From SCREAMS to DREAMS

Intervention Strategies for Parents,
Teachers and Caregivers of
Children and Adults with Fetal Alcohol Spectrum Disorders

Presentation by
Teresa Kellerman

FASSTAR

Fasstar Enterprises
www.fasstar.com

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Substance Abuse During Pregnancy
Among pregnant women in the U.S., 23% reported that they drank alcohol during 1st trimester.
3.7% reported that they used illicit drugs (most often used drug is marijuana).
Among pregnant women who reported using illicit drugs, 97% also drank alcohol.

Alcohol is a Toxic Substance. Alcohol is a toxin. Alcohol is a carcinogen. Alcohol is a teratogen.

Alcohol causes more damage to the developing baby's brain than any other substance, including marijuana, cocaine, and heroine.-- Institute of Medicine Report to Congress

Effective Alcohol Advertising: The rate of drinking during childbearing age has been increasing.
Effective FASD Awareness: The rate of drinking during pregnancy has finally started to decline

The Great FASD Awareness Gap: The rate of drinking reported by pregnant women in their first trimester is still very high: 23%.

FASD Awareness: We have primarily been targeting pregnant women. Are we making a difference? Should we be targeting all women of childbearing age? Who else?

How Much is Too Much? Binge drinking causes the most damage, but moderate and light drinking can put the baby at risk as well. There is no safe amount of alcohol during pregnancy.

Surgeon General, March of Dimes, American Academy of Pediatrics:
"Zero Alcohol During Pregnancy"

Some doctors are still telling their pregnant patients that one drink a day is okay. (Not true!)
One Drink a Day…During the course of pregnancy = 39 baby bottles full of booze.

"Of all the substances of abuse, including heroin, cocaine, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus."
-Institute of Medicine 1996 Report to Congress

"FAS represents the largest environmental cause of behavioral teratogenesis yet discovered and, perhaps, the largest single environmental cause that will ever be discovered."
-Riley & Vorhees, 1986

Risk factors
Age of mother; Amount of alcohol, BAC; Timing; Susceptibility of fetus
No safe level of alcohol has been established

Birth Defects Comparison: 3,890,000 babies are born each year in U.S.
200 with HIV
1,000 with Muscular Dystrophy
2,000 with Spina Bifida
3,000-4,000 with Down Syndrome
5,000-7,000 with Fetal Alcohol Syndrome
35,000-50,000 with Fetal Alcohol Effects

Risk Statistics
53% of women of childbearing age are drinkers
Half of all pregnancies are unplanned
Conception more likely with alcohol use
15%-20% of women continue to drink during pregnancy
3%-6% of women continue to drink heavily during pregnancy

Children in Child Protective Services
90% come from families where alcohol is abused
About 75% are thought to be alcohol affected
Unless they have full FAS, they are not likely to be diagnosed or recognized as FASD

How Alcohol Affects the Developing Fetus
Tiny molecule passes through placenta. BAC in mother = BAC in baby. Placenta is functioning about 15-18 days. Baby is vulnerable to structural damage from weeks 2 through 12. Brain is vulnerable during entire pregnancy.

Women with increased risk of drinking during pregnancy
Female students
Women who smoke
Single women
Women with college education
Women in households with income over $50,000
-- CDC Study

About Birth Mothers…
Birth mothers who drink do not intend to harm their babies.
Some birth mothers quit drinking after they find out they are pregnant.
Almost all birth mothers who continue to drink are victims of sexual and physical abuse.
About half of birth mothers have undetected Fetal Alcohol disorders themselves.

What About Dads?
Men's drinking can have adverse effects on their offspring
Increased risk of learning disorders
Increased risk of mental illness
Inherited addiction tendencies
Men's drinking strongly influences their partner's drinking behavior

Definitions of FASD Diagnostic Terms
FASD – Fetal Alcohol Spectrum Disorders
FAS - Fetal Alcohol Syndrome
pFAS – Partial Fetal Alcohol Syndrome
FAE - Fetal Alcohol Effects
ARBD - Alcohol Related Birth Defects
ARND - Alcohol Related Neurodevelopmental Disorders

More Acronyms
NWS - Neonatal Withdrawal Syndrome (97%)
ADHD - Attention Deficit Hyperactive Disorder
SID - Sensory Integration Disorder
CAPD - Central Auditory Processing Disorder
~~FDE- Fetal Drug Effects~~ (there is no such diagnosis)

Diagnostic Criteria for FAS
Low birth weight
Microcephalia
Facial characteristics
CNS (brain) damage
History of prenatal exposure to alcohol

Physiological Characteristics
Small head
Growth in 10th percentile
Facial characteristics
Malformation of the heart or other organs
Poor hearing or vision
Susceptibility to infections
Increased or decreased muscle tone

Facial Characteristics in Infancy
Small eye openings
Smooth philtrum
Thin upper lip

Labels: Pros and Cons
Sets individual apart as "different"
Makes us feel uncomfortable
Helps get past denial
Offers an explanation, not an excuse
Can lead to appropriate treatment
Minimizes secondary disabilities
Labels Without a Diagnosis: Dummy, Jerk, Stupid, Retard, Screw up, &*#%&@

FAS is the Leading Known Cause of Mental Retardation
But most individuals with FAS have normal intelligence and normal appearance
Only 16% qualify for DD services (Developmental Disabilities)
Which systems provide comprehensive services for children/adults with FASD?

Most Cases of FASD are Invisible
Only 11% of children with FAS or FAE receive a diagnosis by age 6
The facial features of full FAS are not always easily recognized, even by diagnostic specialists
Only babies exposed to alcohol on days 21-24 will have facial features.

Why is FASD Different?
Often unrecognized or misdiagnosed
Symptoms are invisible
Normal appearance and intelligence
Birth mothers are blamed and judged
Lack of support from family/community
Overshadowed by neglect/abuse
Discomfort with "fetal" issues
Denial about alcohol as a drug
Wide array of developmental levels

Invisible Gap: One Person – Many Levels of Function (Array of Abilities)

FASD* Accounts For 10% of Kids in Special Ed – Dr. Sterling Clarren
* those with recognizable, diagnosable FAS or FAE

There's One in Every Classroom
Exposed and affected
Not recognized as FASD
Not diagnosed as FASD
Possibly labeled as…?

Neurological Signs in Very Young Children
Irritability
Feeding problems
Sleep disturbances
Delayed development
Strong startle reflex
Sensitivity to external stimuli

Neurological Signs in School Age Children
Difficulties with bonding and attachment
Inappropriately affectionate to strangers
Inability to form healthy relationships
Poorly formed conscience

May lie or steal
Stubborn, compulsive, tantrums
Arrested social development
Poor judgment, lack of impulse control

FASD Symptoms Are Perceived as Behavior Problems
Typical behaviors or FASD?
- Willful misconduct
- Manipulation
- Trying to get attention
- Lazy

Most Symptoms Are Invisible
Sensitive to external stimulation
Attention deficits (may have ADHD)
Memory deficits
Poor judgment
Lack of impulse control
Emotional and social immaturity

Conscience Development: Stunted at 6-Year-Old Level

Children At Risk
Almost all affected children have a serious problem secondary to FASD. Children with no visible symptoms are at higher risk of having secondary problems in adolescence and adulthood.

Secondary Disabilities
94% - Mental health (ADHD, depression)
80% - Trouble with independent living
80% - Trouble with employment
70% - Trouble in school
60% - Trouble with the law
60% - Confinement in prison or institution
45% - Problems with sexual behaviors
50% - 70% Adults abuse alcohol/drugs
--Streissguth 1996

"The girls get knocked up, the boys get locked up." –Dr. Christine Loock

Protective Factors
Early diagnosis
Eligibility for services
Appropriate intervention services
Stable home environment

Streissguth Study Shows…

By the time the children with FASD start school, most of their birth mothers have died
Only 10% are being raised by birth parents
About 10% are with relatives
About 80% are in foster/adoptive care

Greatest Challenges For Teens With FASD
Behavior problems become more pronounced
Physical symptoms are less apparent
More than half of adults with FASD have clinical depression.
43% have threatened or contemplated suicide.
23% have attempted suicide. --Streissguth 1996

FASD is Brain Damage: Neurological dysfunction is organic
The corpus callosum and frontal lobes may be smaller than normal.

Areas of the Brain Affected by Alcohol
Corpus Callosum - processes information between right brain and left brain
Cerebellum - motor control
Basal Ganglia - processes memory
Hippocampus – learning, memory, judgment
Frontal lobes - executive functions, impulse control, judgment

"Executive Functions" of the prefrontal cortex

Inhibitions	Judgment
Planning	Self monitoring
Time perceptions	Self-regulation
Internal ordering	Regulation of emotions
Working memory	Motivation

Most Serious Effect: Poor Judgment

Co-occurring Disorders

Sensory Integration Disorder	SMI: Serious Mental Illness
Overload M.O. - lash out or shut down	Bipolar
Attachment disorders	Schizophrenia
Neurological	Depression
Psychological	Misdiagnosis or Missed Diagnosis?

Effective Intervention
There is no single program or plan that works for all persons. Each plan needs to be based on the person's individual needs. Clear understanding, realistic expectations. Creative problem solving

FAS is just the tip of the iceberg

Children with FASD are Literal Learners

They may not always remember, understand, or be able to apply what they learn.

The 4 As of FASD
Awareness: increase knowledge and understanding
Assessment: collect data about individuals, environment, community
Acceptance: change your perspective, adjust your expectations, face reality
Action: Change takes time

Awareness
Understand that behaviors are related to neurological dysfunction
Raise awareness at level of individual, family, and community
Awareness Day September 9th - Every day is Awareness Day

Assess the Situation
Assess abilities and deficits of individual
IQ test, Vineland Adaptive Behavior Scales
Assessments for mental health, SID, CAPD

Assess the family
Recognize parenting skills and wisdom, document alcohol exposure

Assess the community
Safe environment with 24/7 supervision, reasonable expectations that match abilities

Assessment Questions for Young Children
Caregiver other than birth mother?
Immature? (impulsivity, frustration tolerance)
Attachment disorder symptoms? (eye contact, cuddling)
Sensitive to sensory stimulation? (meltdowns in public)

Assessment Questions -Robin LaDue 2000, Streissguth 1996
History of alcohol abuse in birth family?
Multiple home placements?
Special ed classes in school?
Suspended or dropped out from school?
History of depression? ADHD? abuse? neglect?
More than 1 job in past 2 years?
Trouble managing money?
Are friends older or younger?

Acceptance
Permanent brain damage
Parenting not always the problem
Behavior management not effective
Abilities fluctuate, inconsistent
Functional level = CA/2

Don't be fooled by appearances
Adjust goals and priorities
Reasonable expectations
Impact of environmental factors

What Works for Infants…

Sleep:	Dark quiet room
Feeding:	Small frequent meals
Devt Delays:	OT, PT, Speech
Toileting:	Patience, pull-ons
Hyperactive:	Child-proof house
Tantrums:	Positive Behavior Sup.
Irritability:	Avoid chaos

Practical Applications For Common Problems

Reinforcements
Token rewards, consequences not very effective
Rewards: concrete and immediate
Visual boundary markers
Masking tape, labels, trays, frames

Time out = quiet time to self calm
Safe Haven = mentor, helper, aide
Communication log, organizer
Minimize stress
Minimize distractions and sensory stimulation

Positive Approach

Offer cheerful encouragement
Allow for "off" days
One-on-one with eye contact
Gentle pressure on shoulders

Use appropriate humor, silliness
Repeat, repeat, repeat
Practice, practice, practice
Adjust your expectations

Links to Success in School:

First Three Years	Parent is primary teacher, reads to child, plays with child daily
Preschool	Group leader recognizes child has good days and off days
Kindergarten	Classroom aide allow child to work at child's own pace
Elementary School	Principal provides safe haven for child who is overwhelmed
Junior High	Counselor is available and visible during non-class times
High School	Mentor assists student with assignments after school
Transition	Job coach provides supervision and guidance at work site

We are the links! From birth to adulthood, each of us becomes a link in the chain of the child's successful moments, from one year to the next.

Classroom Success

Explain FASD to everyone
Enlist affected child in peer education
Enlist affected child to help in classroom
Use buddy system
Close monitoring at all times
Placement of desk close to teacher

Avoid fluorescent lighting
Minimize copying from blackboard
Modify or minimize homework
Use communication log with parents
Minimize food additives

Memory Enhancement

Instructions: simple, concrete steps
Show the child how
Visual cues: symbols, signs, charts
Teach one skill at a time
Hands on activities, sensory, tactile
One-on-one read along stories
Real life applications and nature
Music and rhymes

Watch Out For…

Peers who might take advantage of child
Peers who are not healthy role models
Playground, cafeteria, locker rooms, gym
Before/after school time, between classes
School bus (bus aide, sit in front)
Defensive, angry parents
Adversarial positions: work as a team
Team members who don't "get it"

Intervention Strategies: SCREAMS Model

Structure: routine, rules, KISS
Cues: for meds, appointments, manners
Role models: TV, movies, friends, family
Environment: avoid chaos, stimulation
Attitude: understand neurology of FAS
Medications and healthy diet: restore balance and control
Supervision: many need 24/7

BEAM Rules for FASD Behavior Management

Behavior
Environmental
Adaptation
Model
The Fasstar Trek Model: BEAM ME UP, SCOTTIE!

Factors for Consideration in Teen and Adult Years

Accountability
Arrested social development
Communication skill deficits
Co-occurring conditions
Attention deficits
Sensory integration disorder
Medications
Diet
Pregnancy and paternity
Sexuality issues
Money management
Behavior issues
Information processing deficits
Independence

What works in the court system

Assessment of IQ and functional abilities
Education about FAS/ARND
Probation with reasonable expectations
Therapy with mentor, coach, one-on-one
Outdoor programs
Sanctions/Incentives may not be effective
Success depends on continued support
Build on talents

The person with FAS will always need an external brain.

Key words are "always" and "external."—Drs. Susan Doctor and Sterling Clarren

What Works for Employment Programs

Small work groups
Open air environment
Communication log
Positive redirection
Play "What if…?"
Educate everyone
"External Brain" that works
Mentors work!
The great outdoors works!
Families work!
Love works! (But love is not enough)

Circle of Support – What happens when we let go?

Independence

Percentage of individuals who are capable of living and working independently…10%

Self-Determination

For many, Self-Determination becomes Self-Termination
The smarter they are, the greater the desire to be normal, the more resistance to being controlled, the higher the expectations, the higher the risk for failure. Independence for many will lead them to homelessness, hospitalization, institutionalization, prison, or the morgue.

Adjust Your Expectations

"The greatest obstacle that individuals with FAS disorders must overcome is the chronic frustration of not being able to live up to the unrealistic expectations of others."
--Dr. Calvin Sumner, FAS/ADHD expert

Tri-Level Man

The teen/adult with FASD can be functioning at many different age levels at same time.

Reasonable Plan Needed for Transition to Adulthood

Riding the Roller Coaster of FASD

Grieving the loss of normalcy
Coping with fear and frustration
Finding hope for the future

Family stress is very high for parents of children with FASD

F.A.L.L.O.U.T. What we can offer parents

Friendship
Acceptance
Listen
Learn
Organize
Understand
Talk

Grieving the Loss of Normalcy

Our grief may hide in…
Depression
Sadness
Over indulgence
Anger at the "system"
How can we channel our grief?

Getting Grounded
What am I experiencing today?
What am I feeling right now?
Am I grateful for something today?

Finding Balance A
What was life like for you before?
What were your expectations for life?
What is life like for you now?
What has been lost along the way?
What dreams have been dashed?
What feelings do you have about the loss?

Finding Balance B
What are the realities of your life today?
What longings call from within?
What reasonable hopes can be shaped?
What small steps can be taken to turn your hopes into reality?
What blessings have been realized?

Staying Alive with the F.A.S.D. Survival Plan
Food: balanced diet, healthy weight
Alcohol: in moderation or not at all
Smoking: quit now, avoid smokers
De-Stress: exercise, rest, support

S.M.I.L.E.S.
Stress: Minimize your own chaos
Meds: Balance your brain chemicals
Inspiration: Find your inner strength
Let Go: Plan for your child's future
External Brain: Make safety net
Support: Accept help, find resources

Resources
NOFAS www.nofas.org
The Arc www.thearc.org
FAS Community Resource Center: www.come-over.to/FASCRC
FASSTAR www.fasstar.com

DREAMS
Dream a new dream for your future
R&R – Rest and relaxation
Enjoy life and celebrate successes
Act as if your dreams are coming true
Mother yourself, find a mentor
Step into the future with hope

There is hope for a better future for individuals with FASD and their families.

Learn more about FASD here: **www.fasstar.com** and click on the Mother-Child graphic