. Families can better assist the child in dealing with various developmental needs in different ways, once the ongoing condition is acknowledged and understood.

Source: Adapted from Levine, Carey, Crocker & Gross (1983); adapted from Schowalter (1979)

PHASES:  
RECOGNITION, ADJUSTMENT & RESOLUTION

**"OH YES!"** (Things finally make sense)

**"Oh NO!"** (This is real and ongoing)

**"OK..."** (Now, what to do differently)

Source: Rathbun (1992)

## Section 3: The Stress Map: Symptoms and Strategies

### Topic 5: Speaking "Porcupine": Symptoms at Home and in School

Parents see the brain through actions and behavior: by seeing what a child can or can't do as others at their level would. Sleeping, feeding, relating to touch, sight, sound, taste, smell, and other sensory information, mastering movement with coordination of balance and posture, and having emotions, thoughts and communication with others are brain's work which is seen through *behavior*.

The chart below outlines the core developmental tasks a baby masters in the first months of life. The baby's brain does this work just by staying alive from day to day. The tasks below are the core of later, more complex behaviors that show the interaction between one's brain, body, and surrounding environment. When a fundamental gap in ability persists, the child may compensate through another ability or avoid the weakness, depending on opportunities available to grow despite the challenge. Think about how often we depend on our basic ability to respond to and interact with our surroundings to meet our needs. Do we usually put words to the capacities below? These functions instead become the "background" of daily pursuits, i.e. people don't have to tell their eyes how to adjust the pupil according to variations in light level inside or outside, as the brain acquired this skill and built some "automated" programs during infancy which provide this response to specific conditions (cues) that activate it.

#### Brain Basics in Newborns: Brazelton Behavioral Categories

<b>Category</b>	<i>Measured Behavior</i>
Habituation	How soon the newborn reduces responses to specific repeated stimuli, e.g. light, sound, touch.
Orientation	How often and when newborn attends to auditory and visual stimuli.
Motor Maturity	How well newborn coordinates and controls motor activities.
Variation	How often newborn exhibits alertness, state changes, color changes, activities and peaks of excitement.
Self-quieting behaviors	How often, how soon, and how effectively the newborn can use own resources to quiet and console self when upset or distressed.
Social Behaviors (cuddliness)	How often and how much the newborn smiles and cuddles.

Table is revised from Martin, Leonide L., and Reeder, Sharon J. (1991). Essentials of Maternity Nursing. Philadelphia: J.B. Lippincott Co.

When the above tasks flow smoothly and adjust easily, the child has gained **self-regulation**. Regulation is learned, and practiced until it is automatic for most people. Variations in regulation are normal, for example, some of us need soft music to fall asleep, and others prefer absolute quiet. Once one's threshold for response to common conditions is practiced, people "automatically" seek adjustments to maintain regulation, as it serves much like an invisible platform on which tasks that are more complex depend.

In many adopted children with prenatal exposure to alcohol or other drugs, regulation is delayed in some areas, or impaired. Sensations evoke startle, or don't rouse the child at all, and other extremes.

This is hard for parents to pinpoint and describe, but they are not imagining that some basic gaps are present in how the child is responding to seemingly "normal" daily conditions, i.e. the brain seems to be interpreting the world as noxious, or simple ways of responding are not automatic, but rather are more difficult for mysterious reasons.

Though ADHD may be present and medication effective to manage it, neurosensory differences may persist for which there is not a specified single medication. Rather, new skills for use in the child's home and school settings may become crucial to daily stress tolerance.

The literature on early childhood discusses how new skills are supported through a process called "scaffolding". It's a useful idea: a scaffold provides the temporary structure needed in order for something to be expanded upon or built up. With children, play allows practice of many new skills emerging at various rates (even in the range of typical development). For children with damage to the basic organ doing all the processing and linking work above (the brain), need for extra scaffolding may continue beyond that needed by others without brain injury. Though not necessary in all domains, where there is difficulty, the need for extra time, support, and smaller steps, as scaffolding, can be essential despite the aura of 'perceived' ability. The children tend to look better than they perform over time. This inadvertently sets parents up for a very confusing scenario!

Specific neuropsychological tests can show how the brain is functioning, i.e. the Reitan Trails Making Test, Stroop, Vineland Adaptive Behavior Inventory, and others. Parents don't have these behind the couch at home (at least most of us don't). So, what parents "see" by watching tasks and keeping a homework log in this curriculum is how the brain does its work (or at times, cannot). Parents begin to notice the child's stamina and pacing for routine, and ability to master age-typical tasks over time. The hard part comes when *sometimes parents do see typical ability*, while almost as often, but randomly, it seems to just slip away. On days, off days. Good days, bad days: but always learning. Then, relearning and rehearsing.

**Fatigue, irritable mood, headache, and confusion or disorganization despite familiar routines can be common "invisible" target symptoms in children and adults with damage to the central nervous system.** These symptoms can reflect the vulnerability of how hard the brain works to regulate and respond, to maintain automatic adjustments that keep pace with the environment. Parents see similar symptoms with head injury, stroke rehabilitation, Alzheimer's disease, and other brain syndromes. With alcohol related disorders, there may be actual changes to brain structure that show on an MRI, lobes that are malformed, lesions, or other difficulties, or there may be more subtle neurochemical or neuroelectrical abnormalities which can have significant implications for how smoothly and efficiently the brain can regulate, learn and apply learned information to the demands of daily living.

With the introduction of MRI technology, researchers investigated two 16-year-old children (1 male, 1 female), who did not have FAS but whose mothers were considered "alcoholic" and drank heavily during pregnancy. Both children also had a history of behavior problems and cognitive impairments. Their IQ scores were 64 and 69.

Doctors stated results from the MRI scan of both children showed, *Gestational alcohol exposure has consistently been associated with perseverative behavior, difficulty with spatial memory, and understanding behavioral outcomes. Interestingly, the basal ganglia have been linked to the ability to change behavioral set, spatial memory, and goal-directed behavior. Thus, some of the behaviors in children with prenatal alcohol exposure may be the result of abnormal development of the basal ganglia.*

There is no one specific site that is always revealed as "the part of the brain that's not working right". Rather, there may be certain areas of damage, with a larger problem being that the circuitry of the brain, which communications between areas can be compromised. In essence, this prevents the brain from being able to reliably and flexibly juggle input and output so that a person can relate to the world as others do.

As children grow, so do the demands on the brain, to learn how to handle complexities of life. Fatigue, headache, pain, or tiredness in the hands or other extremities are all physical stress indicators that may signal when the brain's "stress threshold" has been reached or exceeded.

*In a follow-up study, the scientists studied 20 male mice exposed to alcohol during gestation. Autopsy results of the animals' brains showed a smaller caudate-putamen area. The authors stated, "Interestingly, the caudate-putamen has been suggested to be part of a general learning system, in that lesions (damage) to this area can produce widespread learning and memory deficits (24)."*

*Thinning or absence of the corpus callosum can occur, as well as a wide variety of other changes.*

Difficulty with executive functioning, more complex work of reasoning and problem solving involving the frontal lobes, appears quite consistently in the literature on Fetal Alcohol exposure. This explains why many children can manage through 3<sup>rd</sup> grade, but seem to "hit the wall" as curriculum from 4<sup>th</sup> grade on requires greater internal organization and use of simultaneous mental functions, i.e. holding concepts in parallel so as to compare and contrast them, and increasing abstraction.

*"Up until third grade, children are learning to read. Many children with prenatal exposure to alcohol can become good at reading. However, from fourth grade on, children have to start reading to learn. That's when many children with alcohol related disorders fall apart. Comprehension and application of concepts encoded in language patterns involves different brain functions. Children can read the words, but still not have any idea of what they mean, or what must be done with them. It's frustrating because they can read, yet not understand what's read."*

Dr. Jay Edwards, Psychologist

## Executive Functions

Executive functions (prefrontal cortex)	Effects of alcohol exposure on executive functioning
Inhibition	Socially inappropriate behavior (younger, or "odd")
Planning	Inability to link cause & effect, apply consequences to actions
Time perception	Inability to abstract, can't grasp concepts of time or money
Internal ordering	Difficulty processing information, organizing, prioritizing
Working memory	Trouble with storing/retrieving learning information
Self-monitoring	External prompts, cues needed; cannot read "significance" of own actions in context of others' cues; inaccurate self-appraisal
Verbal self-regulation	Externalizes self-talk (out loud) to "hear one's own thinking"
Motor control	Motor planning, sequencing or execution weak or spotty
Regulation of emotion	Difficulty with gradation of feelings; "fine" or "furious" with little range or shades of feeling, huge reaction to small slights
Motivation	Avolition; disconnected "drive", needs strong external motivators; lethargy or hyper; short term goals only, can't retain "tractor beam" on steps for goal completion over time

Most parents are familiar with basic ideas about what motivates children. Parents provide, nurture, and protect, as do teachers or other helping adults. Children need nurture, attention, limits, safety, and security from adults in order to grow up and provide these to the next generation. When parents see "inappropriate" behavior, for example, lack of responsibility (or ability to respond appropriately to conditions typically handled in a certain way at a certain age) parents want to shape it into something more suitable: to coach, guide or encourage other choices. The more outlandish or unexpected the action, the more urgency adults feel about helping a child master the situation properly. It may involve making things right with others, or regaining one's self-control. When the child's involuntary behavior is viewed as a choice, parents instruct and offer better choices. When it is repeated despite instruction, parents try to address motivation. When motivational measures backfire, parents are stumped, unless parents go back to the beginning: **observation**. What if the gap in appropriate behavior is not a choice, but a reflexive reaction or habitual pattern?

When a symptom flares, but is not recognized as a symptom, it remains, increases or compounds. Some clues are hard to decode because they engender discomfort, i.e. a 5-year-old child blowing nasal mucus at another child or the parent. Regressive or aggressive behavior may seem out of proportion to what precipitated it. It may be helpful to remember that these are two common defensive styles. When children's defenses rise, they seem to be experiencing a sense of threat, hence the need for self-protection (defense against perceived attack or threat).

Is the child sensing risk of loss of safety, nurture, comfort, or security? Though it is natural to want to stop defensive behavior, and sometimes it seems extreme, parents often face further havoc trying to force control or enforce immediate compliance: the child *will* accept limits *NOW*. Part of what drives strong parental reactions is their appraisal of potential danger: if a child yells, what is next? Hitting? Harm? Most parents want to nip escalating maladaptive behavior in the bud, and most children can adjust quickly to adult signals. What happens when behavior is defensive (without perceivable cause) and slow to shift due to poor regulatory ability?

What parents see may be a child whose growing, learning, brain uncouples information. Information may not connect or be used in context. Children with prenatal effects may have unique “logic”, or be incomplete thinkers: some information gets locked in, some pieces left out, and other information remains known though not applied in typical ways to situations where it obviously pertains, because the obvious simply was *not* obvious, or generalized, due to brain impairment. Parents learn to see patterns that give a clue to these difficulties and sporadic mastery:

- ⇒ Poor ability to signal need for help despite having been told what to say.
- ⇒ Sudden “spikes” of aggression (no gradation of affect, or middle ground, just “fine” followed by “furious”),
- ⇒ Poor social negotiation and limited play skills (i.e. lack of ability to read emotion cues in other’s faces, voice, or language patterns such that reciprocity is impaired, lack of turn-taking, swapping or other problem-solving skills.) Preoccupation with self-concern, and missing another’s point of view despite coaching by adults,
- ⇒ Rapid escalation of reflexive actions (fight/flight) – reacts too fast, too strong, and doesn’t know why. Impaired frontal lobe functions (stop, think it through, say cues to self, say out loud, etc.) Behavior shows disproportionate self-protection. The child’s brain seems to “slip the clutch”; lacks discrimination of emotion or scaling of stressors, i.e. can tell *discomfort* from *danger*.
- ⇒ Alexithymia – Emotional “blank spots”, inability to communicate feelings in words, then regression or aggression (had tightness or gnawing sensation in stomach or viscera, mistakes this for “hungry” or doesn’t understand what emotion is present despite knowing the names of feelings such as, mad, sad, scared, etc.)
- ⇒ Lacks caution, rule or logic adherence -- child cannot decode own feelings, can’t use feelings as guide for problem solving, i.e. though child can say the rule, when engaged in actions that break it, child lacks the meaning linked with warning or other emotional associations (visceral tightness such as “uh-oh” sensation or dread in pit of stomach). Where there is no *felt* deterrent, consequences are ideas without associated emotional significance.

When reflexive or defensive behavior occurs instead of speaking to signal need for help, communicating calmly, simply, and slowly may help parents avoid further escalation. Language may go offline when the midbrain is overaroused. Notice physical stress signs such as narrowed pupils, set jaw, a frozen expression or blank face, child holding breath, etc., as cues that the child needs to regain composure before actively problem-solving.

Few children ever get off the school bus, walk in the house, and announce their needs in this way:

“Gee Mom, my hyperacusis was bad today. The bus was so loud; I’m getting a migraine. I’m so nauseated I don’t even want my snack. I need to go in my room, sit in my closet in the dark with some pillows for about 20-30 minutes first, get some proprioceptive compression, then after my stress hormone level is lower, I’ll need snack to help me regulate my body chemistry, then get some help with my homework.”

With time and structure, however, children with alcohol effects can improve their coping and advocacy skills for using accommodations to keep stress at tolerance or below under general circumstances.

Parents want the child to speak up when something is wrong, but how do they discuss such symptoms? This is where parents may see the child's signals and coach new ways of meeting needs.

Where are the headaches, the facial, vocal or body gestures (tics, stereotypes, self-stimulation habits), distraction, irritability, or perseverative behaviors happening throughout the day, or week... or the month? A pattern of good days and bad days? A gradual performance decline, increase in stress signs, big explosion or implosion, then rest and regrouping, then good days again? Parents step back, slow down, and sort out what they see, when they see it, and exactly what is happening (instead of what they thought it meant towards them). As Yogi Berra quipped:

"You can observe a lot just by watching..."

## Topic 6: THE STRESS MAP: 3 Symptoms & Strategies

Parents use The Stress Map to come to grips with what is different about their child's responses to daily stressors, what gets stuck, and what helps each of their unique children. A central concept for preventing deterioration in persons with FAS is *understanding how stress may play a role in defensive reactions.* Since each child functions just a little differently than other children, even alcohol exposed peers or siblings, parents need to make a personal stress map that fits each child. Though the principles will help parents organize what they actually know, only parents have the needed details about how their child performs over time that capture the pattern of a child's unique abilities and struggles.

When central nervous system damage interferes with memory, learning, and behavior, a child may seem stubborn or badly behaved. When parents take a closer look, the child may be getting lost, stuck, or agitated by the pacing, amount, or complexity of tasks considered "routine" to those without brain disorder. Even repeated instructions and explanations may not be enough to ease distress, when it's a "bad day" for the child's brain. Parents report more anger, aggressive or regressive (younger) behavior, and defenses such as hiding, bullying, whining, lying, and outright denial of obvious difficulties. This behavior may seem out of scale with what set it off (if we can even find extenuating circumstances that did). Denial is a symptom: consider it a primitive form of self-protection, like an emotional reflex. As strange as it seems, denial is not a chosen behavior, but a default behavior – it crops up when children feel cornered or threatened. Unfortunately, even if not actually being cornered or threatened, the child's sense of this is very compelling and reactions occur like a reflex. The child may come on big (making claims, blaming someone or something) when they are feeling small (confused, cornered, helpless).

Parents want children to match behavior to varied contexts. Social rituals depend on codes, for example against lies, about respecting others space or property, shaking hands to show courtesy and agreement not to be aggressive to one another, protecting or providing for those younger or weaker, hugging family members to signal affection and intimate space, etc. These rituals and gestures form a code of mutual agreements that help people make sense of changes in the flow of social organization and action. Patterns of proximity, timing and sequence of communication hold layers of meaning adding complexity to spoken communication. Meaning becomes inferred and applied over time; it is not openly negotiated over and over each day. We extend it to our property or possessions. These are "invisible" rules in operation over time, unless one has to renew such concepts on a daily basis.

Rules and limits teach children wants from needs. Children learn to accept and depend on parents, acquire ability to soothe, delay gratification, practice patience, etc. However, children with alcohol effects may have very different responses to needs and wants over time. Parents report how the child who has FAS, when caught with cookie still in hand, will adamantly deny having taken it, pleading contradictory explanations one after the other with utter, heart-wrenching sincerity, none of which are plausible or match up with each other! (The symptom is called 'confabulation', common in brain disorders where gaps in memory are filled in

with random information). Confabulation may increase with stress, i.e. when the child gives several mutually contradictory stories or fragments of possible explanation, which nonetheless are quite impossible by simple observation, but which the child with organic brain damage insists are true. It is as if the feeling is what's true — the speech makes a word picture that captures the feeling. Yet, logic shows faulty reasoning in the hard spotlight of examination.



Asking for simple answers to simple questions can require extra parental patience. Parents try to help, give a reminder, and get snapped at for their efforts. "I know I'm not stupid!" "I never did that!" "I don't that!" "You didn't tell me!" and other defensive reactions intimidate, confuse or anger the parent, because, after all, they *are* trying their very best to understand and help with next steps.... can't a parent get *anything* right? Parents need to stop personalizing, yet what, if anything, can stop these struggles over *every little thing*? Parents feel bad that the children are uncomfortable, but attacking their advocates is not helpful either.

Living well with a chronic condition depends on "anticipatory coping". <sup>ii</sup> A huge missing piece for children with alcohol and other drug effects involves learning how to soothe, *then, when stress is reduced, communicate*. This can sometimes be easier through pictures, gestures, or other signals, instead of words. Parents learn to back up, back off, look, and think through what is happening...as if watching a porcupine who bristles, then balls up until it can calm down.

As infants, children with alcohol and other drug related effects could have differences in regulating states of alertness, rest, hunger, etc. Like little porcupines whose bristles react too strongly, some are over-aroused and can't calm easily (flat, high-pitched cry, inability to be consoled). Others are hard to rouse, can't stay alert to feed (lethargic, falling "asleep" during suckling). Temperament studies in infants indicate such basic "settings" between one's brain and surroundings, the emotional vocabulary of 'states' we show are pathways that then get strengthened through experience, or myelinated, prior to school age. Up to age 6, children learn and refine movement and language skills to translate what they doing into a spoken representation of an action. After this age, we expect them to respond to cues and use language, instead of actions, to negotiate their needs. Stimulation differences, communication, and social relatedness evolve into interaction patterns a child masters...or has trouble mastering successfully. Problems with arousal, discerning meanings of facial or vocal cues, and having smooth transitions between activities...all of these we take for granted in "communication" and "behavior management". What if making the connection from stimulation in the environment, to action, to language demands extreme effort due to brain differences, and we don't know when a child is stuck? For example, the child gets headaches by the time a half hour in the preschool classroom has gone by...would they say "My head hurts. I can't hit, so I need a quiet resting spot." Typically not. Stress overcomes them as the discomfort builds, and we see crabby mood, hitting, shoving, or tantrums. Imagine how many times a day these simple mismatches happen and the role of stress relative to behavior makes more sense. Stress responses are possibly the biggest cultural difference between persons with alcohol effects and the outside world. They get very lonely when we don't understand! What happens to "porcupines" is so often different from what we think.

What does it look like?

## Porcupine Tools

As with other forms of brain injury, someone with alcohol effects who is stressed and can't calm down becomes overwhelmed, somewhat disoriented or agitated, then aggressive or aversive (fight or flight). Aggressive reactions signal us that arousal is up (fight); we try to talk them out of it and aggression increases. Avoidant reactions confuse us because we expect verbal negotiation (if a child is able to speak) before they run away. They need to "hide" in a safe spot to calm, and then talk afterwards. Reducing stimulation allows stress hormone secretion to recede. The child has a harder time making sense of stimulation, is over-alerted, and needs extended calming time before further processing of ideas or sensations using language. A porcupine who bristles too easily, balls up and has a hard time soothing gets stuck, but without a way to *say what happened until*

Behavior management may be the goal, but this term implies that a person is always cognizant of the factors affecting their behavior. With a central nervous system that over- or under-reacts to cues, discomfort, and confusion may occur suddenly or accumulate into sudden "floods", but remains involuntary! By the time a person calms down and figures out what they misunderstood, they feel helpless, frustrated and ineffective. They didn't "master" their environment, and this makes them feel vulnerable. The higher a child's intelligence, the more painful it is to have "bristle attacks" and misread the world around them, hence the denial.<sup>iii</sup> Reaction formation and denial are mental defenses against loss that occur to help them compensate: I'm not helpless or vulnerable...I have power! (I come on big when I'm feeling small).

Reducing denial comes from normalizing the "stuck" experience over time, without shame. Coaching the child using phrases like "getting your body safe/ or your words safe" can take many forms:

- a low-stim activity (cocooning in a beanbag)
- a high-stim activity to release motor overflow (kicking boxes or kneading clay, until agitation ebbs down)
- naming a physical cue (face hot, stomach tight, hands fisted) NOT an emotion yet.
- showing, not telling, pointing using picture selection or drawing.



Interventions at this point are not about reasoning in conversation.

Showing what's stuck is often easier than saying it. Children can show what it's like in their head, their heart, stomach, hands, etc., with art materials as a beginning to naming physical sensations, matching them to emotions then seen, as well as felt. If we find out where, when and how the stuck episodes take place, we can better understand how to reduce stressors, change environments, coach them in use of gestural or verbal signals to cue the "outside" world to slow down for them.

The key is understanding when stress has overwhelmed their senses, decision-making, and ability to process and communicate in language. Using calming strategies to contain and slowly reduce stress lowers the feeling of being overwhelmed, cornered, and alone, as if no one understands. As interventions work to help the child calm and normalize loss of control without blame, denial can reduce. Owning differences leads to advocacy: "this is how it works for me." Mapping out when and how "bristle" episodes happen builds solutions. Parents and children create a "porcupine toolkit" for easing tension, overcoming misunderstanding, and mutual mistrust.

## Topic 7: Talking about FAS/ARND with Children

Each child with alcohol or other drug related disorders is first and foremost, a child, and second, a person with strengths, and third, an individual with an “invisible” handicapping condition; that is, not all children with such exposures have the characteristic facial or musculoskeletal anomalies seen with the full expression of Fetal Alcohol Syndrome. Parents and clinicians sometimes report that as they personally adjust to the reality of these conditions, children spontaneously began to ask more questions about their histories, symptoms and struggles, as if responding to an unspoken sense of permission to develop a framework for communicating about their culture of being as it effects daily life. Conversation can be useful in expanding one or two ideas related to the child’s observation of what is easy and what is hard, and when.

Using characters in parallel stories about symptoms offers a non-threatening way to explore thoughts and feelings at some emotional distance. “The Little Fox” series is one example of how material about the needs, strengths, and supports for people with FAS and other alcohol related disorders are handled in the family and community.<sup>1</sup> Adults benefit from previewing all materials and discussing them first, to prepare simple, honest answers and self-reflection. Mothers and fathers tend to process recognition, grief, resolution, and other realizations in different ways. There is no one “right” way to resolve reactions like denial of the disability, minimizing, anger, or disappointment over unmet expectations, and other typical responses. Rather, moving through these parenting responses can be eased by discussion with other fathers and mothers in parent support group. While one parent’s ache to provide, nurture and protect is being retooled through the learning of new skills, the other may be maintain the former ways to keep the “breaks” on the pace of change and adaptation in the family. Though there are no perfect ways to go through this, many families find that gaining assessment and intervention brings both relief and grief, and that grief is a beginning, rather than an ending; some family ways will change, some will remain, and others may require adjustment for everyone concerned. The main “emotional safety” rule is to avoid the tendency to blame, i.e. no family ever ends up stuck because they wanted to, and these disorders tend to be invisible and are only now becoming better understood. It takes time to get stuck, and it will take awhile to get unstuck. Parents need patience with themselves, as well as their children.

### Young Children:

Young children are very immediate and physical. Though they may speak, they are still gaining the mental circuitry linking what the body is doing, and the sounds, gestures and words used to convey the action (to symbolize it in these other ways). Meanwhile their basic capacity to regulate may be immature or spotty, causing alarm when they should have mere interest, lethargy when they should be attentive, and other over- and under-reactions, keeping them somewhat “mismatched” with their surroundings, despite parental attention to meeting daily needs. Reassurance, calm and structure help ease confusion:

Consistent, warm, reassuring support from parents and medical personnel, i.e. “That is hard, huh? You gave a good try.”

Feelings are physical to them. Say what you see and keep the focus on the body (not the outside stimuli), i.e. “eyes -- tears” said with sad voice, the word “sad”, the heart “ow” in the chest, etc. Gestures or

simple signs (paralanguage) help bridge "body talk" to speech, and drops away when language skills get stronger.

Young children need to trust adult care, limits, and safety. Their own reactions may be exaggerated and alarm them further.

Use concrete language ("picture-talk") about animals or plants to describe differences (i.e. dogs have special ears that hear things well, owls like things darker and wake up at night, flowers have soft petals like tender skin, etc.)

Help the child belong in the natural world with other living things by pointing out and appreciating differences, i.e. differences are the norm in nature, not sameness.

They cannot easily tell you about overstimulation; they show how it affects them, or act it out. Spontaneous urination despite toilet training can indicate more serious stress accumulation or poor stress de-escalation. Varying touch and pressure to extremities may calm or organize them when words or talking makes everything worse.

They cannot tell you about gaps in their comprehension; they repeat things over and over when trying to grasp what was heard, or being unable to unplug emotional surges.

Their body sensations, feelings, thoughts, and actions are "seamless", not discrete aspects of their subjective awareness. The "emotional tone" underlying all other understandings of themselves and the world tends to layer onto this physical-sensory baseline (managed at the mid-brain level).

Adjusting their environment to accommodate their physical differences can be soothing and help them experience healthy "fit" with their surroundings (they may need to babble or sing to themselves aloud, cocoon, have lower light intensity or indirect light, other "odd" environmental accommodations).

Young children don't have any way of knowing that others' experiences are different from their own. They think adults hear what they hear, etc., taste what they ate, etc.; know their thoughts or events of the day (still a magical sense of merged awareness with mother, as if she is an extension of the child's self and sensory map).

They have as much trouble accepting themselves when things aren't working as adults do; only they have less ability to put this into words. When unable to master their own bodies, they feel intense helplessness, which can also trigger disproportionate spikes of fear or anger, without much range (full fits or fine, happy mood with almost no gradation of feelings in between).

## School Aged Children:

School aged children may understand simple explanations of the condition and want to know what is different about their bodies. Children are concerned about what caused their difficulties, and if any other children have it or if they are the only ones. They want to know that someone else has felt the same way they have, and what he or she does about it. Tell about symptoms and strengths, and validate struggles and successes. **NOTE: Adults discussing brain differences with children are cautioned to avoid use of medical slides meant for adult audiences.** Instead, visual metaphors created by children provide a safe and concrete language of expression for their experiences without overemphasizing deficits, i.e. "it's like a wall in my brain and sometimes a mouse gets through"... "in my head it's like snow on a TV screen -- it's hard to tune in on one thing."

There is a need to come to terms with realness of the condition, i.e. "Will it go away?" Some things might change, and some won't. Your ears will always hear noises better than mine will. You might always like... (activity like reading) better than.... (some other activity like math). However, you might be less frustrated if we...(modify the situation).

The more intelligent the child, the more he or she will sense differences from peers. Children can use art, poetry, songs, etc. for self-definition, strengthening emotional coping skills. **NOTE: Pretending 'it will all go away' or there is nothing to worry about patronizes the child's effort to communicate their reality and daily experiences.** They need our validation and support to begin to make sense to themselves about what is different.

Children may show initial relief "Oh, I'm glad I'm not stupid." Then, there is usually a stage of bereavement when they realize that symptoms will continue. These can be framed as "differences", i.e. "what's hard for you" and "what's easy for you". Periodic grieving or disappointment may surface when the environment is unyielding and extra support is needed, i.e. ask, "What's not working?"

Grief reactions may include anger, and need to be vented in safe ways. Anger expresses a sense of self, and discontent with any harm to the self, whether it was intentional or not. An expression of power, the fuel of anger can be used constructively, i.e. as a signal that something hurts, or that a change is needed.

Repeated questions about why the birth mother drank during pregnancy may indicate the child is struggling to accept the "unacceptable", that they were hurt by someone they depended on. It is less about why (because life is not about fairness), and more about how sad and frustrated they feel when things are hard for them. They need honesty, encouragement, and reassurance more than technical explanations; answer simply and ask what it's like for them.

Others can't fix these symptoms, and that is hard to adjust to, however, some children say, "I don't know how it would be any other way; I just know this is how it is for me." They can only compare the way it works for them to what they see on the outside with other children and adults. They may value contact with different people of all ages and with many kinds of physical challenges and situations. They love to have something to offer, and often have particular ability with the elderly, younger children, animals, and others whose special needs can be seen (i.e. in wheelchairs, on crutches, etc.)

They want dignity (as we all do) -- a role in their own self-care. Being a good "self-manager" can include learning how to let people know certain body cues so adults can help the child decode what is or isn't working in the environment, or working differently inside them, and one next step they can take to deal with it.

At all ages, children feel more powerful when they help to create solutions for coping with their tougher symptoms (i.e., puts radio on between stations to create white noise for sleep disturbance, or other strategies). This may include use of certain soothing methods when agitated, or otherwise facing challenging circumstances.

### Adolescence:

Tasks of adolescence clash directly with what it means to have a chronic condition. The child is coming to terms with body changes, and the uncertainty of physical symptoms can complicate their sense of their bodies and self-image.

Sexuality may provide gratification, pleasure, acceptance, approval, and social connection that are rarely attained in other pursuits. Focusing on strengths and building on other successes is crucial for balance, so that other gratification and acceptance is readily available and enjoyed (horseback riding, painting, dancing, swimming, etc. physical and expressive pursuits).

Older children may want to know what to tell friends if asked, i.e. "I do it this way instead because that works better for me. Different people do things different ways." They need simple, honest discussion, and vary in their choices about what they want others to know. One said, "I want helpers to know; but I don't want kids to, because they would tease me." Respect choices about disclosure. Walk it through and role-play if the adolescent wants to.

Teens with FAS/ARND can be very tactile and often hunger for approval, needing play, and contact others would associate with only younger children. Occupational therapy may provide intervention to assist self-soothing and adaptive coping, and help accommodations planning for classroom or vocational environments.

Urges towards independence can conflict with the need for security and some dependency; children may go back and forth between being "very big and able", even rebellious or risk-taking, and being little and seeking extra reassurance.

Over protectiveness can aggravate these struggles. Choosing structure, not control, can be confusing at times. Complications caused by symptoms may cause them episodic distress, as this reminds them of their vulnerability.

Disappointments do occur. Averting extremes of response can be helped by honest, realistic, hopeful, and constructive discussion about the dilemmas posed by the condition, and possible options. Questions need to be answered honestly and respectfully; adolescents hate to be patronized and don't want adults to beat around the bush.

Adolescents may benefit from talking with other adolescents (or even adults) who have successfully coped with the same condition. They feel less "alien", and learn from role models who embody intactness and good functioning. Peer support groups can provide a continuity of guidance and mutual encouragement, as well as appropriately support diversity.

Particular skills can be taught through mentoring. This can increase feelings of mastery while providing experience of making a positive contribution that is of value to others

<sup>1</sup> 1 LaDue, R. & Hartness, C., et al (2000): *Journey Through The Healing Circle: A Training Series for Foster Parents*, Washington State Department of Social & Health Services (DSHS 22-457A (X), Division of Liscensed Resources.

## Brain Syndrome: 4 Core Signs

Robert Taylor, M.D., describes these signs of brain syndrome:

DISORIENTATION

RECENT MEMORY IMPAIRMENT

DIMINISHED REASONING

SENSORY INDISCRIMINATION

Taylor calls the following "presumptive clues" that "must be considered" indicative of organic brain disorder:

*HEAD INJURY*

*CHANGE IN HEADACHE PATTERN*

*VISUAL DISTURBANCES*

*SPEECH DEFICITS*

*ABNORMAL BODY MOVEMENTS*

*SUSTAINED DEVIATIONS IN VITAL SIGNS*

*CHANGES IN CONSCIOUSNESS*

Source: Taylor, R.L. (1990): Distinguishing Psychological from Organic Disorders, Screening for Psychological Masquerade, Springer Publishing Co.

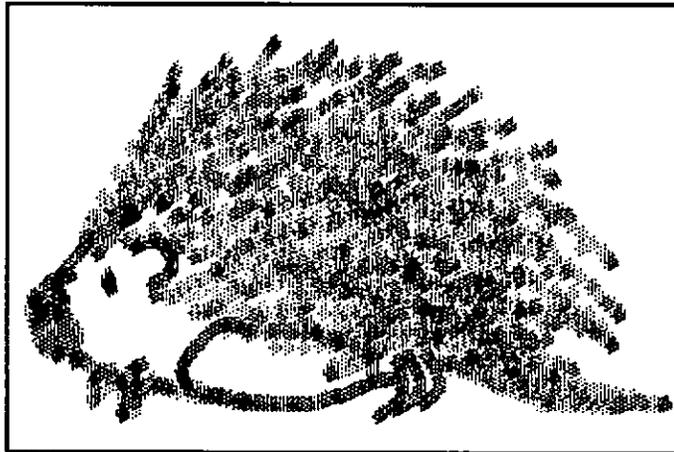
## PORCUPINE MODEL: CNS SYMPTOMS & STRESS

The **central nervous system** helps us adjust to conditions around us. Brain damage can make a person much more vulnerable to stress. "Normal" changes in a day may be overwhelming. Reactions happen quickly. Creating a language for understanding physical and emotional responses helps a person signal others when stress has built up so that de-escalation and soothing strategies can preserve the person's ability to cope.

Thinking of a porcupine can help explain common problems.  
Here is a porcupine having a good day: stress is low enough to be comfortable.

When he is calm, his bristles are down.

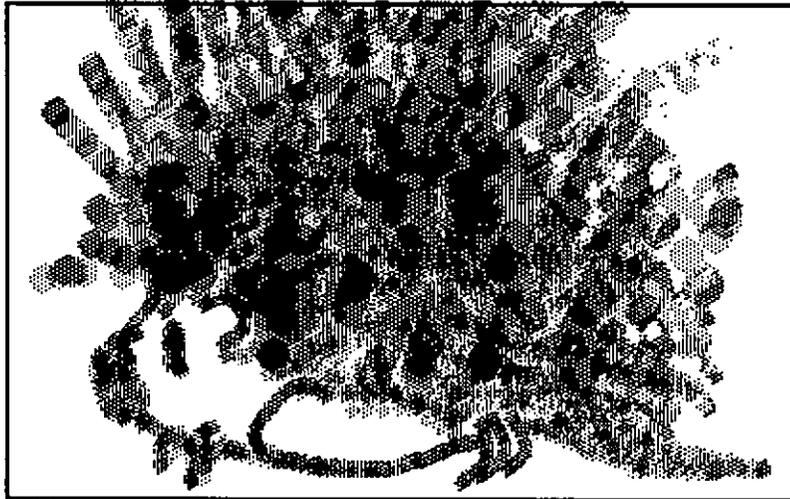
What color is his stomach?



Add stress, from either the outside or the inside, and porcupine's arousal system flares.

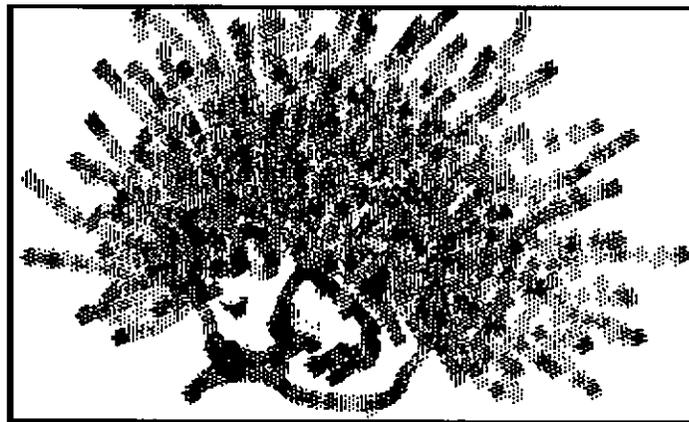
Now he's having a  
**BRISTLE ATTACK!**

What color is his stomach now?



In full bristle, porcupine explodes on the outside & implodes with stress on the inside. Stimulation builds, overwhelming the damaged central nervous system. Tantrums escalate if more thinking or talking is demanded than what the brain can manage at once.

Stress causes fight or flight reactions. If stress builds past the "bristle attack" (fight) stage, a porcupine balls up to hold off perceived attack from danger (flight). People with brain damage may get anxious, angry, or panicky, while having a blank expression (like we see with autism). Though they are capable of speech, they can't think straight to talk, link sensations, and solve problems all at one time. They try to run others off, flee, i.e. go off school grounds, run home, shut down in their rooms, roll themselves in blankets in the corner of their bed, or sleep for long periods. It's as if they are running on empty, exhausted, drained, shaky, and unable to solve problems or talk things through. After some soothing period, they may be able to "talk through / walk through" what was set off.



Now he's in a ball. He just wants to calm down and feel safe again.

What color is his stomach?

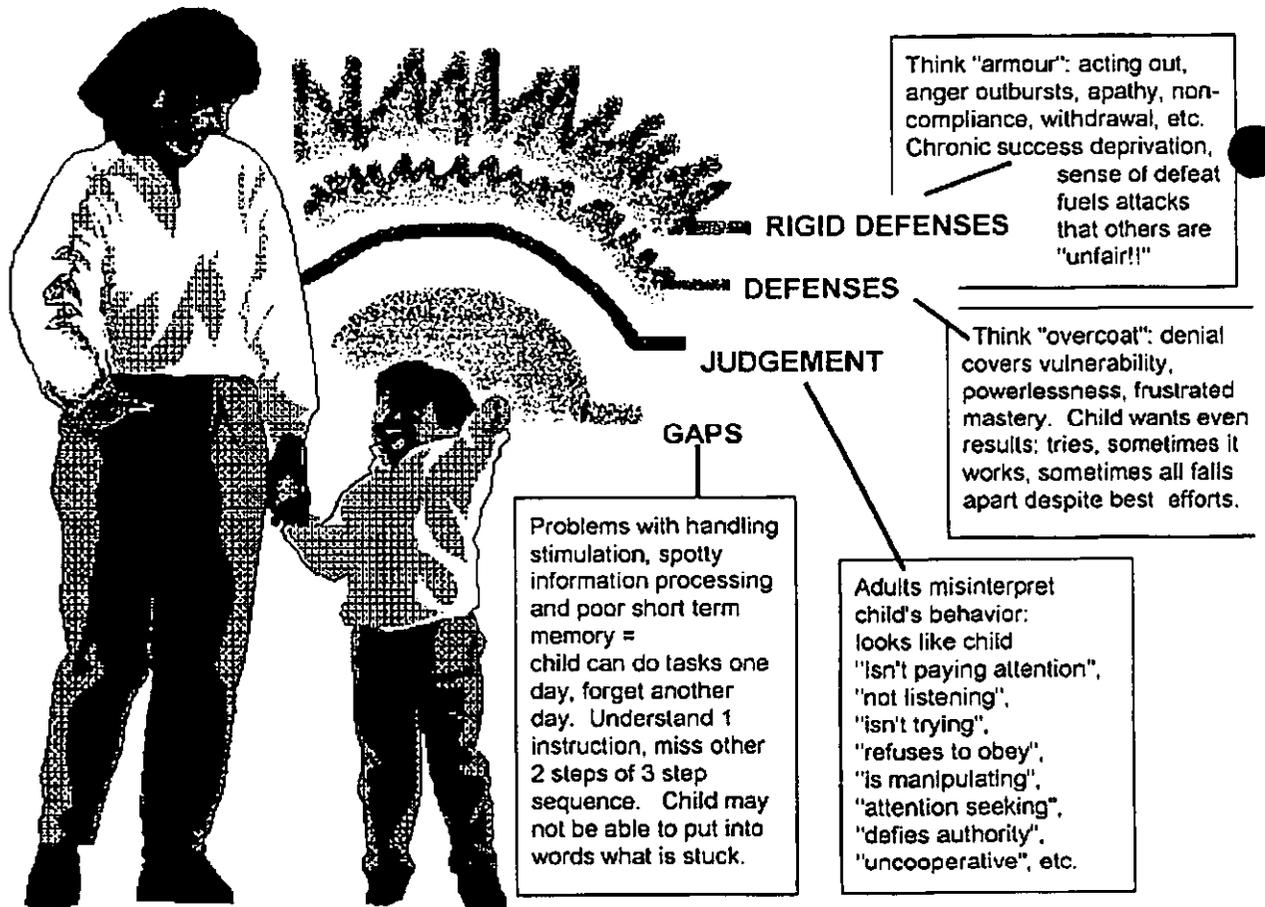
Children and adults with brain-related arousal and regulation problems have many symptoms we all have, only in a more severe or extreme range. As these responses to stimulation have always been part of how things work for them, they don't know that we are not having the same experiences. If we know when they are supposed to eat, go to the bathroom, go to school, go to sleep, etc. how come we don't know when they are under stress or in pain? Quite literally, they don't know that *we don't know*, when we seem to know everything else. They don't usually tell us hyperacusis, headaches, aphasia or other symptoms are especially bothersome that day, UNLESS, we attend to physical signals. Linking cues with the conditions that worsen them, and communicating about these differences in a validating, non-blaming way amounts to learning to speak "porcupine". Though not a cure, this approach eases isolation & misunderstanding.

## FAS/ARND SYMPTOMS & DEFENSES

FAS and Alcohol Related Neurodevelopmental Disorder (ARND) occur when prenatal alcohol exposure has damaged the child's central nervous system. We can't see the brain on the inside -- instead we see outward behavior.

1. **GAPS:** Subtle neurological symptoms, or "soft signs", interfere with the child's ability to perform consistently as expected. These cues are often mistaken for willful misconduct.
2. **JUDGEMENT:** When symptoms are seen as intentional misbehavior, the child with challenges gets stuck, then cornered. Behavior modification efforts may cause more stress.
3. **DEFENSES:** Like an overcoat, defenses protect us against spoken or unspoken blame. The more cornered a child feels over time, the stronger the defenses needed to compensate.
4. **RIGID DEFENSES:** Like armour, defenses grow rigid and maladaptive when the child's ability to cope is chronically overwhelmed. This takes time to happen, and is harder to remediate once difficult patterns are in place.

Recognition and intervention can help prevent discouragement and preserve resilience for creating workable coping strategies and positive environments.



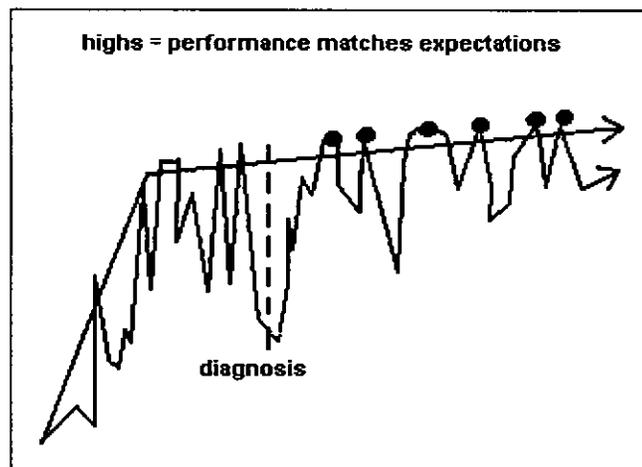
Source: Adapted from materials by D. Malbin & A. Rathbun, 1992

## MAKING A STRESS MAP

The performance of many children with FAS over time often reveals a confusing pattern of good days and bad days, highs and lows. Highs are where the child meets or exceeds expectations at home or in school, like the dots above the line in the drawing below. Children with FAS have capacities and strengths that may develop as easily as other children (mechanical ability, art, music, physical activities, skill with animals, etc). This partly explains why parental expectations can remain high despite evidence of the child's weaker ability in other areas. There are those days when they CAN perform certain tasks as others do (or as they may have days before) which makes the inconsistencies even more confusing to parents and teachers (and the children, themselves).

### DIAGRAM 1: Good Days

When children perform up to expectations, i.e. have those "good days", parents may think to themselves, "He's just fine. See, he CAN do right if he tries." or "She really isn't that badly off. I was imagining it. She doesn't really have FAS. Maybe it's just alcohol effects..."



**Exercise:** Think back on recent "high spots". Describe three examples of "good days" at home or in school. What does a good day look like, i.e. what does your child do (or not do)? What is your reaction when things go well?

Example #1:

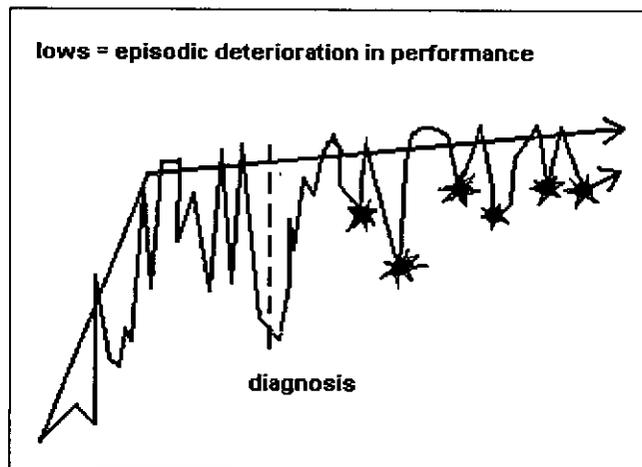
Example #2:

**Exercise:** What do you like best about your child? List your child's abilities (strengths, interests, capacities, skills).

**Exercise:** What is one way to improve coping or success at home or in school using at least one of your child's inherent qualities?

## DIAGRAM 2: Bad Days

When a child CAN do it (sometimes), parents and teachers exert effort trying to force even, consistent performance, reasoning, "But he DID IT LAST TIME! I KNOW he can." The adult believes in the child's ability and wants to engage motivation. The child persists despite setbacks and proves mastery, despite the ups and downs of the practice period. It is natural to want any setbacks to be overcome with repetition, i.e. mental rehearsal or practice, as complexity of life demands increase with maturity. Parents say "He's still doing this at eight! What's going to happen when he's 18? I have to get through to him now and MAKE him do this, or else I'm failing him." Then the reality hits: periods of intact performance meet with sporadic episodes of neurobehavioral deterioration, what Malbin (1993) describes as random reinforcement of inappropriately or uniformly high expectations. Predictable inconsistency in performance can contribute to a cycle of mutual misunderstanding and distrust, i.e. a parent resigning herself that child is globally incapable and "can't learn at all" if select kinds of processing are compromised, such as dyscalculia impeding practicing drills of the multiplication tables.



**Exercise:** Describe 3 examples of when your child hits the "low spots". What do you see?

Example #1

Example #2

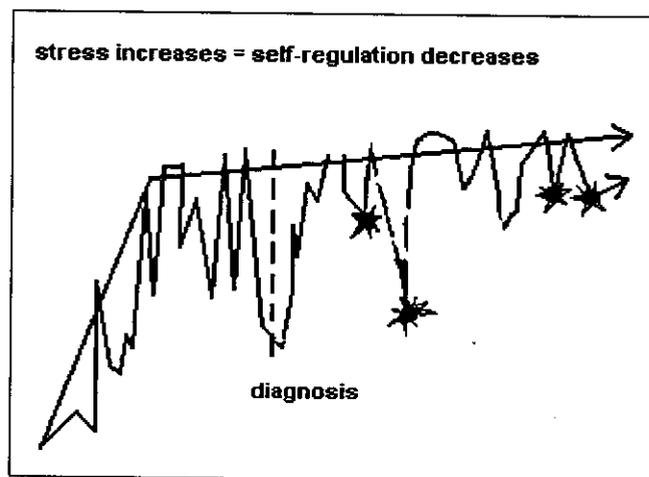
Example #3

**Exercise:** What's your reaction? What feeling comes up for you when these low spots occur? Is your concern or fear about the present, past, or future?

### DIAGRAM 3: Stress Episodes: Decoding the Signals

Parents and teachers try to stimulate learning by enriching environments, providing many choices, extra after school activities or sports, and keeping the schedule full to prevent boredom or "getting into trouble". When brain damage is present, however, the child's ability to adapt and accommodate to routine conditions, pace, demands and events is more vulnerable, even if these conditions are pleasant. Enriched environments can simply tire the child with alcohol related disorders or FAS, so that she is constantly functioning on the edge of mental fatigue.

Subtle physical (somatic) warning signs, like "red flags" may be the only signals of depletion. *Distress* can snowball when the child's physical warning signs worsen, and pressure to solve problems increase. Anxiety or defensiveness can compound difficulties from slow cognitive tempo, sensory over- or undersensitivity, and irritability.



Children with FAS can experience increasing physical indicators of stress, yet not be able to link the physical discomfort to what is causing it. Remember impaired ability to link the internal sensation with the word for the emotion, or know how to speak to others about it (*alexithymia*). Defenses build when this happens. Underlying helplessness, threat or confusion can be engendered by routine age-typical requests from adults, parents, and teachers alike. Chronic success deprivation makes defenses stronger, more rigid: think of an emotional "overcoat" of protection hardening into "armor" to fend off a world seen as unfair and impossible to please. Apathy, explosions, and constant crisis suggest stress dosing is often exceeding the person's threshold. Environmental modifications, medication consultation, Occupational Therapy, family or individual therapy, or other supports may be useful in remediation or rehabilitative work.

**Exercise:** Check the signal behaviors your child shows when stress is building:

- Flat affect (blank facial expression), stony look, "deer in the headlights" look
- Perseverates; repetitive behavior or speech
- averts gaze, stares and "refuses" to talk
- blank gaze, then "blows up"
- clenched hands
- blames everyone or everything else; accuses parent "You're mean! You don't love me!"
- flaps or waves hands
- voice sounds robotic, flat, tense, little vocal intonation (prosody)
- voice loud, orders, demands, bossy, rote phrases, insults
- incessant complaints of hunger, despite meals & snacks
- hoarding food
- hoarding evidence of food taken
- hoarding shiny objects, bottle caps, wrappers, "treasures"
- collecting broken items
- rocking, banging
- thumping, pounding on things or persons with hands or head
- pounding head or other body parts to sleep
- stomps feet
- locks self in room
- punches walls, doors
- chest tight, restricted breathing
- stomach tight - can't eat
- stomach ache - despite adequate meals
- headaches
- rubs eyes
- rubs body
- compulsively touches private parts despite coaching otherwise
- increased masturbation (in private or public places)
- picks at body, rakes skin, pulls off scabs
- bites self or others
- twirling, spinning
- chanting, singsong phrases
- twists hair
- pulls hair out
- chews/spits food
- mouths non-food objects, eats non-food items (glass, plastic, other)
- increased facial or body tics, including bizarre vocalizations
- curses, swears
- urinates on self or belongings, hides soiling
- increased episodes of nighttime or daytime wetting
- episodes of involuntary loss of bowel control – day or night
- hiding, and / or smearing feces
- runs, bumps, or slams into walls, hard things or people

*Krystal (1978) describes how loss of ability to identify specific emotions to serve as a guide for taking appropriate actions. He noted that this inability to link language to specific physical states was related to aggression against self and others.*

*In PET scan research by Rauch, et al., people showed reactions in the right hemisphere of the brain when this occurred. They had increased blood flow in the areas that handle emotional states and flight or fight reactions (i.e. the midbrain region had to work harder). In addition, there was decreased use of oxygen shown to Broca's area – the region in the left inferior frontal cortex that generates words for internal experience.*

*This sheds light on the "freezing" reaction we may see when some people with FAS or other drug effects can't put feelings into words, having that "deer in the headlights" blank look, leaving emotions to be mutely expressed by dysfunction of the body.*

***Example:** A child with ARND has spotty ability to follow a string of instructions. Parent tells her to stop watching TV, pick up her shoes, and go clean her room. The child leaves the room forgetting to turn the TV off, leaves the shoes behind and goes to her room. The parent finds her sitting in the messy room fiddling with a toy, and in exasperation demands "What are you doing? You are supposed to clean up, not play!" The child looks "frozen", doesn't answer, and soon urinates on herself, despite being old enough to know where the bathroom is (right around the corner from her room).*

*In brain terms, the child gets lost in the many brain processes involved, then sits there confused. When found, she can't answer the question and can't find the words for her distress. Her brain recognizes tension in her parent's voice, she feels "yelled at", and she gets tense, but again, can't find the words. Urination happens as a reflex to the sensation of being cornered and without recourse. She is confused and disoriented, then afraid, then angry as a defensive posture of being unable to escape or overcome the stressors. Discomfort was read by the brain as danger, causing a primitive, involuntary defensive reflex instead of a thought out, chosen response.*

Learning to communicate about stress symptoms may remain a challenge for people with FAS. Remember that processing and putting words on what is stuck, either in the external environment or internally, finding and holding in one's mind (either in parallel or in contrast) sensory, visual, or sound inputs that are first encoded, to be retrieved later, then rearranged or compared. This is complex cognitive activity most of us take for granted. Fatigue or competing input can clutter connections being made, even if the original mental or sensory images were understood at the time. Just because these impressions are input, does not mean they are retained, organized, easily found, replaced, or reconfigured when missing. Physical stress indicators and body sensations can flare and set off a chain of additional mental and emotional responses, almost like internal reflexes rather than chosen behaviors. Teaching recognition of signals involves slowing down and helping the child pinpoint body sensations (even before one knows what they mean). What are the properties of the physical sensation, i.e. cold, hot, tight, loose, jumpy, hard, etc.?

#### DIAGRAM 4: Stress Signs: Red Flags

Mark the physical distress signals or “red flag” sensations from the previous list that you see happen to your child when  
at home (with an H) and, or,  
at school (with an S), to track the build-up of stress.

Parents can learn to recognize the above signs and practice ways to respond instead of react. (The difference is in the feel: panicking with the child? or able to maintain perspective and support?) How a parent responds to relieve or contain further build-up of anxiety, regressive “meltdowns” or aggressive “spikes” may vary from child to child. For many, attempts to stop the behavior cause it to worsen. Winding it down or shifting the expression of the behavior into a more benign means of containment often engenders less resistance, due to the fact that perseveration (the inability to ‘unstick one’s thoughts or feelings from a rut) remains “locked on” until it “wears down”.

#### DIAGRAM 5: Stress Accommodations

Providing safety and containment for your child when he or she needs to wind down as a step to regaining capacity to “calm down” (to literally contain one’s impulses without undue aggression to self or others) begins by seeing what children instinctively do under pressure, i.e. running or hiding can be about slowing or limiting input, while yelling or fighting can involve need to overcome what is overwhelming by having a sharp direct focus. Parents may want to help children adapt these instincts and reshape them somewhat to improve success.

**Difficult Behavior****Containment / Wind-down Strategy**

Banging on desk

Banging on clay on a work board or in plastic dishpan  
Kneading, punching bread dough

*Kicking rungs of chair*

*Kicking a bungee chord or shock chord strung around chair legs so that lower legs and shoes bounce off without sound, still feel motion impact*

Slams into things or people

Slams into stacked mattresses, gym mats, pile of pillows

Throws self on floor kicking and thrashing

Throws self in "squeeze tube" (3 beanbag chairs duct taped into a large tube in which child can crawl into the center to kick legs, flail arms, and feel compression sensations on trunk, back, arms and legs)

*Slams up against wall bumping down hall to class*

*Rolls up inside of gym mat, gets dose of "rolling" like a hot dog with OT providing compression doses.*

*Occupational Therapy providing Wilbarger Brushing Protocol using dry surgical brush technique to reduce tactile sensitivity, create safe-touch tolerance (parent can be taught to administer doses)*

Bites arm, chews own skin until getting sores or bleeding

Asked if "Mouth needs help?" and coached to bite or chew large teething objects with soft-firm surface to accept jaw pressure, uses jerky, surgical tubing bracelet, other props

Twirling and spinning

Sensory integration swings, spandex swing, platform swing, others with various motion patterns for sensory organization and regulation training

Twists hair or pulls it out

Doll heads or koosh balls with long strands to pull, twist for fine motor rehab, doing finger crochet chain stitch strands, cat's cradle string tricks

Curses foul language, screams with little provocation (big reaction to little slights)

Neutral response of observing "mean mouth attack" that gets child stuck wanting comfort but aggressing nervously until someone comprehends the fear, disorientation or confusion. Acceptable phrases for venting tension -- "curses" make-believe foul language "BLUNDERBUSS!!" or other dramatic

Picks fingers until bleeding, picks scabs until scarring, rakes skin

Asked if "hands need help?" and coached in manual stress relief (Murphy, 1993), i.e. use stress ball with smooth or bumpy textures, stretchy elastic for pulling and stroking, beads on elastic for rolling, etc.

## Section 4: FAS Accommodations and Environments

### Topic 8: FAS Accommodations & Environments

#### Rethinking Rich Environments

By S. McIlhenny, 1994

The summer after Sarah turned ten years old, we decided to redecorate her room to a grown up style. We planted flowers together so we could dry them and make decorative arrangements, and we spent hours choosing just the right fabrics in shades of rose to make ruled curtains and a matching quilt for her bed. We repainted the walls of her bedroom and stenciled a border around the ceiling edge. An aunt gave us a set of pictures and samplers, which Sarah had received as a baby, along with baptismal gifts. The walls were covered with mementos, flower arrangements, and handmade decorative items. It turned out to be a lovely room, and Sarah loved the way it looked and was proud of all the work we had done together, as mother and daughter.

As the school year started, Sarah found it increasingly difficult to keep her minds on her studies when she was working on homework in her room. She lost all ability to keep her room organized and clean. She had accomplished this task well the year before, and that was one of the reasons for the decision to redecorate her room over the summer.

After observing her frustrations and asking her to explain how she felt about her room, I realized that the sensory input from this lovely room was simply overwhelming to her. She needed simplicity, so that she could maintain order.

We began by removing all items from the wall, packing them away with the explanation that perhaps she could hang them again on the walls of her first apartment, when they would be spread out over a larger area. We removed all furniture except for a bed, a dresser, and a drafting desk (which is kept in the tilted position so that things cannot be stacked on it). We chose white "high tech" style furniture. We purchased crates with lids in which are kept art supplies, sewing gear, dolls, and accessories. We bought a foam rubber mattress and placed it under her bed, so that she cannot push other things under it. We made a duvet for her bed, which simplifies daily bed making.

Even though the realization came to me that this was really the best environment for this child, it was not without a sense of loss. I felt I was being a "good mom" in doing the decorating project with Sarah. It took awhile to realize that for this little girl, I was still being a good mom – maybe the best mom for her.

#### *KEY IDEAS*

- **When stress is present, what kind of response is necessary?**
- A clarification or check-in (think tune-up)?
- Changing the stress level (accommodation)?
- Or, a containment strategy for managing overload (crisis de-escalation) so things can settle enough to be worked out later?

## Topic 9: Parenting for Resilience

### Anger to Awareness: Roles, Rules, and Expectations

Many parents find it hard to shift out of power struggles, and continue to feel stuck in an adversarial relationship with their child with alcohol related disorders. They don't want to feel angry "all the time" once they learn about the child's disability. It can come as a surprise to consider the crisis of increasing anger as an opportunity. The Chinese character for "crisis" depicts two symbols together: one image represents "danger", paired with "opportunity". Anger is an intense and sometimes frightening feeling, however this energy can be used positively when parents learn what it signals. Anger is not the opposite of love, indifference is. Anger can be a normal part of grieving, of coming to terms with losses. The level of anger you feel will give you some sense of the amount of strength you actually have as fuel for the journey of reconstructing new ways to relate to your child(ren). Instead of stuffing feelings or going to other lengths to avoid feelings, parents find it productive to talk them out with the group. Anger may mask sadness, hurt, fear or vulnerability. The feelings are not intrinsically good or bad, or positive or negative. Parents often tend to judge the feelings (trying to deny them because they don't like them). The following information will help parents reconsider the ways their actions (based on feelings) work or don't work to resolve impasses with their child, or other family members.

Darald Hanusa texts- cited with permission



## Topic 10: Advocacy – From Reaction to Action!

Once parents learn to read their child's symptoms and respond with different interventions and accommodations, parents and children may experience some changes in their relationship, shifting from adversaries to allies. As an ally, the parent practices responding instead of reacting when episodes occur, and helps to dose environmental demands, slowing and simplifying input to the stress threshold shown by their child. The parent becomes a translator, helping the child communicate back and forth with the environment, and helping those less familiar with the child's ways become conversant and tolerant, able to recognize and revise or develop solutions with the child's help.

As former feelings of helplessness, failure and grief are replaced with awareness and understanding, parents begin to advocate so that the child and his or her teacher or other key players in the circle of care can experience relief as well. A sense of wanting to prevent further unnecessary hardships arises, which is mentioned in the literature as a stage of *crusadership*. Parents may be recycling their former anger and exhaustion into new ways to provide, nurture and protect. This is a sensitive time, however, in that a parent's proactive energy can have many expressions, which despite virtue, may still benefit from further preparation to the field of advocacy as a whole, especially when having to walk the line between a medical condition which looks like a mental health problem and can include involvement with disability services. Each system has its own ways. It can be very hard for parents to feel such passion about their child's needs and have to learn the ins and outs of collaboration, especially when handling implicit barriers in systems (which are inevitable). What seems so logical is often so inane and difficult and parents new to this part of the trail find such dilemmas incomprehensible. Parents are at risk of personalizing (again) and becoming defensive (again), but this time with other adults who come from various points of view and tend to confuse their concern for overprotection, and need to prepare for over control, and passion for authority problems or other character traits. Naturally, not all parents are skilled negotiators, patient and always looking for a win-win, but in this area, parents face the challenge of having internal pressure to assure changes right away (as soon as they gain awareness themselves) but still having to pace themselves in order to be most proactive, instead of snapping back in reaction mode. Burning bridges by displacing one's own retrospective feelings of grief and blame onto others dealing with the same missing information, i.e. teachers, counselors, or physicians, does little to make use of the opportunity "to educate and improve the child's lot", as pediatrician Dr. John Stirling says. Irritation and outrage may be warranted, but the conditions that engender it often arise from the very same lack of information that exists in rehabilitative work with other brain disorders. Science is still just coming to terms with the brain and its workings, and most professionals, including teachers and special ed teachers, may not have been trained in rehabilitation with neurological abnormalities that are hard to pinpoint and measure.

Parents can expect some difficulty getting the message of the diagnosis and diathesis, and the individual implications across. This is normal, not personal, and simply requires some tools to ease potential defensive dialogue. Malbin (1993) provides a useful model for normalizing how missing information about the brain can fuel mutual

misunderstanding with schools. The model could just as easily apply to dialogue with counselors, physicians and relatives or others who work with the child. She discusses the blame-blame-blame triangle: *bad child* □□*bad parent* □□*bad teacher*□□*bad child*, etc. Missing information about the brain means when people view the child's behavior, they cannot see neurobehavioral impairment, behavior looks **bad**, and they try to assign a cause, which then spills over to the adult in charge at the time of the behavior in question. A parent may think "bad teacher", teacher think "bad parent" while neither wants to think "bad child", though they may be frustrated about how stuck the child is despite familiarity with routine tasks. One rarely thinks "bad brain day", though this is closer to the truth than many would admit. For many reasons, the triangle becomes an accidental leg-trap of feeling blamed and wanting to avoid accusation, which can obscure what *is* bad, namely that the child's symptoms do interfere with everyone's best efforts, most of all the child's! The good days/bad days are not volitional. The neurobehavioral performance is spotty, off and on, confusing, causes things to work well one day and ball up the next. This is hard on the child, the parent and the teacher, and what emerges over a week or a month is a pattern of consistent variability *THAT IS NO ONE'S FAULT*. It is not that one person could do their job without a mistake and the child's behavior would clear up completely.

Society has accepted that a family's ways have a significant impact on how children come to see themselves. With the era of emphasis on personal growth, clichés about "dysfunctional families" abound. Though the same families showing difficulties may also have some redeeming strengths, these do not receive as much attention in the popular culture. Schools are aware of problems in families and need more active participation than ever from parents (who have run out of time between jobs and raising families). Schools are also experiencing negative media attention and many parents have lost confidence that their children will receive a free and appropriate education, i.e. mistrust of policies or procedures at a larger level can play out with individual staff left to defend the larger system when feeling put on the spot. Parents and teachers may be uncomfortable trying to work with each other even without the complication of doing therapeutic parenting and therapeutic teaching techniques for a child with a brain disorder.

Our culture views both schools and families in some inaccurate, unrealistic and negativistic ways while maintaining high expectations of both, with fewer resources and cultural supports than 20 years ago. It is a climate that pits natural allies against one another, which distracts from how clearly these false arguments obscure the precious common ground: everyone wants the child to experience more success and to love learning over the course of their entire lives. Parents and teachers can skirt mutual accusations and avoid the blame trap by focusing on sharing observed stress signs, how the child regroups, and other everyday information. Open discussions lead to simpler ways to support the child despite waxing and waning capacity and variability throughout the school year, and academic career, on into maturity.

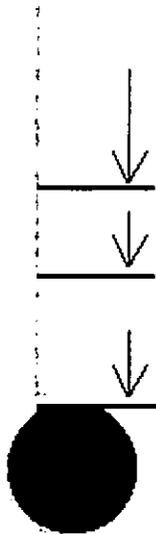
As schools often focus on fairness and equality, it is easy to slip into images of success based on sameness. Yet, it is fundamentally unfair, and real, that all people are made with individual variation and some may have more or less obvious differences, i.e. handicaps, musculoskeletal conditions, featural formations and malformations, etc. Differences can be mistaken for deviance, and deviance confused with dangerousness. A societal climate of heightened sensitivity to potential danger causes people to react much more strongly to defensive behavior, which even in typically developing, healthy children includes regression (flight) and /or aggression (fight) in response to stressors. The key here is to remember that normal stress is exceptional stress to children with neurological impairments. Parents may want to ask one another: when was the last time you saw an image of a health family dealing with some kind of medical condition, disability or cognitive difference? Where did you see the people, i.e. on TV? In a grocery store? School? Church, synagogue or mosque? Etc. How were others responding?

School provides the risk of being singled out for differences, and having to learn how to cope with this, as well as rehearsal for tolerance of diversity in within a micro-community. How comfortable adults are in respecting a child's understanding and expression of his or her differences sets the emotional climate for how children can work through their growing understanding of differences. Parents and teachers can work together to discuss what is best in qualifying a child for extra supports, i.e. through a 504 plan in General Education or an IEP (Individualized Education Plan) under Special Education. Just as important, is how the parent and teacher assist the child to have genuine access and emotional support as needed to help the child gain skills for self-advocacy and participation in a range of learning environments. Who the child shares personal information with and under what conditions is a right the child has which parents and teachers need to be sensitive to, just as they would their own privacy. Self-help phrases and social skills around the child's condition can be rehearsed, so as to provide the children a similar sense of mastery given their condition that other children develop with other kinds of chronicity. Humor should not be used to humiliate or shame, and hopefully is understood as a way to vent discomfort safely but not at another's expense (i.e. talking dramatically about a child within earshot). Respect is foremost. It can be helpful when in doubt, to assume the best, rather than the worst, yet plan to maintain frequent contact with all participants in your child's circle of care.

*"Interventions ... should be focused on bringing the person back into balance. Nothing in a person's existence can change without all other things being changed as well. Hence, an effective helper is one who gains understanding of the complex interdependent nature of life and learns how to use physical, psychological, contextual and spiritual forces to promote harmony."* Cross et al (2000)

## THE BAROMETER: RATING STRESS REACTIONS

An old rhyme claims "the barometer is falling, black clouds are on their way, the weatherman predicted we'd have a storm today": **the barometer falls when pressure in the atmosphere increases**. A sense of building "pressure" is a useful analogy to what happens to children with Alcohol Related Disorders amidst daily or weekly routines. As stress builds, behavior deteriorates, overloading their capacity to adjust, organize or strategize.



Responses could involve:

A clarification or check-in (think tune-up),

Changing the stress level (accommodation),

Or, containment (crisis de-escalation) for managing overload pending new strategies.

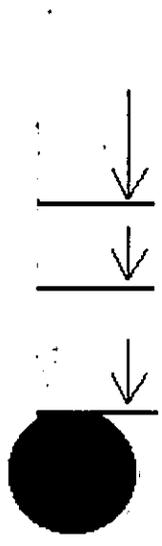
**Do-able** = When stress is tolerable, the child's level of functioning matches external conditions.

**Discomfort** = When those conditions change or internal symptoms worsen; mismatch begins.  
(1 source of distress)

**Danger** = When mismatch escalates; outside conditions challenge child's stress threshold beyond manageable capacity (2 sources of distress)

**Crisis** = Stress overload is acute; coping skills decompensate to basic capacity  
(safety, rest, crisis triage, containment, stabilization)

List factors below that add up to do-able, discomfort, danger, or crisis levels of stress in your child.  
What automatic reactions do you show at each level (especially when hooked by the child's distress cycle)?



Do-able:

What I do:

Discomfort:

What I do:

Danger:

What I do:

Crisis:

What I do:

## FROM RELAXATION TO READINESS & BACK AGAIN

### JUMPING ON BOUNCY SURFACES

- Mini trampoline
- Bed mattress
- Jumping on the floor
- Jumping from a low step and landing hard on both feet
- Jumping and crashing into piles of pillows or beanbags
- Bouncing while sitting on a therapy ball
- Holding handle & bouncing on a hippity hop ball velcroed to the floor
- Pulling up on a rope and dropping down to the floor

### PLAY WRESTLING

- Include slow movement, heavy resistance, rolling, pinning down
- Chase and being chased
- Bear hugs
- Climbing and crawling over/under pillow
- Beanbag chairs
- Jungle gym
- Wheelbarrow walking
- Obstacle course
- Waterbed mattress filled with air
- Foam rubber filled sheets sewn together

### SWINGING

- On tire inner tubes
- Sling chairs
- Platform swings
- Net hammocks
- Spandex hammocks

### HEAVY WORK

- Push on wall, push down on chair

Jumping for sets of 10, 20, 30 times in a row  
Moving furniture, heavy push cart  
Wheel barrow walking  
Push wheel barrel  
Trapeze  
Scooter board  
Crawling in tunnel  
Carrying heavy objects  
Pounding toys  
Modeling clay  
Push/pull activities (row, row, row your boat)  
Hamburger / or Hotdog Game

(rolling up in a blanket, "ordering" different kinds of safe touch as "mustard", "relish", "catsup", etc. – long slow rubs, squeezes, light pats, tickles, or chopping strokes with the sides of the hands, etc. applied to the clothed child on outside surfaces of arms, legs or back. Adult stops immediately when child says "stop", inquires "more?", and let child direct how much and which kind of safe touch is provided)

## NEUROBEHAVIORAL APPROACHES: BEHAVIOR & ENVIRONMENTS

Neurobehavioral specialists who work with brain rehabilitation find two key ideas helpful in structuring their approach to children and adults with brain injury.

### IDEA #1 - ENVIRONMENTAL CONTROL

The idea of “environmental control” is about matching structure to symptom management. Involving accommodation, the focus is on removing or changing external factors that may contribute to deteriorating behavior.

Factors include:

People’s attitudes & emotions; non-verbal communication, voice tone, speed of speech, expressions

Inclusion issues: *helper’s level of acceptance, avoidance, fear, hostility or fatigue over person’s symptoms or their condition varies (i.e. drooling, tics, etc., may offend or disgust some helpers & not others)*

Sound level; loud/soft, background, tones

Number of people; type of people (*similar/different, age, gender, culture, physical characteristics*)

Scope or duration of activity (*sustained, intermittent, random, scheduled*)

Timing or pacing of activity (*time of day, portion of day, leisurely, rushed, timed, self-selected*)

Small or large space child is managing in (*room, area, contained, addiculated or open*)

Level of props - sensory, visual, motor, soothing/resting equipment (*carrels, plain visual surfaces, marks or visual cues, vestibular, proprioceptive or motor stimulation equipment, beanbags, headphones, weighted mats, vests, heavy blankets, music, etc.*)

Level of mediating prompts, verbal or non-verbal assists (*cues, aides, reminders, gestures, soothing programs*)

**Behavior communicates a child’s needs.** Too often, we evaluate behavior and plan *without assessing the environment*. Neurobehavioral support involves making select changes to reduce stress when the brainwork of thinking and feeling becomes overload. Some settings require more flexibility, modification, or structure to provide adequate support.

### IDEA #2 - STIMULUS CONTROL

This concept emphasizes a developmental approach to managing atypical reactions to stimuli (based on functional traits of the individual). The focus is to help children manage reflexive reactions (hyperarousal, poor modulation, etc.) and coach adaptive, help-seeking behaviors and other coping strategies for daily environments.

NOTE: This is NOT the same as trying to extinguish problem behaviors (behavior modification) by imposing “consequences” for unacceptable actions.

Instead, the child with involuntary over/under-reactions learns or relearns through auxiliary processing. The helper becomes an external brain; a “coach” who helps to break down processing into smaller, step-wise tasks then paces the activity. The helper validates the child’s early signs of atypical stress reactions to ordinary routine; “Something is stuck?”. We walk the child through a brief physical inventory: pointing out familiar signals of when capacity to inhibit, regulate, or modulate responses are exceeded. Stress deterioration in behavior can include:

Fatigue (looks like not trying, “I can’t”, “don’t know”, difficulty initiating tasks, or increased hyperactivity, restlessness, disorganized activity)

Confusion despite known directions or facts (can’t remember or attend to the obvious),

Disorientation (nods at instruction, goes & gets lost in the hall or can’t find own locker), and/or

Perseveration – (“cannot” redirect, stays “stuck” in repetitive action or verbal protest)

Aggression / Regression (language goes offline, behavior communicates needs at a more primitive developmental level)

With time and coaching, the child practices a gestural cue others can observe. Eventually a verbal cue may be paired with the gesture. This is not about the child grasping auditory cues and generalizing them quickly to all situations wherein overload may occur. Evaluation and comparison of converging factors takes time. Rather, a particular set of autonomic stress indicators (involuntary reactions) emerge, and *register* with practice, as “stop signs”. Stopping may prevent further deterioration. Mediated learning, through coaching stop signs, and other tools, teaches the child use of stress support techniques for routine conditions that others no longer need. These simple measures can later be adapted to adolescent and adult settings as needed.

EXAMPLE:            Aggressive behavior in school

Burgess tells how a teacher saw a 6-year-old speaking child about to strike another each morning as the girl entered the classroom. Instruction on saying “hello”, time outs for hurting a peer, and other approaches failed for two weeks. Seeing a lack of social reciprocity, affect cue recognition and decoding skills, the teacher identified the child’s lack of “a greeting pattern” despite her ability to speak and chatter. One morning just before the child’s strike, she caught the girl’s eye and modeled the intention: the child needed a *signal for contact*. The teacher expanded reaching out to strike into waving hello, exaggerating the gestural pattern paired with facial affect we know as *greeting*, by looking intently at the girl and waving to her. This registered, and the girl suddenly mirrored waving to the teacher. Still waving, the teacher then pointed to the child about to be struck, and the striker started waving to her peer also. Scripted language was added in after a few weeks.

The teacher organized the child’s behavioral intention into purposeful communication through steps of coupling the motor pattern, affect display, proximity, and finally spoken language. She noticed the missing pieces in her natural needs within the classroom when the child’s language system repeatedly failed and default prelanguage behavior did not resolve despite typical interventions. Instead of giving consequences for missing developmental skills, she taught the missing skills by chaining what was present to the next parts of the developmental sequence between motor work and language work. Using what the child already had online (motor activity, movement and gesture), and building from there, she avoided the frustration of ineffectively insisting on trying to jump start an entirely different set of circuits that had already proved to be less available (the language and speech system). The child with brain injury could feel “contact” instincts, but not motorically organize what to do with them (just like a 15 month-2year old child). Neither could she initiate how to replace

actions with the symbols for actions that we call words and language. The teacher recognized the speaking child still had developmental gaps due to brain injury and *coached gestural prompts to bridge* social interaction needs until spoken social greeting routines (script with gestures) could be coached, videotaped, rehearsed, shown on a felt storyboard, danced and sung, etc., encoding the needed array of multi-sensory signals into the child's brain. Social skills seem emotional and instinctual, yet are sequences involving several areas of coordinated brain activity that these children may need extra help with.

Temper tantrums are a normal, necessary signal that a child is a separate person from mother and is practicing how to tolerate having mastery over some of what is around them, but not the level of control an adult has. When toddlers feel anger, it is only sensed as a huge surge of physical energy with feeling. It feels so powerful they really don't know it can't make them or their parents explode and die. There is the energy of it, and also awe or even alarm, for some children, at the intensity they feel. With practice, they learn it is big but not catastrophic by repeating the process of how the body energy grows, peaks and returns to calm: when no one is destroyed, everyone is still okay and they, too, feel better. They learn it is useful fuel to ward off or overcome obstacles, and that it doesn't last forever. Typical anger or even raging may occur a few times a week for some months, and last up to @ 20 minutes, but by 3 years of age, children have grown into self-calming skills such that they can feel angry, express this safely, and return to emotional equilibrium within 10 minutes to a half an hour. In some stages or in relation to certain events, children may have more anger for a period of time, especially if hurt, sadness, trauma, loss, or helplessness are present.

Example: Prolonged anger storms, agitation, confusional states

Anger episodes reported with alcohol and other drug-exposed children are often more frequent, longer, and more severe, out of proportion to events, or may show a delayed onset from when distress was felt. Parents report rages in which children break favorite toys (repeatedly), drop to the ground howling, arching and stiffening the body. They report children head-banging despite safety measures, showing excessive aggression and injuring themselves or others (biting, clawing, raking skin). Though these are not that uncommon for toddlers, a child of 7, 10, or 14, would have typically grown out of this. Rage episodes are reported to get worse when parents try to reason with them or talk it out. The episodes may go on for an hour, up to several hours a day, or occur at "full intensity" seemingly out of the blue, or "spike" several times a day with little provocation.

**These are not temper tantrums.** They are "anger storms" of abnormal mood regulation – children cannot calm down on their own well, and require possible equipment and/or medication interventions specifically to learn calming strategies. A cascade of neurochemical alarm signals is released like a lightening storm at sea, flooding them with stress hormone. The capacity to process language is offline; the midbrain is over-raught.

Strategies: Winding down through use of lowered lighting, a nest of beanbags under a desk or table, or similar hiding areas can be used so they can flee (instead of fend off like a steam kettle). Children may seek out their closet or another dark area, squeeze under or beside their beds, hide beneath pillows, or swaddle in blankets or occupational therapy props such as weighted blankets until breathing is regulated. Language only returns when their physical alarm state has ebbed, i.e. the stress hormone in the bloodstream has reduced. Again, de-escalation of involuntary agitation is the first need. Making sense of what overloaded their circuits comes afterwards, usually in slow, piecemeal fashion, perhaps over the

course of a few conversations with time and verbal structure by the parent to help link what became uncoupled, overwhelming, or internally disorganized.

Example: Episodic daytime or nighttime wetting or soiling, despite known toileting skills

Children with FAS may have “accidents” on through elementary school, and sometimes adolescence and even adulthood. This doesn’t mean a parent “hasn’t trained the child how to toilet for himself yet”, as one parent was admonished by a teacher prior to understanding this common symptom. Rather involuntary urination or loss of bowel control can worsen under stress, when capacity to register and react to bladder urgency signals with spatial reasoning and motor planning is in competition for attentional focus other input, such as directions from a parent or teacher, or similar daily demands. Denial despite the obvious smell or wetness is a common reaction. It is a primitive defense against feeling defeat or lack of mastery over one’s own body. Denial helps children preserve a sense of capacity despite the obvious: their brain “missed” important information causing unpleasant events from which there is no escape. Others noticed, and will notice again. The child needs mental protection against defeat and discouragement over not being consistently able to do what others their age are able to do to meet adult expectations.

As these and other symptoms are involuntary, not intentional, a child who shows denial or rationalization is showing a reflexive defense against feeling incompetent. Children cannot just give up indefinitely, though they may need to take a break to summon willingness to try again. They do get discouraged by having to work so hard at what seems “automatic” for others. Variations in how long it takes to recoup mood, focus, attention or skill sequences, and how severely behavior deteriorates under routine conditions, form an individual’s pattern of good and bad days, or good and bad hours.

Whether in the classroom or later in the work force, citizenship skills are strengthened when persons with MHDD conditions:

- 1) Gain the understanding and support of others,
- 2) Play some part in helping to shape environments for their success, and
- 3) Contribute their unique abilities within a community (sphere of influence). All people want to experience belonging and purpose, and persons with alcohol related conditions are no different.

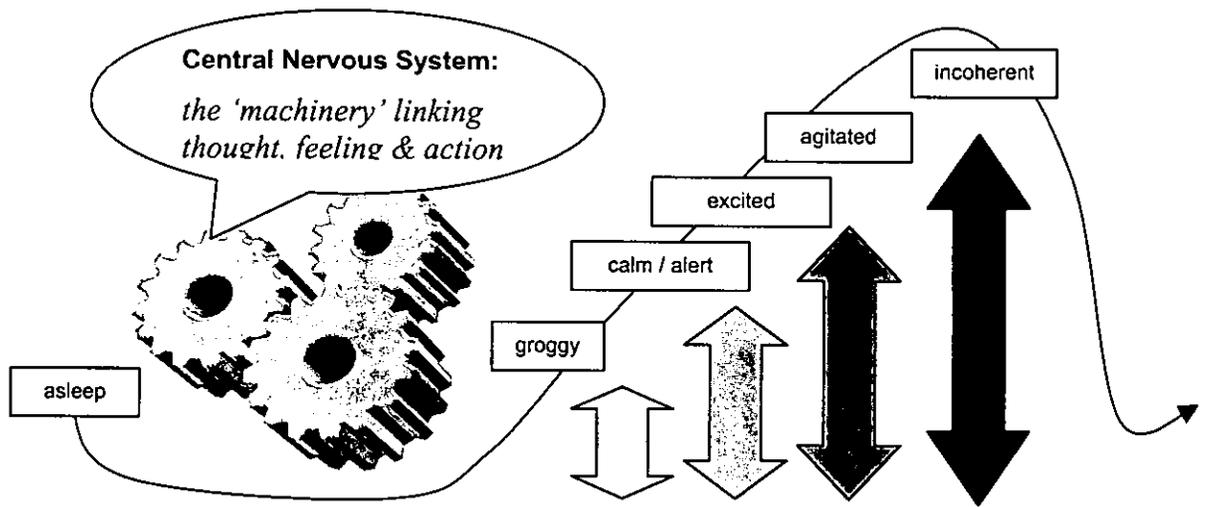
Adapted from: Appleby, Carter, Feeney, & Slifer (1992); Burgess (1992); Rathbun (1993); Carmichael-Olson, Morse, Huffine (1998); Linder (1989)

<sup>1</sup> Carmichael-Olson, H., Morse, B., & Huffine, C., (1998): "Development & Psychopathology: Fetal Alcohol Syndrome and Related Conditions", Seminars in Clinical Neuropsychiatry, October edition.

<sup>1</sup> Schowalter, J. (1979): "The Chronically Ill Child" (Chapter 49), Basic Handbook of Child Psychiatry, Vol. 1, Development, (ed.s; Noshpitz, J & Berlin, I.), Basic Books.

<sup>1</sup> Bolea, A. (1986): Psychotherapy and the Lonely Patient, Haworth Press.

## "Brain On Board": States of Alertness



<p>Stress sign:</p> <p>Accommodation:</p>
<p>Stress sign:</p> <p>Accommodation:</p>
<p>Stress sign:</p> <p>Accommodation:</p>

Adapted from sources including Prigatano, Shellenberger & Williams, Krankowitz, Ayres

## PUNISHMENT, DISCIPLINE & BELIEFS: What's Your Goal?

**"When discipline is viewed as a teaching opportunity we can see that there are no magic techniques that work for every problem or every child."**

Parents and teachers expect to prepare children for adulthood by teaching them self-control and increasing accountability. In general, the literature points out that:

Children are **punished** when:

- their behavior is controlled through fear
- they behave to avoid a penalty imposed by an adult
- the adult stresses what *not to do* (instead of what to do).

Punishment **causes** children to:

- feel humiliated
- hide their mistakes
- blame others or themselves
- fear lack of control to handle future problems

Children are **disciplined** when:

- they see the possible consequences of their actions
- they see other choices that might help
- they practice controls for themselves

Discipline **teaches** children to:

- learn how to balance their needs with those of other people
- feel good about themselves and their ability to choose
- become increasingly independent

This can leave teachers and parents of children with FAS or drug effects feeling desperate. Learning self-control and social skills comes from being able to:

1. Remember one's actions.
2. See outcomes or consequences from them.
3. Mentally picture or rehearse other possible options before action.
4. Control your own thought patterns and choices.
5. Chose one's own actions in comparison with information about what others are doing.
6. Be able to repeat this process in varied situations and time frames.
7. And, do all this "automatically" during a daily or weekly routine.

Many cultural and intergenerational beliefs teach us to expect this. Implicit assumptions influence standards of adult behavior, varying somewhat by culture. The following exercise will help you look at your assumptions, and the practical implications of your beliefs when parenting children with central nervous system damage. WHAT IS YOUR GOAL FOR YOUR CHILD? WHAT ONE MESSAGE WILL THEY COME AWAY WITH?

#### EXERCISE:

Think of someone you knew in the past whose behavior did not match the above list of responsible behavior.

What kinds of things did they do or not do?

What happened to you or others because of their actions?

How did this shape your attitudes and behavior?

Write three things that stuck with you from that point on as a "personal code":  
(i.e. "I will never....", "I will always....", "When I have kids, I will make sure that ....."

Source: Briggs, Briere, Baker & Brightman; adapted by Tracey Johnson, MSW, with A. Rathbun, M.A., A.T.R., NCMHC

## THE 10 STEPS OF A PARADIGM SHIFT

In times of crisis (high turbulence), people expect, in fact, demand great change. This brings two results:

1. More people try to find different ways, i.e. new paradigms, which will resolve the crisis, thus increasing the likelihood of paradigm shifts.
2. Crisis mentality causes more people to be willing to accept new and different ways to solve the crisis, increasing the opportunity to change paradigms.

This sets the stage for radical change, characterized by the following steps:

- Step 1** The established paradigm begins to be less effective.
- Step 2** The affected community senses the situation, begins to lose trust in the old rules.
- Step 3** Turbulence grows as trust is reduced (the sense of crisis increases).
- Step 4** Creators or identifiers of the new paradigm step forward to offer their solutions (many of these solutions have been around for decades waiting for this chance).
- Step 5** Turbulence increases even more as paradigm conflict becomes apparent.
- Step 6** Affected community is extremely upset and demands clear solutions.
- Step 7** One of the suggested new paradigms demonstrates ability to solve a small set of significant problems that the old paradigm could not.
- Step 8** Some of the affected community accepts the new paradigm as an act of faith.
- Step 9** With stronger support and funding, the new paradigm gains momentum.
- Step 10** Turbulence begins to wane as the new paradigm starts solving the problems and the affected community has a new way to deal with the world that seems successful.

When the community is comfortable with the new paradigm, the tolerance for new ideas drops off, completing the cycle, until new problems trigger a new cycle of changes.

Source: Joel Arthur Barker (1992)

## *"You and I"*

By Dorothy Beckwith  
Fetal Alcohol Syndrome Family Resource Institute

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

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

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

I contact you. I am a pest.  
You contact me. You are compiling information.

I raise my voice. I am losing control.  
You raise your voice. You are authority.

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

The child with Diabetes needs nourishment and insulin, the child with  
ADHD/Fetal Alcohol gets Time Out.

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

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

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

I'm tired. I lack follow through.  
You are tired. It's time for your break.

I ask if outside specialists, who can validate Christina's reality, can be a  
part of the team. "No problem."  
I try to schedule so that it may happen. "Now that's a problem."

Because of logistics and prior commitments, I can't get to a team meeting.  
I don't understand the importance.  
You can't get to a meeting. You are important.

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

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

I let her sleep in. I am unstructured.  
You let her sleep in (it was 9:30am). You are giving her a lazy Sunday.

I ignore the behavior. I am a softie.  
You ignore the behavior. She's just doing it for the attention.

I comment on a behavior. I am overcritical.  
You comment on a behavior. You are observant.

I had realistic expectations of you.  
You have unrealistic expectations of Christina.

I am five minutes late. I apologize.  
You are twenty minutes late. You give no explanation.

Christina has behavior problems. You are rude.

In my care, she's encopretic. I've failed to adequately monitor her diet and make sure she does her bowel management program.  
She continues to be encopretic in your care. You refer her to a colorectal specialist.

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

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

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

## TECHNIQUES FOR PROFESSIONALS: HELPING FAMILIES WITH FAS / OTHER DRUG EFFECTS

### 1. Recognize the biological dimension.

Listen for soft signs of organicity along with environmental losses or stressors; ask questions about what early symptoms or behaviors the family may remember which seemed odd or unexplainable during early childhood and school years. Ask about scenes that stick out in their minds during family events, holidays, or other notable times. Check for typical phrases the child makes about himself or that others often say describing his behavior. Ask about physical preferences or aversions, (i.e. reactions to light, sound, hot or cold water, presence of headaches, fatigue, eating & sleeping patterns, problems with hygiene, dressing, or other self-help tasks, memory).

### 2. Solicit the illness story.

Ask what brought up family concerns about possible prenatal exposure. Parents may describe a time when "they just knew something wasn't right". Who did they tell? What responses did they get from other family members, friends and professionals? Attempts to get help have often been unsuccessful; yielding stated or implied blame, dismissal, patronizing, pathologizing, avoidance or denial. Parents often report being treated like they "were crazy" and having no safe place where their concerns were taken seriously. Let them discuss how difficult this has been.

### 3. Respect defenses, remove blame, and accept "unacceptable" feelings.

Parents may see one child as the problem, only to learn in time that other children in the home also have symptoms of prenatal exposure. Give parents time to absorb and process the many implications of prenatal exposure or FAS over time, with normal reactions in some areas and slow remediation potential in others. Normalize the presence of strong feelings (i.e. anger, guilt, grief). Pressing them for expression of feelings prematurely adds more stress; instead, let them grieve at their own pace. Mirror the emotions by telling stories of other parents' responses to their child's symptoms, eventually identifying feelings which repeatedly occur in response to certain patterns of interaction between adults and the child. Normalize the stresses of dealing with chronicity; assist their recognition of feelings as cues to be taken seriously.

### 4. Maintain communication.

Families who initially ask for information may digest the reality of their child's organic brain damage in small doses. Be flexible about the pace. Awareness brings up grief, and some families may have no images of what resolution looks like. Their denial works like brakes on a car, slowing the process of accepting the "unacceptable" by protecting them from overwhelming discomfort. In time, the other feelings emerge: many are overwhelmed, exhausted, frightened of the enormity of their feelings or anticipation of their children's feelings, and afraid of the future. Take an incremental approach and ask if they want to know about workshops, literature on FAS/Drug Effects, or groups available. Ask what kind of support would be most useful for them. Assure them that there is no one right way to begin the process of healing. Provide them a mechanism to begin observing and recording the patterns of difficulty for future problem-solving efforts. Validate family strengths.

**5. Attend to developmental issues.**

Discuss timelines and expectations, with plenty of room for grief, anger, denial, bargaining and other signals of the grieving process. Examine parents' belief and values from childhood rules and roles, cultural factors, stereotypes, externally imposed demands from schools or other systems, unspoken internalizations.

**6. Reality is the first step to improving resilience.**

Acceptance of reality and validation increase empowerment, improve resilience, and lead to a sense of efficacy. Human beings need to make sense to themselves. When they do, and things fit, there is meaning to their struggles, even if grieving and adjustment continues. Talk about strengths and weaknesses. Talk about patterns of interaction, and symptoms. Mention environmental factors which can compound organic symptoms. Share some stories of other parents or children with FAS/FAE casually; this provides a structure for them to comment from. Clients will answer "no" if some of these things don't happen to them; they may tell you what does often happen and when, if you ask and aren't afraid of what you will hear. (Your own comfort level is responded to as if by radar). Remember, it is not your job to "fix" them. You have the opportunity to support and encourage them in learning how to try differently rather than harder, and developing their own solutions in context.

**7. Leave the door open for future contact.**

Families may be undecided about what form of support will be most useful to them. You may be asked to facilitate advocacy efforts, assist coordination of the continuum of care, provide consultative or other support services, conduct therapy or facilitate a parent's support group. Clients may need a host of literature and other educational materials to help them link with existing resources, or modify these to better meet their family's needs. Support the family in their steps to obtain needed services, or develop ones that will fit. Know that you are part of a larger picture, and do your small part to increase the range of support for this issue. You don't have to fix it, and, you need not hide from it.

Sources: Adapted from Table 4.1, Medical Family Therapy Techniques, developed by McDaniel, Hepworth & Doherty (1992).

## AN OPEN LETTER TO TEACHERS

By Gary L. Flanders

Dear Teacher,

Please do not think that I am a bad parent. My child has what the medical profession calls an attachment disorder. This disorder affects children who did not, for whatever reason, emotionally bond to their birth mother [or father], and who then carry on this lack of bonding with later mothers. The vast majority of children who have this disorder are adopted, and therefore not living with birth parents.

Here are a few things that you may find helpful as you deal with my child in your classroom. I want the best for my child, and I also want your day to go well in your classroom. I don't suggest these things to be arrogant, to suggest that you couldn't figure them out for yourself, or to tell you how to run your classroom. I offer them as ideas for things these children respond to better than what we would traditionally consider as appropriate behaviors and consequences with a child.

Children with attachment disorder tend to need the following:

- A tight, but loving, structured environment where the rules never change, but the consequences often do.
- Adults who say what they mean, and mean what they say, and who don't rely on giving lots of chances before consequences fall.
- Someone who will not be easily manipulated by a child who desperately needs to be in control of all interactions with adults, and who understands that these children are expert liars who can fool even experienced teachers and counselors.
- Someone who will check out all the facts before giving my child any benefit of the doubt.
- Someone who understands that, if a child is "flunking out" in all other areas of life, getting schoolwork done must sometimes take a back seat.
- Someone who knows that there is a reason for why my child is doing the things she is doing, and that, until she stops acting out, she will have a very sad life, and so holds my child responsible for her actions and doesn't excuse those actions because of my child's problems.
- Someone who realizes that my child is quite superficially charming with adults she doesn't have to be in a family relationship with, but lacks the ability to have true closeness with family members, especially parents.
- Someone who will not prejudge my parenting skills without asking me why I do certain things with my child.

- Someone who understands that my child doesn't show affection to her parents, but will ask to go home and live with you as a way of distancing from me.
- Someone who will be a strong, consistent adult with my child so my child can feel safe enough to be able to go back to being a child, and
- Someone who calls me to check out the stories my child tells before jumping to the conclusion that the child must be telling the truth because of her apparent sincerity.

Thank you so much for reading this letter, and I hope we can talk more about this wonderfully challenging child I have brought to your classroom. If you want more information about attachment disorder, there is a website at:  
<http://www.attachmentcenter.org>.

Cordially Yours,

## FOUR MYTHS ABOUT LEARNING

1. **Learning is unpleasant (children must be made to do it).**

FACT: All people are learning, all of their lives.

2. **Learning is best accomplished by sitting in a chair listening to someone talk or by reading silently.**

FACT: Studies show that people retain:  
10% of what they hear  
50% of what they see & hear  
80% of what they see, hear & do.

3. **Failure toughens children and makes them strong, i.e. life is full of failures and they should get used to it).**

FACT: Chronic success deprivation teaches learned helplessness and apathy.

4. **To really learn something, drill on it, over and over.**

FACT: Humor, emotion, and action are keys to interest and retention.

Sources: Seligman (1973), Wallace (1992), Newsweek (1993) Vol. CXXI, #22.

## HIDDEN TASKS IN "HOMEWORK"

A 12 yr. old child with FAE was stumped by her teacher's instruction to 'do as many of these math problems as you can in class, then finish the assignment for homework'. With normal intelligence but **slow cognitive tempo**, she could only complete 4 problems during class time. She spent 2 hours on the rest at home, running out of time for other homework in 4 academic subjects she'd managed to write down in each class and carry home (an accomplishment in itself!) She gave up completely when she couldn't figure out how to prioritize homework tasks (**executive functioning deficits**) and still couldn't finish all her math problems. She'd done many but did not turn them in because until all were completed it wasn't 'the assignment' it was just 'a few problems done', that wasn't what the teacher wanted, and she would get in trouble. The general principle, to turn in work she'd done to get credit for it, never registered with her (**impaired ability to abstract**).

The pressure grew. The child got stuck on how to tell anyone so they'd understand (**stress overload decreases processing ability**). The dilemma continued until end of term when she was missing 29 assignments (**chronic success deprivation**). Her teacher thought allowing her to finish assignments at home "would give her time", but time was only one part where her disability required accommodation. She was still being asked to:

- grasp concepts in class (**receptive language processing, spatial concept processing**)
- replicate/use the concepts briefly in class (**apply the information**)
- go on to several other subjects before she went home (**change cognitive set, remember each set**)
- retain or relearn the class material at home after it was forgotten without coaching or cues (**sequencing and tracking impairment, memory deficits**)
- make a decision about how much she knew or didn't know, sort & initiate new tasks (**prioritize information, executive function skills**)

This child is "all or nothing". Once she hears words but cannot picture the meaning (**visual processing strengths**) she gets confused, frustrated, ashamed, and scared -- and freezes. Task-analysis was needed: breaking the task down into manageable steps; each task used prompts and cues to help with memory and processing impairments. Stress check-in was crucial for monitoring atypical **somatic stress indicators**: headache, extremities tight, uncomfortable, agitated, wiggly, breath held, face flushed, gaze aversion, fingers stinging, other signs, were identified that interrupted information processing of cognitive task sequence. Emotional **safety** was provided by accepting these unspoken stress signs as "normal" for her, reducing defensive avoidance, apathy, and irritation. She was coached in help seeking when she "was stuck" (**stimulus control**) regardless if she could pinpoint the source or not. The teacher set a specific structure (**accommodations**) to help manage predictable stress (**anticipatory coping**) and keep tasks clear (**environmental control**):

- Here's what to work on (show it). Here's how (model 1-2 steps).
- I'll check with you for stress at .....(small time increment)
- You're stuck? Take a stress break. (model stress reduction skill / use of accommodations & props for soothing)
- Good job! Now do this.....(one task, i.e. 3 problems only).
- Work for .....(short time limit, i.e. 30 min. per night, 1-4 problems)....then stop!

**Sporadic mastery** was expected: for 3 days the child did 4 problems, the next day only 1, with difficulty due to **variability** inherent with brain damage. Close tracking of stress signs provided

the teacher an exact point of reference for coaching the child to ask for help *when it was needed*, to make it safe for the child to use stress management skills she couldn't previously name, make incremental progress in her actual functional ability under daily stress conditions without blame or punishment. The stress signs led to solutions -- and the child gained specific skills for *how to learn*, as well what to learn.

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## A Comparison

Component	IDEA	Section 504
Purpose	The Individuals with Disabilities Education Act (IDEA) is a federal funding statute purposed to give financial aid to states to ensure adequate and appropriate services for children with disabilities.	Is a broad civil rights law which protects the rights of individuals with handicaps in programs and activities that receive Federal financial assistance from the U.S. Department of Education.
Who is protected"	Identifies all school-aged children who fall within one or more specific categories of qualifying conditions.	Identifies all school age children as handicapped who meet the definition of qualified handicapped person; i.e. 1) has or 2) has had a physical or mental impairment which substantially limits a major life activity, or 3) is regarded as handicapped by others. Major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself and performing manual tasks. The handicapping condition need only substantially limit one major life activity in order for the student to be eligible.
Responsibility to provide a free and appropriate Public Education (FAPE)	Both laws require the provision of a free appropriate public education to eligible students covered under them including individually designed instruction. The Individual Education Program (IEP) of IDEA will suffice for Section 504 written plan. Requires a written IEP document with specific content and a required number of specific participants at the IEP meeting.	Does not require a written IEP document but does require a plan (many schools do use a written form called a 504 Accommodations plan. It is recommended that the district document that a group of persons knowledgeable about the student convened and specified the agreed upon services. "Appropriate" means an

"Appropriate education" means a

"Appropriate" means an

	program designed to provide "educational benefit". Related services are provided if required for the student to benefit from specially designed instruction.	education comparable to the education provided to non-handicapped students, requiring that reasonable accommodations be made. Related services, independent of any special education services as defined under IDEA, may be the reasonable accommodation.
Special Education vs. Regular Education	A student is only eligible to receive IDEA services if the multidisciplinary team determines that the student is disabled under one or more of the specific qualifying conditions and requires specially designed instruction to benefit from education.	A student is eligible so long as s/he meets the definition of qualified handicapped person; i.e. (1) has or (2) has had a physical or mental impairment which substantially limits a major life activity, or (3) is regarded as handicapped by others. It is not required that the handicap adversely affects educational performance, or that the student need special education in order to be protected.
Funding	Provides additional funding for eligible students.	Does not provide additional funds. IDEA funds may not be used to serve children found eligible only under Section 504.
Accessibility	Requires that modifications must be made if necessary to provide access to a free appropriate education.	Has regulations regarding building and program accessibility, requiring that reasonable accommodations be made.
Procedural Safeguards	Both require notice to the parent or guardian with respect to identification, evaluation and/or placement. IDEA procedures will suffice for Section 504 implementation. Delineates required components of written notice.	Written notice not required, but indicated by good professional practice.
Evaluations	Requires written notice prior to any change in placement. A full comprehensive evaluation is required, assessing all areas related to the suspected disability. A multidisciplinary team	Requires notice only before a "significant change" in placement. Evaluation draw on information from a variety of sources in the area of concern; decisions made by a group knowledgeable about

	<p>or group evaluates the child. Requires informed consent before an initial evaluation is conducted.</p> <p>Requires reevaluations to be conducted at least every 3 years.</p> <p>Requires reevaluations to be conducted at least every 3 years.</p> <p>A reevaluation is not required before a significant change in placement. However, a review of current evaluation data, including progress monitoring is strongly recommended.</p> <p>Provides for independent educational evaluation at district expense if parent disagrees with evaluation obtained by school and hearing officer concurs.</p>	<p>the student, evaluation data, and placement options. Does not require consent, only notice. However, good professional practice indicates informed consent.</p> <p>Requires periodic reevaluations. IDEA schedule for reevaluation will suffice.</p> <p>Requires periodic reevaluations. IDEA schedule for reevaluation will suffice.</p> <p>Reevaluation is required before a significant change in placement.</p> <p>No provision for independent evaluations at district expense. District should consider any such evaluations presented.</p>
Placement procedures	<p>When interpreting evaluation data and making placement decisions, both laws require districts to:</p> <ul style="list-style-type: none"> <li>A. Draw upon information from a variety of sources</li> <li>B. Assure that all information is documented and considered</li> <li>C. Ensure that the eligibility decision is made by a group of persons including those who are knowledgeable about the child, the meaning of the evaluation data and placement options.</li> <li>D. Ensure that the student is educated with his/her non-handicapped peers to the maximum extent appropriate (least restrictive environment).</li> </ul>	
Grievance procedure	<p>An IEP review meeting is required before any change in placement. Does not require a grievance procedure, or a compliance officer.</p>	<p>A meeting is not required for any change in placement. Requires districts with more than 15 employees to (1) designate an employee to be responsible for assuring district compliance with Section 504 and (2) provide a grievance procedure for parents, students and employees.</p>

Due Process	Both statutes require districts to provide impartial hearings for parents or guardians who disagree with the identification, evaluation or placement of a student.	Delineates specific requirements.	Requires that the parent have an opportunity to participate and be represented by counsel. Other details are left to the discretion of the local school district. Policy statements should clarify specific details.
Exhaustion	Requires the parent or guardian to pursue administrative hearing before seeking redress in the courts.	Administrative hearing not required prior to OCR involvement or court action; compensatory damages possible.	
Enforcement	Enforced by the U.S. Office of Special Education Programs. Compliance is monitored by the State Department of Education and the Office of Special Educations Programs under the Superintendent of Public Instruction.	Enforced by the U.S. Office of Civil Rights.	
	The State Department of Education resolves complaints.	State Department of Education has no monitoring, complaint resolution or funding involvement.	

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## *Facing Fetal Alcohol: A Birth Mother's Thoughts*

*I remember sitting in the examining room for my first prenatal visit to the medical school. I was about 7 weeks pregnant and completely devastated. I knew my life was crumbling and I was in no shape to be a parent. I was 22 years old, eating disordered, alcoholic, and acting out with acute post traumatic stress symptoms from childhood sexual abuse, domestic violence and parental alcoholism. I came from a white upper middle class family of attorneys: I knew that what pregnant women do is go for prenatal visits, so I went. I didn't want to be there because I didn't even want to be pregnant.*

My husband's father was a priest, and his family told me the baby belonged to God, my husband, and me. I felt so guilty that I cancelled the abortion I'd scheduled in terror. I didn't feel worthy to live, much less take good care of someone else. I'd already been in the emergency rooms of hospitals and college medical clinics for overdoses of prescription medication with alcohol, and passing out from days of starving. To me, that was evidence enough that I couldn't take care of someone else. I couldn't even manage my own life.

The resident never asked about any family history of alcoholism or abuse. He talked with me about my health and nutrition, and asked, "Do you drink alcohol?" I answered "Yes" with a knot in my stomach (it felt RIGHT to drink – I needed it). He said, "How much do you drink?"

I said, "Once in awhile...I have a couple of drinks...not every day." Alcohol felt right, but I would never be like the alcoholics in my family – mean, Dr. Jekyll-Mr. Hyde drinkers whose drunken rages hurt everyone in the family! I needed alcohol but not daily, like they did. I was different.

He said, "Do you drink to relax, then?"

I was relieved.

"Yes. I'm a very nervous person, and I'm really pretty uncomfortable being pregnant."

Uncomfortable was putting it mildly. My past was full of memories of my body taken over against my will, and now it felt like it was happening to me all over again. Something, someONE was going to move in and I had no control. I was a failure because this was someone I was supposed to love, and all I could feel was fear, resentment, and buried rage. He offered me a rationale:

"Well, if you're more relaxed, it will probably relax your baby."

Good. I could still drink.

He added, "Just don't overdo it."

I promised, as I promised myself in the months that followed, "I won't."

I couldn't understand why I kept breaking those promises, I'd swear to myself and others, I would not get drunk that night. I'd just have two drinks like the doctor said would be okay. 3 to 5 nights out of the week, I'd plan to have 2, and even could on some nights. Then, the next time, I'd find myself drunk on 5-12 or more drinks despite my promises. I was horrified with myself. I was in a working band, and drank like everyone else around me or less: only they weren't pregnant and they didn't start having the world fall apart inside from the guilt and the shame. They'd get drunk, play music and look like party animals. I'd get drunk and look like a monster. Worse, I felt like a monster.

The bass player' wife, a nurse, looked at me one night as I gulped my fifth glass of wine (just starting to feel the buss, at last). She reached over for my hand and said,

"Hey Honey. You've got a baby in there. You might want to slow down, okay?"

I bristled and spent the rest of the night trying to sneak drinks without her knowing, because I couldn't get the craving to stop. The shame got worse.

At the prenatal visits and weekly natural childbirth classes we went to, nothing was said about my small size until the med school scheduled me an ultrasound at 8 months. I'd just bought my first pair of maternity pants. I felt atrocious. Fat, despite my attempts to look like the most "unpregnant" pregnant woman. When I ate, my nutrition was first rate: whole grains, juice, protein, and calcium. I took my vitamins daily. But I was mortified over the loss of control over my body. No one asked about drinking or drugs.

Something snapped in me when I actually saw the baby on the ultrasound. I went home in complete anguish, sobbing alone with that tiny being inside "God, I'm so sorry baby! I don't know how to care for you. I can't even take care of myself! I didn't mean to hurt you!"

I spent the next month in withdrawal, sweating, trying to stay sober. I lost it one night at a gig we were playing and drank so much I couldn't walk. I felt like I was going into labor, and in the middle of the night, bumping down a back road in the rear of our van full of sound equipment, I begged the guys in the band to take me to an emergency room. No one, not even my husband, the lead guitarist, would take me. I sobbed and passed out hoping not to wake up.

I managed out of sheer terror after that night to stay sober until my child was born, scared I'd ruined her. She was born by natural childbirth methods and everyone told me she was the prettiest baby they'd ever seen. I drank again during nursing. The LaLeche League materials said wine or beer helped the milk let down. She often fell asleep at the nipple, and was generally rather lethargic, but I just felt spared to have such an "easy" baby. Everyone remarked how wonderful she was. Somehow, she had escaped unharmed. What unspeakable relief.

I continued to drink and accrue disasters and mounting shame and defiance as my attempts to stop or cut down failed, and others began to notice my loss of control. I drank from age 19 to 25 and inside of that period, could no longer get a buzz from five or more drinks. My behavior deteriorated and I drank "moderately" with others (to cover), so that I could go home and drink the amounts I craved. I binged 3-5 nights, with increasing hangovers, remorse, and a failed marriage. One evening when my child was one, I'd gotten drunk after work and passed out. My housemates called the paramedics. I was treated and released for alcohol poisoning with no questions asked about possible alcoholism, and no referral for follow-up or treatment.

After that episode, I asked my housemates, "Do you think I could be alcoholic?" I was terrified they'd say yes, and terrified they'd say no, which meant I was simply going crazy.

They looked shocked and laughed comfortingly,

"NO! For gosh sakes, you've just been through a divorce. You got drunk. It happens."

I made my fifth attempt at seeing a therapist, and finally the symptoms of my abuse were recognized. I was appalled when she asked me, "Have you ever been molested?" I flushed red and retorted, "Yes. Why? Does it show somehow?!" She never asked me about alcohol. As I began to work on the trauma, the nightmares and flashbacks and other symptoms got much worse, and my drinking escalated wildly. Drinking was failing me and I had failed a life. I'd be drunk and in flashbacks, unable to get "away". I signed a suicide contract for 10 months after my plans were identified.

I was working a day job while trying to stay in the band after my divorce, when my last drinking episode occurred. I drank on the job, went into a blackout, quit my job in a scene, and became suicidal. I was told much of this 36 hours afterward. My only memories are of searching the house to find my child

(someone had picked her up and brought her with me), and waking in the dead of night to a voice in my heart saying, *"You are an alcoholic"*.

I went and begged for my job back. I went to AA with my child on a blanket on the floor. The corporation I worked for had never seen a woman alcoholic and provided no employee assistance. There was no treatment and I had no support or childcare as it was.

When I told the other members at group therapy I was going to AA, they exclaimed, "You couldn't be an alcoholic! You're too well educated.", "You're too young! That doesn't happen to women your age!", and other dismissals.

My horror at work had been so painful, I had no doubt. My worst fear was that I'd further hurt my child by killing myself if I ever drank again, which would leave her alone in the world with no one to care for her. I went to AA daily for well over a year not for myself, but for her.

As my years in AA and recovery grew, I sought out therapy for my child and was initially told that I was overconcerned. After six months, the therapist said,

"Well, she seems fine to me. Very friendly. She may need help later, but for now (age 4), she's done."

Her pediatrician told me that I was in recovery now, and shouldn't live too much in the past, attributing my expression of concern over my daughter solely to guilt. I talked to her teachers, school officials, friends and professionals about my drinking history with her and was reassured over and over that I was overconcerned.

A private school teacher recommended she repeat first grade, citing slow cognitive tempo, "daydreaming" and problems with attention, difficulty with sequencing and tracking, and trouble carrying out instructions. I discussed these concerns with the principal of our neighborhood public school, hoping my child could start over there with less pressure. She was placed ahead despite my requests. Sporadic mastery and a verbal, charming manner masked her sense of chronic failure and frustration. Distress played out at home in the form of gouging furniture and exhaustion: her fatigue and sense of defeat had accumulated to the point of school refusal by fourth grade.

The second therapist I took her to used art, and insisted that her math problems, memory deficits, and other symptoms of subtle learning problems would remediate on their own when she "had more emotional energy for school work". I believed it must be all my fault for her growing up in a recovering household, though in my recovery, I had gathered parenting techniques from reputed books and methods and drew heavily upon my former skills with children from working in camps, summer programs, and other childcare settings providing child-centered learning opportunities. Despite my educational background and training, when others pronounced her difficulties solely emotionally based, I capitulated, figuring I just wasn't a healthy enough parent (despite 6 years of depth therapy, years of continuous abstinence and involvement in 12 step programs, and a remarriage of several years with the birth of another child in recovery).

I first saw literature on FAS when I was working at the Oregon Council on Alcoholism and Addiction. A co-worker began to talk to me and I adamantly insisted my child did not have FAS. I avoided reading any more about it for another year. When I read my next article, my child had been in therapy going on two years, school problems had not remediated, our family life had been continuously improving since my remarriage when she was three years old. The article discussed FAE and I froze. I read, and it was a portrait of my daughter. I poured over the literature and called every colleague I could to ask their level of

information, seeking people who could evaluate her. Finally I called the authors of the article, who were conducting research in Seattle, where we eventually took part in a longitudinal study.

I grieved hard, and alone for the better part of six months. I began to ask my daughter about some common things that happened for her at school and at home. I heard her answers differently and started to validate her difficulties. I fought the school to hold her back and let her repeat fifth grade before pushing her on ahead into middle school. I approached her therapist with the information on fetal alcohol. I found ways to deal with my own pain, and later began to talk with my child about the things that were hard for her because I drank during pregnancy with her. As she grieved, she'd cry and tell me how she loved me but couldn't accept it that I had hurt her by drinking.

She said, "Did you know drinking would hurt me?"

I said, "I was afraid it would. But I was very sick and couldn't stop on my own. I was hurting myself and you, and couldn't stop until I got help to get well."

When she said "How could you!!", I just nodded crying with her while she sobbed.

*I told her honestly: "It is very hard, and very sad that I hurt you when I was sick with drinking alcohol. You never deserved to be hurt. It hurts you that this happened. You can feel hurt and be angry. I love you and I'm so sorry."*

She would cry and hold me, lamenting, "I love you and I'm so mad at you! It is hard to love you and know that you hurt me back then. Because you are my good mom, now, and I don't want to be mad at you. But I am!"

She was mad, and hurt, and the pain took another 1 ½ years for us to process. The relief was immediate, however, in that when she heard the actual works, "Fetal Alcohol Effects", she said,

"It is real? It has a name? It's not my fault!" and cried tears of relief, asking to meet other children with the same condition.

*This has proved pivotal for acknowledging what is hard for her, and helping her build on her many strengths. The problem behaviors began to ebb away. She still has symptoms, and we have found ways to deal with those. Her grief has resolved, though at times in adolescence, she would grieve pieces of what she imagines she might have been like had I not been drinking during my pregnancy with her. It was the truth that allowed her to shift from feeling like she was a problem, to being a person with a problem, that has a name and can be dealt with. I was grateful to have found ways to handle my own grief so that I could be present and available when hers needed room to flow. I am also grateful for the one woman, the nurse, who in her way, tried to help. The discomfort made a connection, and the connection made sense eventually.*

If I could change anything in this world it would be that my child was harmed by my disease. I thank the universe that my second child was not. We are living proof that even in families from generations of alcoholics, sobriety and health can happen and the devastation *can* be stopped. My children have experience of choices for a healthy life that were not available before we created them together. That's what the truth does – it takes down the walls so that we can face life on its own terms together.

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**SHORT MICHIGAN ALCOHOLISM SCREENING TEST**  
(adapted to include drug use)

1. **Do you feel you are a normal drinker?**  
(Do you feel you are a social user?)...By normal we mean you drink or use less than or as much as most other people?
2. **Does your partner, or family ever worry or complain about your drinking or using?**
3. **Do you ever feel guilty about your drinking or using?**
4. **Do friends or relatives think you are a normal drinker or user?**
5. **Are you able to stop drinking or using when you want to?**
6. **Have you ever attended a meeting of Alcoholics Anonymous (or Narcotics Anonymous)?**
7. **Has drinking or using ever created problems between you and your partner, or other family members?**
8. **Have you ever gotten into trouble in any area of your life (relationships, work, legal) because of drinking or using?**  
(Have you ever had domestic or marital trouble because of drinking or using?)
9. **Have you ever neglected your obligations, your family, or your work for two or more days in a row because you were using or drinking?**
10. **Have you ever gone to anyone for help about your drinking or using?**
11. **Have you ever been in a hospital because of drinking or using?**
12. **Have you ever been arrested for drunken driving, driving while intoxicated, or driving under the influence of alcohol or other drugs?**
13. **Have you ever been arrested, even for a few hours, because of other drunken behavior?**

This form adapted from Selzer et al. is commonly used in the place of the long form Michigan Alcoholism Screening Test.

**Scoring: 0-1 point = no alcoholism, 2 points = possible alcoholism, 3 points = alcoholism.**

### The CAGE Questionnaire

1. Have you ever felt you should **CUT DOWN** on drinking (or using)?
2. Have people **ANNOYED** you by criticizing your drinking (or using)?
3. Have you ever felt bad or **GUILTY** about drinking (or using)?
4. Have you ever had a drink (or drug) first thing in the morning to steady your nerves or get rid of a hangover (**EYE-OPENER**)?

The CAGE questionnaire assesses the possibility of a drinking or chemical problem. A "yes" answer to 2 or 3 out of 4 items strongly suggest the presence of alcoholism or chemical dependence (Mayfield, et al.)

## GENDER SPECIFICS: THE SMAST ITEMS & WOMEN

### 1. Do you feel you are a normal drinker?

This question brings up the symptom of denial:

"I party, but I'm not like an alcoholic or anything, I don't drink (or use) everyday...I mean everybody goes out sometimes with their friends, you know...." ...her denial is not helped by the stereotype we all have in this culture that an alcoholic is someone who drinks every day.

Try to ascertain the number of times per week the client imbibes, how much on these occasions, and what is being used, consumed, OR PRESCRIBED:

"Well, about how many times a week do you find yourself going out with friends?", and "When you do go out, about how many drinks do you have in an evening...do you only drink, or is there some cocaine or dope around, too?"

"Are you taking any medications on a regular basis? How often do you take these? Have you ever found yourself taking more than what was prescribed, or taking them at shorter intervals?"...

Expect that she will make contradictory reports, minimize, and discount the frequency and amounts. THIS IS NOT BECAUSE SHE IS TRYING TO BE DISHONEST WITH YOU; RATHER IT IS BECAUSE SHE DOES NOT KNOW WHAT SHE IS DEALING WITH IS A DISEASE AND SHE IS EXPERIENCING DENIAL, DELUSION AND COMPULSION AS CORE SYMPTOMS. She experiences FEAR, SHAME, and DISHONESTY WITH HERSELF (OUT OF WHICH IT IS HARD TO BE HONEST WITH YOU, THE INTERVIEWER.) She feels she should be able to control it, and is trying to demonstrate that she hasn't lost control (loss of control being the hallmark of addiction.)

### **Does your partner, or family ever worry or complain about your drinking or using?**

Often the client's partner is addicted, in which case his behavior may show signs that appear more dramatic such as antisocial behavior, i.e. bar fights, bullying, domestic violence, staying away from home. His may be so "out front" that comparatively, hers appears mild and less dangerous. The key here is that progressive addiction is dangerous to her, and unfortunate for others as an outgrowth of that. Women suffer serious health complications much sooner than men, advancing through early, middle, and into late stage addiction in from 5 to 10 years (telescoped interval, discussed by Schukit, Gomburg, and others.)

A common complaint to look for however, is that others may worry that she becomes "overly emotional" or "unpredictable", i.e. anger outbursts. The behavior cited would be atypical of her in her general adaptation to those around her.

Therefore, be sensitive to the reality that alcohol and drugs lower her inhibitions allowing for freer expression of both positive and negative behaviors, and that her environment may see any change as negative. The key here is to identify HOW her behavior changes, WHEN it changes, and WHAT are the "complaints", and by whom. Note especially self-destructive behaviors including unsafe sex when drunk or high, suicidal behaviors, violent outbursts, inappropriate risk-taking, mixing medications with alcohol, driving drunk.

The complaints of loved ones offer valuable information about the nature of potential support for her recovery, or risk of sabotage to development of self-caring behaviors she will be asked to learn to help her disease stay in remission once abstinence has begun.

**3. Do you ever feel guilty about your drinking or using?**

Women feel enormous guilt and shame. A double standard exists for male and female alcoholics; the man is "a party animal" and "the life of the party". But the saying goes, "There is nothing more disgusting than a drunk woman".

Add to this the stigma of having a disease most see as an inability to control oneself. **She can't understand why she has seemingly lost control, and struggles to convince herself and others that she really still is in control. Feeling overpowered always produces feelings of victimization. As she tries one control strategy after another, and these eventually fail, she feels very victimized and at fault. She cannot see the brain chemistry and liver-cell adaptation going on inside her body that produce the symptoms of loss of control, changes in tolerance, and inability to regularly predict outcome once ingestion occurs.**

**4. Do friends or relatives think you are a normal drinker or user?**

**5. Are you able to stop drinking or using when you want to?**

Due to brain chemistry and liver-cell adaptation, unpredictability begins to occur: perhaps she can drink or use "like usual" on one occasion, and then 3 days later experience inability to stop, getting drunker "than usual", or feel drunker sooner. She may cite how many times she has stopped (gone dry for several days, weeks, months, or years.) However, obviously, these attempts to stop or "slow down" have failed or she wouldn't be using or drinking at present. Really stopping means total abstinence from all mind or mood altering chemicals, period.

**6. Have you ever attended a meeting of Alcoholics Anonymous (or NA)?**

Only 1 in 30 women stays in AA after a year's time. Many women may have tried to go to meetings and been overwhelmed with feelings of unsafety sitting in a room mostly filled with men (whose symptoms and stories they may not relate to.) The newly abstinent alcoholic/addicted woman suffers cognitive distortion and other physiological symptoms that impair her ability to reason and choose. She has black and white thinking,

global distortions, and other barriers to generating healthy options for herself. If the first exposure to a 12-step meeting or treatment environment is uncomfortable, or ill-suited to addressing her needs (besides her own internal discord which is considerably painful in acute, sub-acute, and post-acute withdrawal stages), she will likely assume she can't be helped and that all is lost. This increases her isolation and risk of progressing into later stages of the disease with increasingly severe complications and poorer prognosis for successful treatment outcome.

**7. Has drinking or using ever created problems between you and your husband, lover, parents or other family members?**

Most women are partnered with someone who drinks or uses as much as she does; often more so. Women tend to remain with active alcoholic men; men tend to leave a woman alcoholic. There is often broader use than just her own.

**8. Have you ever gotten into trouble at work because of drinking or using? (Have you ever had domestic or marital trouble because of drinking or using?)**

**9. Have you ever neglected your obligations, your family, or your work for two or more days in a row because you were using or drinking?**

These questions center on how relationships and daily ability to function are effected by chemical dependence. Know that a woman will go to any length to try to keep her addiction from her children, so they may never actually see her use or drink. Look for:

- problems getting to sleep at night (speed, cocaine, alcohol) and problems waking up to get kids to school, or get to work on time (hour late, how many times per week, per month, etc.)
- reports of depression and lethargy; "I have no energy and don't even want to cook or do the shopping..." (can indicate withdrawal, ie. stayed up all night on a coke run, and can hardly pull it together to get through the days activities...)
- irritation with children for daily needs, reports "they never leave me any time to myself"
- fight with partner, domestic life tense with arguments (partner may criticize her use, or she may be using to "keep up with" addict partner, both may use/drink shutting the kids out...)
- client may report "having to get stoned" to stand being around her parents, or other relatives...

Women fearful their drinking harmed their children will be especially vulnerable and need understanding for the depth of their denial, guilt and grief. One alcoholic mother said to an adoptive mother "But I thought he'd be okay because he's with you now." Alcoholic women see themselves as "the bad one", and adoptive parents as "the good one".

**10. Have you ever gone to anyone for help about your drinking or using?**

Statistics show that most chemically dependent women have been seen up to 4 times prior to entering treatment by emergency room staff, physicians, therapists, and attorneys.

They typically go in search of help for:

relationship problems, marriage problems

depression, low energy level

stomach problems, headaches, sleeping problems or anxiety

If asked if they have ever had any problems with alcohol, most alcoholic women will answer "No, I'm just having all this stress in my life" because they think the above problems are causing them to drink, instead of drugs and alcohol being a causal agent of the ensuing problems.

**11. Have you ever been in a hospital because of drinking or using?**

Again, by the time a woman is hospitalized with a diagnosis of alcoholism, she is typically in late stage. Although accidental overdoses occur, personnel tend to think of these as one-time occurrences. In actuality, this is a great risk because it signals the symptom of changes in tolerance that are significant of middle stage addiction. Other hospitalizations may have occurred, but she will typically be diagnosed for the symptoms of the alcoholism or addiction, without the primary disease pattern or etiology having been identified. Her answer would likely be "no", and you must check for ulcers, hiatal hernia, migraines, hepatitis, diabetes, and other possible alcohol-related health problems.

**12. Have you ever been arrested for drunken driving, driving while intoxicated, or driving under the influence of alcohol or other drugs?**

**13. Have you ever been arrested, even for a few hours, because of other drunken behavior?**

Arrest and DUI rates are lower for women than men. Women mandated for participation in Diversion Programs for DUI's typically do poorly as the environment reflects male treatment needs and issues. Women usually are just "hit upon" by men and distracted from attending to the content, or remain compliant and systematically shut out most of the treatment information.

July 16, 2001

Adoption Social Worker  
DCFS  
P.O. Box  
Anywhere, WA 98046-9712

*RE: Child age 6 and Sibling age 3*

Dear Professional:

I am writing to discuss treatment status and progress of the above named children, who have received outpatient services at .....since their referral by your colleague, Hilda Someone, from DCFS last winter. The children and their parents, Hattie Mae and Alvin Adopting, are active in our Special Needs Adoption Program, a project serving special needs adoptive families whose children have alcohol and drug related disorders.

The purpose of treatment has been to clarify mental health and developmental conditions present which reflect an underlying health condition from exposure to alcohol during gestation, to which other drug exposure or environmental challenges may have compounded the child's challenges. Our program is aimed at helping parents and children gain skills to avoid misunderstandings over time that can result in a later disruption. At intake, it was clear that the Adopting's were familiar with "good enough" parenting, but that much more help was required. Their children are more vulnerable children than typically developing peers; they don't handle "routine" stressors as "routine". Both parents were candid that as the children arrived due to a relative placement, they had not been planning to be parents or adopt, and thus experienced many adjustment reactions. Hattie Mae was employed, proud of her work, and when told by a professional along the way that "the boys really needed a fulltime mother at home", had to make a conscious choice about refocusing herself towards different purposes. She adjusted and resolved her earlier concerns and now puts her former energy into working for the boys' needs coordinating their circle of care and services. Alvin acknowledges having initially thought of them as Hattie Mae's responsibility, and having to shift into building his own loving relationship with the children. The marriage underwent a change of focus, and the couple is actively co-parenting and participating with a network of other special needs adoptive fathers and mothers who face similar scenarios.

These are not parents who bring their children and "drop them off for their therapy appointment". Each attends actively, participates and is engaged fully in building healing relationships with each child. Both children have symptoms suggesting that their brains "misread" many natural circumstances as noxious,

due to poor calming and regulation capacities in the brain and body resulting from neurotoxin exposure and subsequent environmental maltreatment. Each one of the children has made some significant gains in treatment to date. The most important are the signs showing they are fully choosing the Adopting's as their parents, looking to them for nurture, structure, limits and safety, and despite struggles, starting to accept parenting from them.

Child, age 6, has Post Traumatic Stress Disorder. The results of his neuropsychological evaluation are still pending to complete the comprehensive diagnostic workup that includes his drug and alcohol exposure status. His anxious control, hyper vigilance, "freezing", silent refusal, and aggression in daily settings are responding to intensive family therapy. Though we anticipate Child to have less neurocognitive compromise than many children with his history, he remains at risk for later academic complications and potential executive function impairment. He has subtle language processing problems causing random gaps in his comprehension and delays in carrying out directions with several steps. His ability to tolerate novel situations or people can reflect exceptional anxiety; where typically developing children show curiosity; he may instead shut down or become disorganized internally, needing extra time to regroup and reduce agitation, confusion or perseveration. The symptoms can be seen presently, but by middle school, will be easily misunderstood unless he develops skills to self-advocate over this difference from other students.

Interventions are directed towards assisting ability to self-calm and regulate arousal to reduce incidence of extreme emotional and physical reactions impeding social and school behavior. He has empathy skills but significant hyper vigilance, causing distortion of cues from others. He is making progress in verbalizing the intensity of his physical responses, but it is very hard for him. His threshold for change is low, and external supports keep him able to show more "scaled" or gradated, instead of extreme reactions, i.e. help him differentiate "discomfort" from "danger". Sensory habilitation techniques for home and school need to be incorporated to reduce risk of secondary psychopathology by pre-adolescence.

Sibling, age 3, appears bright intellectually, but has had expressive language delays; these may warrant speech and language intervention beyond that provided in early childhood education. Sibling has a diagnosis of Phonological Disorder; his language is getting more intelligible, but continued treatment is needed to reduce peer communication problems already developing due to his aggression. Sibling has poor registration of sensory stimulation, is overly aggressive and has met referral criteria for Occupational Therapy. He and his parents are working constantly to expand his social and self-expression skills, self-containment and self-calming skills as his regulatory dysfunction is more pronounced than his brother's. He cannot formally be diagnosed with ADHD or a Bipolar Disorder until after age 4, but his present symptoms are consistent with such conditions. Differentiation can be made as he reaches appropriate age.

The boys' challenges, though different from one another, reflect underlying neurodevelopmental needs for which they will need periodic intervention to preserve adaptive skills for functioning at home and school over time. Need for adjunctive services in addition to mental health treatment, either at particular critical periods, or in supplement to limited services available through the education system must be expected. Financial supports over time will be needed to secure access to assistance that will help them master successively demanding environments which introduce more cumulative challenge for the child and family dynamics than what parents expect at the time of adoption.

With your assistance and support for intervention over time, the Adoptings can make necessary steps towards improving family relationships and anticipatory coping skills to help them focus on the strengths in their children and family.

Sincerely,

Antonia Rathbun, M.A., A.T.R., NCMHC  
Special Needs Adoption Program Manager / Childrens Center

## DEVELOPMENTAL TASKS

### THIRD YEAR (2-3 years old)

- use toilet
- string beads
- enjoy playing alone
- use 100 or more words
- copy a circle
- understand simple stories
- walk up and down stairs
- use 2 word phrases
- imitate parents' routine activities

### FOURTH YEAR (3-4 years old)

- button large buttons
- draw a person
- copy a cross
- count to 10
- count object to 3
- talk in short sentences
- speak to be understood
- balance on one foot for a short time
- play and share with other children

### FIFTH YEAR (4-5 years old)

- catch, throw and bounce a ball
- zip a zipper
- cut with scissors
- name 4 colors
- say simple nursery rhymes
- sort by color and shape
- know some opposites
- share and take turns
- use "and" and "but" in sentences

## NORMAL STATES OF SEX PLAY

**2-1/2 YEARS:** Child shows interest in different postures of boys and girls when urinating and is interested in physical differences between the sexes.

**3 YEARS:** Verbally expresses interest in physical differences between sexes and in different postures in urinating. Girls attempt to urinate standing up.

**4 YEARS:** Extremely conscious of the navel. Under social stress may grasp genitals and may need to urinate. May play the game of "show". Also, verbal play about elimination. Interest in other people's bathrooms; may demand privacy for self, but be extremely interested in bathroom activity of others.

**5 YEARS:** Familiar with, but not too much interested in physical differences between sexes. Less sex play and game of "show". More modest and less exposing of self. Less bathroom play and less interest in unfamiliar bathrooms.

**6 YEARS:** Marked awareness of and interest in differences between sexes in body structure. Questioning. Mutual investigation by both sexes reveals practical answers to questions about sex differences. Mild sex play or exhibitionism in play or in school toilets. Game of "show". May play hospital and take rectal temperature. Giggling, calling names or remarks involving words for elimination functions. Some children subjected to sex play by older children; or, girls are bothered by older men.

**7 YEARS:** Less interest in sex. Some mutual exploration, experimentation, and sex play, but less than earlier.

**8 YEARS:** Interest in sex rather high, though sex exploration and play is less common in than at six. Interest in peeping, smutty jokes, provocative giggling. Children write or spell "elimination" or "sex" words.

**9 YEARS:** May talk about sex information with friends of same gender. Interest in details of own organs and functions; seek out pictures in books. Sex swearing and sex poems begin.

**10 YEARS:** Considerable interest in "smutty" jokes.

**ATTACHMENT DISRUPTION SYMPTOMS:**

**1. Sadism/Violence**

- Cruelty to animals*
- Cruelty to other children*
- Vandalism/property destruction*
- Assaultive*
- Self-injurious*
- Fire setting*
- Accident-prone*

**2. Disordered Eating**

- Stealing and hoarding food*
- Gorging*
- Food refusal*
- Abnormal eating patterns (times, rituals, etc.)*

**3. Counterfeit Emotionality**

- Theatrical display of emotion (Drama King or Queen)*
- Superficial charm/phoniness ("Eddie Haskell")*
- Emotional radar*
- Indiscriminate attachment*
- Indiscriminate and superficial attractiveness and friendliness with strangers*
- Poor peer interactions*
- Poor adult relationships (longer than 3-4 days)*
- Demanding and clingy (Sucker Fish)*
- Controlling*
- Manipulative*
- Child is less likeable over time*
- Poor eye contact*

**4. Kleptomania/Compulsive Lying**

- Chronic stealing (often of objects with no value)*

\_\_\_ *Pathological lying*

\_\_\_ *"Crazy lying"*

**5. *Sexual Obsession***

\_\_\_ *Seductive behavior*

\_\_\_ *Seductive clothing*

\_\_\_ *Open masturbation*

\_\_\_ *Sexual activity with other children*

\_\_\_ *Bestiality*

**6. *Passive Aggressive***

\_\_\_ *Face to face compliance with 'Get Backs' later*

\_\_\_ *Refusal to answer questions*

\_\_\_ *Provoking emotions in others*

\_\_\_ *Enuresis*

\_\_\_ *Encopresis*

\_\_\_ *Nose picking and snot wiping*

\_\_\_ *Incessant chatter*

\_\_\_ *Persistent, nonsensical questions*

\_\_\_ *Property destruction*

**7. *Defective Conscience***

\_\_\_ *Absence of guilt*

\_\_\_ *Denial and projection of guilt onto others*

\_\_\_ *Lack of concern for others, physically, emotionally, psychologically*

\_\_\_ *No remorse for wrong doing*

\_\_\_ *"It's Not Fair" disease*

**8. *Learning Difficulties***

\_\_\_ *Learning disabilities*

\_\_\_ *Delayed cognitive development/learning lags or gaps*

\_\_\_ *Behind in grade level*

\_\_\_ *Communication disorders/problems*

\_\_\_ *Delays in fine and gross motor skills development*

\_\_\_ *Lack of cause and effect thinking*

\_\_\_ *Does not learn from mistakes*

\_\_\_ *Abnormal speech patterns*

*Poor concentration and attention*

*Poor impulse control-appears ADHD*

**9. Distances Self From Care**

*Physical and/or emotional withdrawal from interactions*

*Aggressive*

*Promiscuous*

*Overly compliant (has no needs, no sense of self)*

*Overly competent (self-parent)*

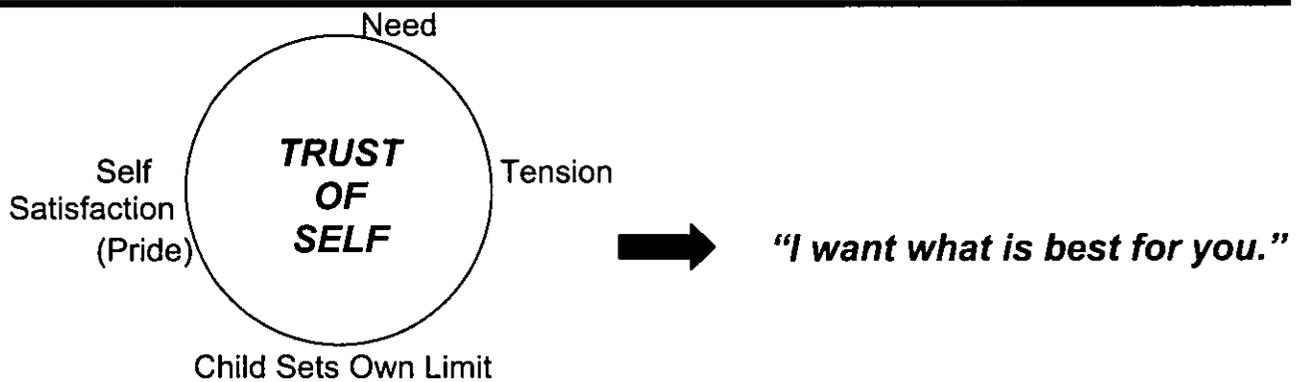
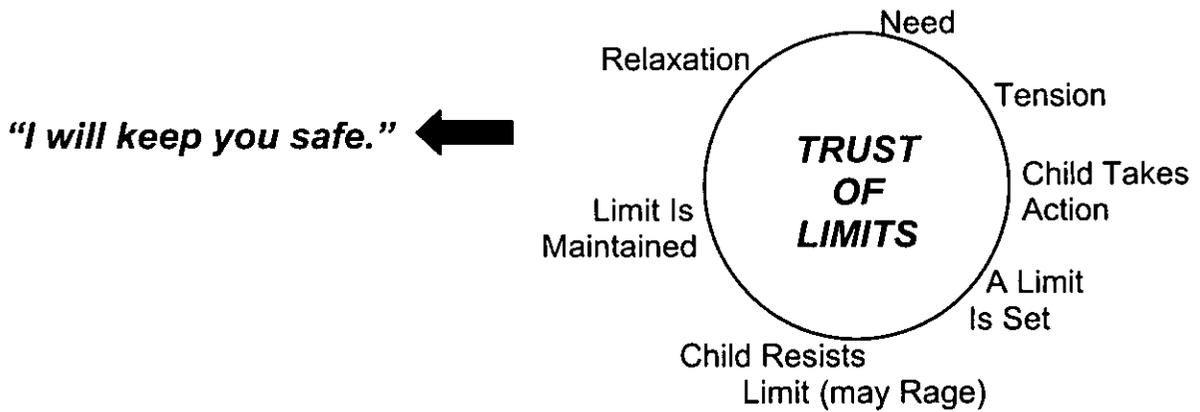
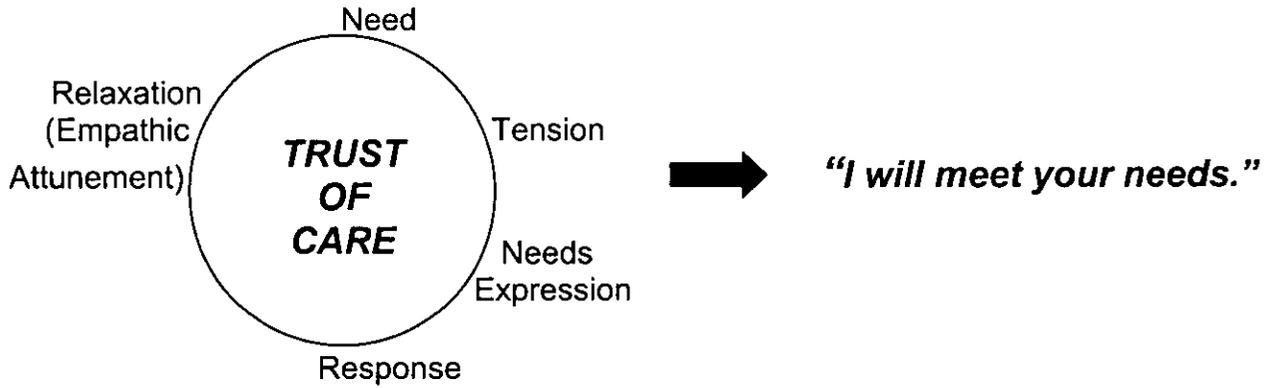
*Preoccupation with blood, fire, and gore*

*Preoccupation with bodily functions*

*Not affectionate on parents' terms (not cuddly)*

*Psychotic behaviors*

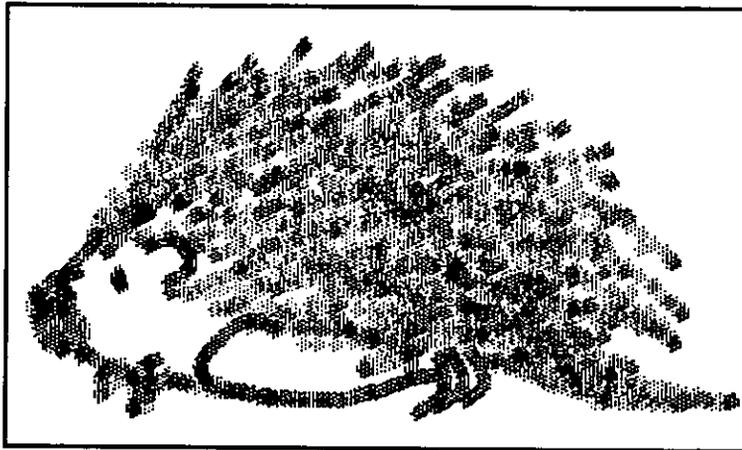
# The Trust Cycles



# MEET PORCUPINE

Here is porcupine.  
He is having a good day.  
His bristles are down.  
They are smooth.  
He is comfortable.

What color is his stomach?



(color) \_\_\_\_\_ means he feels \_\_\_\_\_.

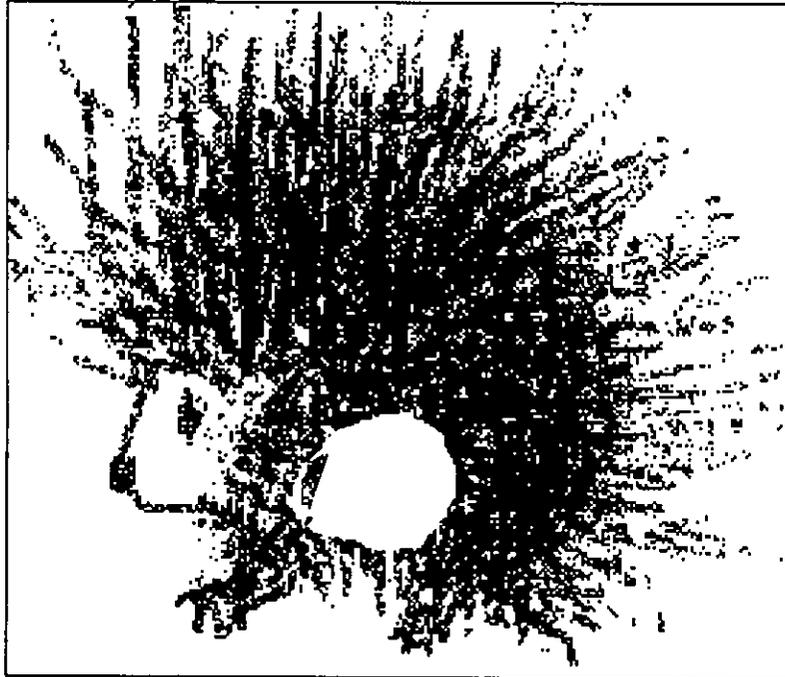
What does it make him want to do?

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Something's wrong.  
Porcupine is stuck.

He's having a bristle attack!  
Now what color is his stomach?



His stomach is \_\_\_\_\_ (color).

His heart is \_\_\_\_\_ (emotion).

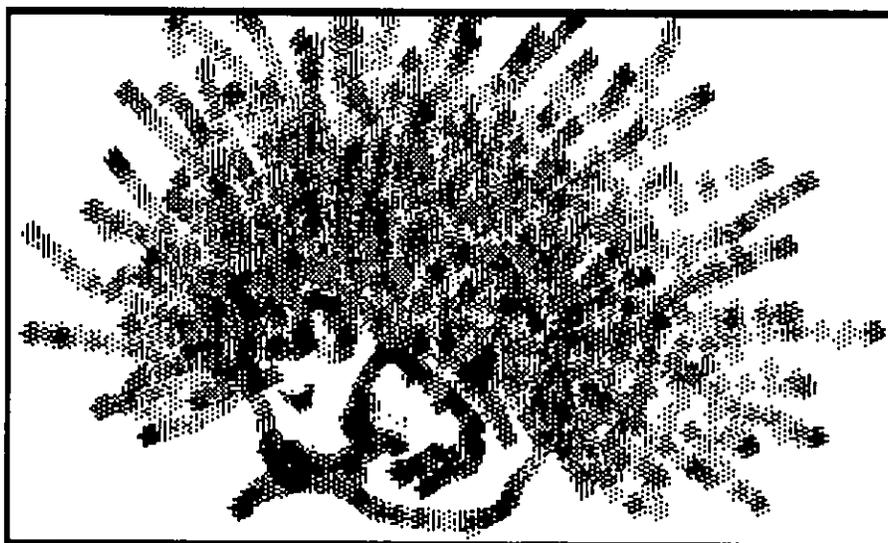
It makes him want to \_\_\_\_\_

\_\_\_\_\_

He's **still** having a bristle attack!  
Now what happens?

He is in a ball.

What color is his stomach?



He is balled up because....

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What should people do when porcupine gets stuck?

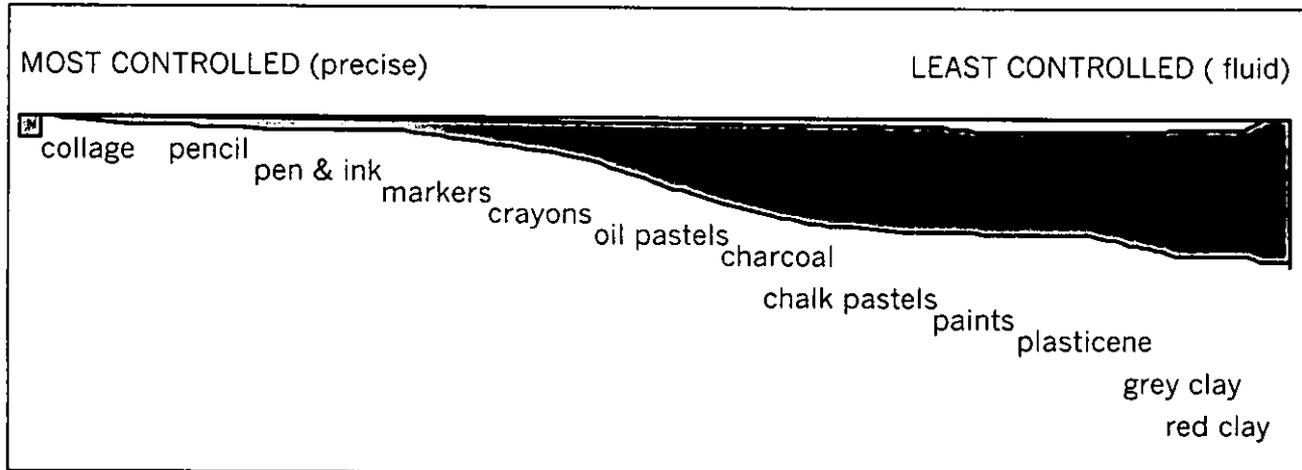
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We understand. Thanks, porcupine!

## ART MATERIALS: THE EXPRESSIVE MEDIA CONTINUUM

Art materials have a range of *tonal* (color or value) and *tactile* (textural) properties. Different materials afford various sensory learning opportunities. Media selection plays a large role in art making. Successful art involvement never involves coercion; we all have media preferences for good reasons! The broader our comfort zone with a range of media, the more tools we can use to support children in developing their own visual/sculptural language.



### Most controlled media:

- Provide structure & firm limits - *they stay where you put them*
- Build patience through predictability - *you can work incrementally over time*
- Offer precision - *you can achieve visual detail*
- Give a sense of control - *you can control the media when you can't control other factors in your environment (symbolic mastery)*
- Provide emotional distance or separation from reality - *you can portray the overwhelming in manageable terms, reducing sensory impact on the brain (black & white vs. color)*

### Least controlled media:

- Stimulate sensation & expression - *they loosen emotional controls & allow expression, and in some instances, regression*
- Build technical and emotional range - *color & textural properties are mastered when media interactions ("mistakes") are explored and resolved*
- Encourage flexibility - *creative tension in work with free flowing media builds tolerance for unexpected changes to be met with innovation & adaptation*
- Foster spontaneity - *fluid or malleable media are very immediate and require response*
- Provide a sensory stimulation - *visual and tactile properties can provide stress relief*

## Picture Talk: Art Therapy & FAS/FAE Relief, Revelation, & Remaking

Eight-year-old Randy with FAS was more gaze aversive than usual when he came to art therapy group after school one day. He had a flat expression, dragged his shoes along the couch, picked on another child, and couldn't soothe himself, even with the stair stepper that usually calmed him after 10 or 12 minutes. Everyone else was sculpting by the time he grumbled and reached for paint, demanding the largest sheet of poster board I had. Wordlessly, his pain emerged from the page: an armless boy, mouth turned down, body tilted as a palm tree in a hurricane. He looked up, then, and rested his eyes on my face. After a long silence, he spoke softly, "It was a bad day."

Kicking the couch and gaze aversion had melted away. Pointing to the page, I offered, "That boy looks sad, Randy." He nodded at the page in front of him, hung his head, and out came the story piece by piece. Afterwards he curled up under my desk asking the other children to help cover him up with pillows from around the room. He told us to press them down upon him several times and hold them. As others went back to their sculpting, he rested in this "nest". By the end of group, Randy helped everyone clean up, no longer abrasive, but friendly and playful. There are times when a picture is worth a thousand words. His behavior appeared to say one thing, but his heart another. His "picture talk" said it all. He gained relief.

Seven-year-old Elise with FAS frantically painted the face of her whole body outline drawing. Suddenly, she exclaimed, -I hate it when mom washes my face. " The others echoed her sentiment, and it turned out the difficulty was not with their mothers, nor washing, nor the water temperature: it was the washcloths. Terrycloth and tactile defensiveness didn't mix. Helen, age eight with FAS said -I want one from the nightgown stuff, that soft kind." Despite anomia, her point was clear, and all agreed with this revelation enthusiastically. Their parents welcomed the children's idea on making hygiene more comfortable. At the next session, the kids crowded with delight over new soft flannel facecloths!

Pictures speak about our perceptions and our emotions, as if we are imagining "out loud". Art therapy involves listening to the language of pictures. For children with FAS/FAE, who have difficulties putting words on thoughts and feelings about their needs and daily environments, the poignant nature of communications through art, poetry, music, dance or clowning can tell us volumes.

The following guidelines may be useful when facilitating art with individuals with FAS/FAE:

- Emotional safety is foremost. The process of art emerges when people feel welcome just as they are. Art experiences can offer relief, instead of pressure to perform.
- Statements like "I can't do this" may signal discouragement, vulnerability or difficulty initiating (frequent with brain injury). Arguing or attempting to persuade increase anxiety and may come across as denying someone else's discomfort. The goal is to provide a gentle path to regaining confidence in creating. Relaxed exploration of materials that engage curiosity or feel most approachable reframes the focus from the person to the media. Expressive media have different properties, therefore preferences or aversions are honored as a legitimate starting point.
- Everyone's art is his or her own. Comments that point out a characteristic in a picture may help invite discussion, i.e., "There's a big blue, wiggly line." or "The animal is looking at the tree." Critique is avoided, as are the questions, "What is that?" and "Why did you make...?" A safe

question might be "Is there a story with this?" The answer might be a simple, "No." Trust is the process.

- There are not right or wrong answers in art. If the maker finds things s/he would want different, we discover what options exist for the next part of the art process.
- Metaphors provide emotional distance. If a person speaks through a character, I answer about the character and do not attempt to bring the subject closer to home. Defenses are preserved. It is easier to maintain trust by working incrementally, than to try to rebuild it once a person feels cornered or exposed.
- Interpretation of art deserves caution. For example, snow in the art of a child from Florida may suggest depression, however when evaluating snow scenes depicted by a child from Alaska conclusions would have to take careful note of the fuller context.
- Mistakes are opportunities to change things, find new combinations and see cause and effect in action. Art media are both structured and dependable: they behave the same way, time after time. Having satisfaction with art processes can help heal chronic success deprivation for children with FAS/FAE: "I did that myself!" or "I never thought I could make something that big!" or "that good!" "First, I thought it was ruined; now it's even better!"
- Themes of "ruined", "broken" or "cracked" objects or characters can parallel feeling damaged, or different, in this case, due to FAS/FAE. These images may accompany grief and adjustment, and change as therapy progresses. Strengths are always present in some form. Think paradoxically. There is something worse than making a picture of oneself as "cracked up", and that is feeling this way all alone and having to deal with it. Someone else knowing means that communication has succeeded. That is a strength!
- Various developmental levels can be seen in art making, i.e., preschoolers make people like tadpoles, adolescents often produce stereotypes that look much like decals of blood, knives or other weapons, skulls, roses, etc. Developmental information must be taken into account when differentiating symbolic content for potential aggression, suicidality, indicators suggesting abuse, or other concerns. What looks alarming may be alarming, or it may be expressive of needs for power, self-protection or the process of resolving conflicting inner feelings. Encourage commentary that is freely offered, reducing reactivity to keep the door open. Judgments made on the basis of a single piece of art are usually unreliable. A minimum of three pieces of art is necessary to most art therapy assessment protocols.
- Art contests or other forms of competition work against the process of remaking the vulnerable self through art. Art allows differentiation and belonging at the same time. What we make is as unique as who we are.

**In a world of words, art still speaks. Hubbard put it best:**

**"Art is not a thing; it is a way. "**

## Why Can't They Just Speak Up?

### THE SYMPTOM FOR THE LOSS OF WORDS FOR FEELINGS IS CALLED "ALEXITHYMIA" (ah-lex-eh-thigh-mee-ah)

Trauma's effects on the brain include when language ability seems to go "offline", a symptom shown by many children with FAS (Van Der Kolk, Mc Farlane and Weisaeth, 1996). Krystal (1978) describes how trauma results in loss of ability to identify specific emotions to serve as a guide for taking appropriate actions. Literally, trauma to the typically developing central nervous system can change permanently how one's mind reads and responds to input. Research has not yet determined how this effects people with pre-existing damage from alcohol or other neurotoxin exposure. Trauma can induce brain adaptation patterns that become reflexive, to protect survival. Since most events are not life or death situations, these default changes are not necessarily desirable over time, and can interfere with quality of family life.

**Krystal noted that the inability to link language to specific physical states was related to aggression against self and others. Safety, stress threshold and stress hormone release become important ideas: alexithymia serves as an obvious clue to the need for answers about what, where, when and how stress threshold is exceeded.**

Note: Alexithymia often occurs in conjunction with defensive behavior that is either aggressive or regressive, such as; acting out despite knowledge of limits, warnings or impending discipline, spitting, biting or gouging, soiling and hiding waste in clean clothes or laundry, smearing feces or urinating on objects or people, and other forms of covert or overt 'unusual' behavior wherein it is hard to discern a purpose to the action or what that person needs from others.

In PET scan (positron emission topography) research by Rauch, et al., people with PTSD who were exposed to environmental conditions that reminded them of traumatic events showed reactions in the right hemisphere of the brain. They had increased blood flow in the areas that handle emotional states and flight or fight reactions (i.e. the brain had to work harder in these regions). In addition, there was decreased use of oxygen shown to Broca's area – the region in the left inferior frontal cortex that generates words for internal experience.

This sheds light on the "freezing" reaction seen when someone with a trauma history later appears blank or wordless over routine events wherein discomfort suddenly escalates (though there may not be literal danger). Once "triggered" by sights, sounds or other

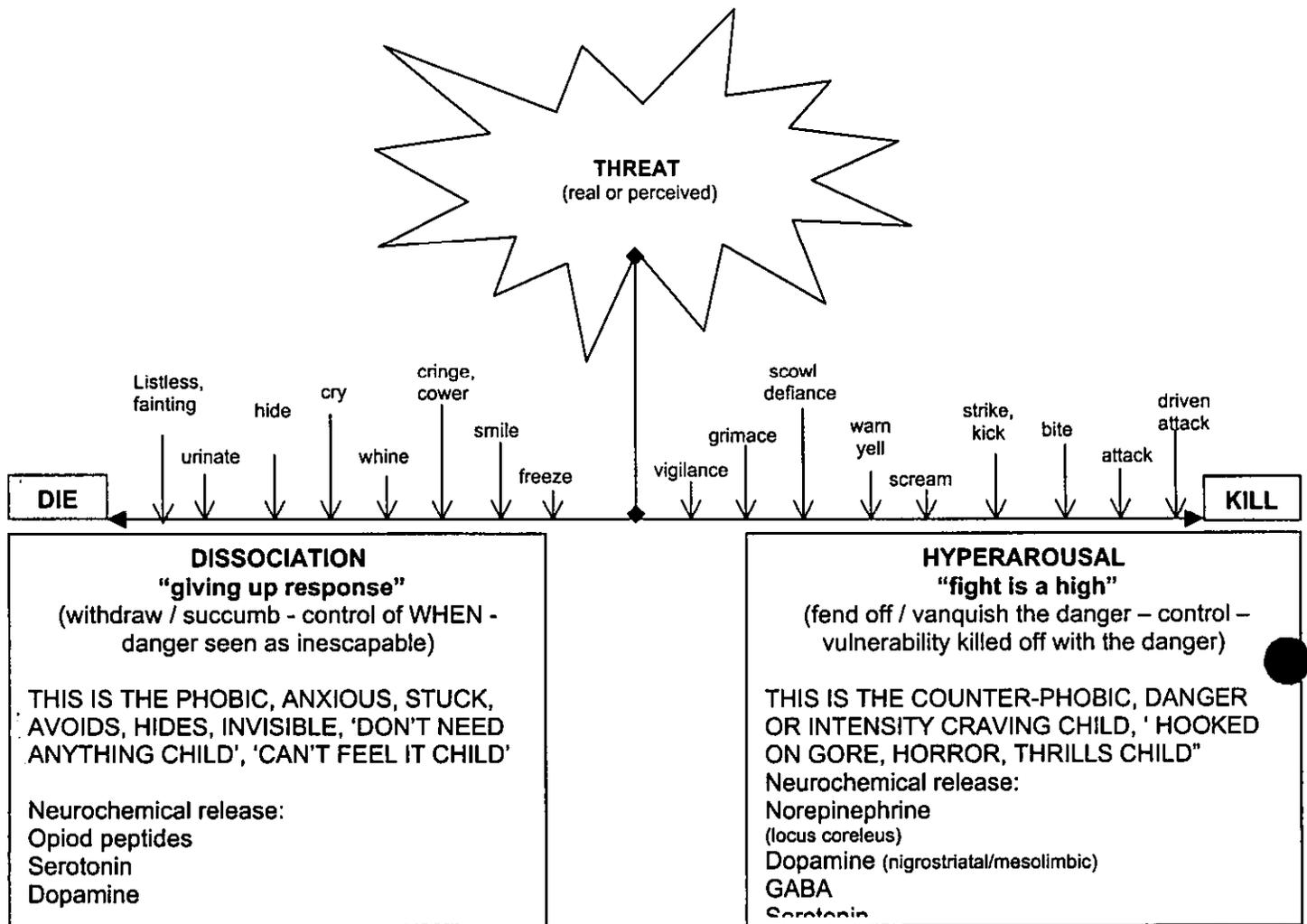
sensations associated with the setting or events of traumatic experience, the person becomes unable to express things cogently. Emotions flood the body seeking containment or an outlet for the stress hormone coursing through the nervous system, i.e. holding one's breath, smiling or laughing in fear, becoming unable to speak, involuntary trembling, sweating, diarrhea or urination, or other sensations.

**Example:** A parent leaves the TV on to a talk show station where dramatic guests shout back and forth in a heated argument, name calling, etc. The parent calls their verbal 5 yr. old over to snack. The child stands not looking at the TV but not obeying parent's call, as if rooted to the floor, immobile, with eyes open but "not there", as parent gets a more frustrated, insistent tone. Child's movement stiffens as if paused on a VCR, despite parent coming over, taking child by the hand and trying to lead him to the table. Once at the table he still looks blank, while one of his hands begins to dig at the skin of the other hand as if to rake it.

On the externalizing side of adaptation to trauma , one show increased acting out or "baiting" aggression towards others who pose no threat, despite known and obvious guidelines or internal values, consequences or negative feedback from others.

**Example:** A highly verbal 5 yr. old urinates on floor 5 ft. from the bathroom where the toilet is in plain sight though the child was asked by a caring and safe adult about needing to go 3 times in prior 15 min. and refused each time. When the adult gets upset, the child later cuts a hole in the parent's bathrobe, completely denying it when confronted and genuinely believing he did not do anything.

## Response Styles: 2 Adaptations to "Threat"



1. A traumatized child is often, at baseline, in a state of low-level alarm (sensitized neural systems). An "event" occurs that the brain reads as threatening (cause injury, pain or catastrophic loss of physical wellbeing or psychic equilibrium).
2. The child responds with either a hyperarousal or a dissociative adaptation, then may swing into the opposite style after the initial neurochemical flood (brain tries to rebalance to baseline). The child's emotional, behavioral, and cognitive functioning will reflect changes.
3. The more overwhelming the sense of threat, the more regressed the child's response (the bigger the "event", the more regressive the behavior).

Source: Perry, Pollard, Blakley, Baker & Vigilante (1995)

## **Cognitive Differences: Why Doesn't He See How He's Acting & Stop It?**

Disorders of self awareness are common after many forms of brain injury, but are poorly understood and managed (Prigatano, 1999). Physicians are without ways to measure disturbances of 'personal experience' scientifically (i.e. in an MRI or other medical exam). Neuropsychological evaluation identifies patterns.

### **3 basic facts about brain dysfunction:**

- 1. Disorders are dynamic – changing with time and environmental demands**
- 2. Damage to different regions = different forms of impaired awareness**
- 3. Disorders of personal experience (consciousness, self-awareness) = disturbance to integration of thinking and feeling.**

### **Prigatano's four syndromes of impaired self-awareness:**

- 1. Frontal heteromodal syndrome – effecting planning, social judgement, impulse control, anticipation, and 'sustaining drive'.**  
When frontal lobes are injured, persons may not experience themselves as having impairments to these areas.
- 2. Parietal heteromodal syndrome – Parietal lobe integrates complex sensorimotor information, i.e. where one's limbs are in space.**  
Impairment can include anosognosia for hemiplegia, and hemi-inattention. **It is involved in integration of attention, organization, and conceptualization.**
- 3. Temporal heteromodal syndrome – Temporal lobe integrates sensory inputs into deep brain structures, permitting memory and language to function, particularly in the left hemisphere, i.e. lesions in the temporal lobe often are associated with lack of insight about the extent of a memory or language impairment, such as anosognosia for jargon aphasia, or complete lack of insight into the presence and extent of their own disorientation about time and place. They may attribute this to factors other than themselves.**
- 4. Occipital heteromodal syndrome – interferes with vision processing, perception and recognition of visual objects, i.e. having cortical blindness but not experiencing this personally (Anton's syndrome).**

Persons with complete syndromes show no emotional distress because they have no awareness of experience of their cognitive deficit. With partial information, they partially experience their disturbance, and show some affective reaction that is either defensive or non-defensive as a coping style.

With non-defensive coping, persons may recognize a deficit exists, but consider its impact minimal. They persist with prior means of coping whether these are safe or unsafe.

Example: A professor with right parietal lesion recognizes he has subtle problems with attention, organization and the ability to conceptualize how to present a lecture. He may insist on returning to teaching because it is how he copes; he enjoys educating young people, it gives meaning to his life as he lives alone. He would resist discussion of no longer teaching and turning his focus elsewhere. This is not just defensiveness per se. He partially experiences his difficulty, yet still relies on methods that have served him well, and still serve him in major areas of meaning for his life.

In defensive cases, the person experiences a threat and the threat produces anxiety and raises concerns about the integrity of the self. Thus, the person will use many defenses to try to reduce the anxiety. Denial may be present, but also projection.

Example: A person with left temporal lesion is partially aware of her residual language and memory deficits develops paranoid ideation. Delusions can then later accompany the anosognia.

This heuristic framework suggests that classifying impairments of self-awareness can lead to a better understanding of the phenomenon of denial or other unconscious defense mechanisms observed in psychiatric illness. Theoretically, the same heteromodal cortical regions that allow self-awareness to emerge may be involved in keeping certain thoughts and feelings from awareness even though persons remain conscious of their environment.

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Correspondence: George P. Prigatano, Ph.D., Barrow Neurological Institute  
350 West Thomas Road, Phoenix AZ 85013  
Phone: (602)406-3671/FAX (602)406-6115  
Email: prigat@chw.edu

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# PROFESSIONAL FAS INTERVENTION VIDEO

"FAS Parent Education & Support Curriculum:  
The Parenting Your Porcupine Series"

## PEER REVIEW FORM

DATE: \_\_\_\_\_ SITE: \_\_\_\_\_

1. I am a professional in the field of \_\_\_\_\_

2. (Please select) I have / have not had prior training specific to FAS spectrum disorders. Prior training was from \_\_\_\_\_.

3. The information presented in the video was not new or helpful to me.  
(circle)  
Disagree            1        2        3        4        5        6        7        Agree

1. I gained information that will improve how I work with families of children with alcohol related conditions.  
Disagree            1        2        3        4        5        6        7        Agree

2. I would recommend this training video to other professionals & parents.  
Disagree            1        2        3        4        5        6        7        Agree

3. This video would be best suited to (circle) parents / professionals.  
Disagree            1        2        3        4        5        6        7        Agree

4. The most important concept I gained from this video was  
\_\_\_\_\_  
\_\_\_\_\_.

5. This concept was already clear in my mind prior to the video.  
Disagree            1        2        3        4        5        6        7        Agree

1. The video does not convey information I would like to pursue through further written curriculum materials.  
Disagree            1        2        3        4        5        6        7        Agree

2. I would improve on the video by doing the following: \_\_\_\_\_  
\_\_\_\_\_.

Length should be \_\_\_\_\_ minutes.

Technical level was (select one) appropriate for parents & families

Appropriate for professionals  
Appropriate for counselor & teacher education.

3. What the video needed was

\_\_\_\_\_ in order to be most effective  
\_\_\_\_\_ in orienting others to diathesis stress techniques.

Thank you for taking the time to comment on this video.  
I can be reached at Childrens Center, 360-699-2244, if the event of  
questions.

**Antonia Rathbun, M.A., A.T.R., LMHC**  
**Childrens Center – SNAP Program**  
**P.O. Box 484**  
**Vancouver, WA 98660**

## **Project Name: Special Needs Adoption Program (SNAP)**

Promoting Permanency Adoption Opportunities Grant #90-C0-0895  
HHRS, Admin. on Children, Youth & Families, Childrens Bureau

Antonia Rathbun, M.A., A.T.R., NCMHC, Project Manager  
Childrens Center / SNAP Program  
P.O. Box 484  
Vancouver, WA 98666  
Email: [antoniarr@thechildrenscenter.org](mailto:antoniarr@thechildrenscenter.org)  
Phone: 360-699-2244 / Fax 360-699-1900

Grant Period: 10/1/99 – 9/30/02

Evaluator: Hank Bersani, Ph.D.

**Summary: The research and products/activities were completed either ahead of schedule or on time, with papers for publication pending.**

Childrens Center is an outpatient mental health therapy provider in Clark County, Washington. We provide solutions-focused intervention to approximately 1,500 consumers yearly. Across a 36 month timeframe, the SNAP project demonstrated:

**Children served: 121 out of projected total of 105 adoptees;  
115% of target population.**

- 64 families invited to research, 5 not meeting study criteria, 42 families accepted research, and 22 declined. Of the 22 who declined, 5 chose clinical services only, and 17 declined participation in any services at all. Of the 42 acceptees, 3 dropped out, 5 accepted and did the pre-clinical services interval only; all remaining have completed their measures. In addition to the above quantitative stats, 30 families have participated in the qualitative study.
- **Our acceptance rate to research was 65%** (compared with 30-50% for similar projects) and we showed an **80% rate of retention to research.**

### **PRODUCTS included:**

- **FAS Parent Training & Support Curriculum: "Parenting Your Porcupine", with accompanying Facilitator's Guide**
  - Conducted study on 12- twelve week parent curriculum groups, exceeded est. numbers.
  - Parent evaluation data consistently rated training "excellent" (6 out of possible 7)
  - Curriculum with Facilitators Guide completed for publication.
- **Promoting Permanency Videos**
  - 2 part video training series accompanies written curriculum:
  - **Parent video** explains diathesis stress principles for new pending/post adoptive families with alcohol related disorders,
  - **Professional video** introduces clinical framework for use of curriculum with recommendations from families on building successful FAS Parent Support Groups.
- **Parent Mentors**
  - 10 Active FAS Parent Mentor families; Phone partners through mentors
  - FAS Parent Mentors hosted FAS "Tuesday Topics" Book Study & Process group weekly
- **FAS Parent Online Network & Community Activities**
  - Email network of 52 adoptive-FAS families
  - **FAS Parent Resources Online** website with newsletter & resources for parents
  - Summer picnics, zoo trips, other – completed and continuing.
- **FAS Children's Network**
  - Childrens groups and buddies activities completed.
- **Porcupine Series: Therapeutic Stories for Parent & Child**
  - 1 children's book and 1 teen video on symptom management & family accommodations
- **The StarChild Quilt Project for FAS/ARND: FASDAY 2001 & community workshops** completed
- **Advanced FAS Family Intervention Training** completed & continued through 2002 upon request.

# PROJECT SUMMARY REPORT

(Please indicate your priority area below)

o Adoption Opportunities Grantee		o ILP/Child Welfare Training Grantee	
<b>PROJECT:</b>	Promoting Permanency: Special Needs Adoption Program (SNAP)		
<b>GRANT PRIORITY AREA:</b>	Adoption Opportunities Grant		
<b>PROJECT DIRECTOR:</b>	Antonia Rathbun, M.A., A.T.R., NCMHC		
<b>AGENCY:</b>	Childrens Center		
<b>AGENCY OR PROJECT ADDRESS and TELEPHONE NUMBER:</b>	P. O. Box 484, Vancouver, Washington 98666 Phone: (360) 699-2244    Fax: (360) 699-1900    Email: <a href="mailto:antonia@thechildrenscenter.org">antonia@thechildrenscenter.org</a> <span style="float: right;"><a href="mailto:childrenscenter@bdsn.com">childrenscenter@bdsn.com</a></span>		
<b>START DATE:</b>	10/1/99	<b>END DATE:</b>	9/30/2002

**PROJECT DESCRIPTION (BRIEF PARAGRAPH):** This research-based pilot investigated a clinical intervention model conducted in an outpatient mental health agency, designed to improve permanency for adopted children with alcohol / other drug exposures & complex MH/DD conditions. Parents accessed a support system & menu of services, including a 12 wk diathesis-stress training curriculum, to assist interventions with their child's specific symptoms, strengths & pattern of neurobehavioral episodes (a pattern C chronicity). The term "diathesis-stress" refers to how persons with neurological impairment (*a diathetic condition or existing organic vulnerability*) experience routine environmental factors as exceptional stressors, which can at a given threshold produce deterioration where persons without diathesis would otherwise show capacity to adapt or accomodate. Parent Mentoring & peer support helped families shift out of the "crisis of disruption", renewing resilience as families with special needs. Children reduced defensive bx & increased use of supports.

## PROJECT ACCOMPLISHMENTS: SNAP GRANT PRODUCTS

**Promoting Permanency - FAS Parent Training & Support Group Curriculum "Parenting Your Porcupine"**

**Series and Groups:** Twelve 12-wk diathesis-stress training groups were conducted using a model curriculum evaluated through qualitative and quantitative methods. Families gave high ratings of course efficacy. The "Parenting Your Porcupine" Curriculum was finalized for publication, and continues in use by parents in the agency's Adoption Support Pgm. Contacts in several states request cross-site replication of psychoeducational diathesis-stress training curriculum groups for adoptive families.

**Advanced Family Intervention Training for FAS & Related Conditions:** Human services professionals are given clinical education in facilitation of diathesis stress training materials for foster, adoption, kinship care, permanent guardianship, and recovering biological families. In-service training for workers increased access, referral, case coordination, and follow-up with adoptive families. Trainings for local education & human services personnel continue to occur @ quarterly and include FAS Parent Mentors who are education staff.

**FAS Parent Mentor, Online & Advocacy Network:** Parent and grandparent alumni serve as Phone Partners, Parent Mentors & Advocates. Online networks for @ 60 parents and @ 50 children were initiated by participants. **The StarChild Quilt Project for FAS** had 6 parent facilitators who held 6 workshops.

**Early Childhood Education (ECE) Interns:** 6 ECE interns worked in families as special sitters & respite persons.

**At-risk Video Project :** Qualitative content analysis of 10 audiotaped 12 week curriculum narratives yielded the thematic content and format for 2 video series, one for Parents and one for Professionals. Each track has 4 segments that discuss core concepts and provide parent and professional commentary to the Parenting Your Porcupine curriculum. The videos are ready for marketing and distribution.

**"Parenting Your Porcupine" Childrens story & Teen video:** A children's book "Meet Porcupine" created to aide parent-child discussion of symptoms & techniques for management & accommodation. The story has coaching text for parent instruction in therapeutic use of themes to enhance the child's communication of symptoms and normalize accommodations. An adolescent FAS video was made instead of additional books, to make concepts for coping with CNS differences accessible to older children, teens and young adults. It features a 20 yr. old with FAS sharing her experiences of symptom management, strengths and family supports.

For your *Project Summary Report* to be included in the notebook distributed to conference participants, it must be submitted to DSG.