Minnesota Organization on Fetal Alcohol Syndrome

MN Organization on Fetal Alcohol Syndrome
FASD: Adapt Your Approach, Change the Outcome!

MN Organization on Fetal Alcohol Syndrome
866-90-MOFAS
Website- www.mofas.org
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Objectives

• Define FASD

• Describe basic brain functioning in relation to FASD brain damage

• Explain basic criteria for diagnosis
Objectives

• Explain the relationship between secondary disabilities and primary brain damage and identify “red flags”

• Identify the association between affected individuals and the justice system

• Discover strategies and resources
Define FASD
What is FASD?

Fetal Alcohol Spectrum Disorders – a set of physical, behavioral, and cognitive disorders seen in individuals exposed to alcohol prenatally

**Lifetime disability** with **brain injury** that never goes away

Broad range (spectrum) of characteristics that vary from person to person
Facts about Fetal Alcohol Spectrum Disorders (FASD)

- FASD = the leading known cause of preventable mental retardation ¹
- Most people with FASD have average IQs
- Rate of FAS (Syndrome) is 1:100 births ²
- Rate of FASD (Spectrum) is 1:100 births ³
- Fetal Alcohol Spectrum Disorders are 100% preventable
On any given day in the United States 10,657 babies are born:

- 1 of these babies is HIV positive.
- 2 of these babies are born with Spina Bifida.
- 3 of these babies are born with Muscular Dystrophy.
- 10 of these babies are born with Down Syndrome.
- 20 of these babies are born with Fetal Alcohol Syndrome.
- 100 of these babies are born with ARND!
Why Does Alcohol Affect the Fetus?

- Alcohol is a teratogen—a substance that the fetus is exposed to that impedes growth and disrupts normal development. It is considered a midline teratogen, especially affecting midline structures of body and brain.
- Crosses the placenta
- Amniotic fluid acts as a reservoir for alcohol. The fetus is still exposed when the maternal blood alcohol level has returned to zero.

“No amount of alcohol consumption can be considered safe during pregnancy.”

U.S. Surgeon General Richard H. Carmona
February 21, 2005
Alcohol & the fetal brain

- Replication- Alcohol interferes with replication of brain cells and may cause early cell death.

- Migration- “Drunk little cells trying to find their way”. Alcohol interferes with the migration and organization of brain cells.

- Myelination- Myelin is a fatty coating that enables brain signals to travel faster. Alcohol causes myelin damage and interferes with signal transmission.
Alcohol is Alcohol
Myth & Fact

• Stop and complete short exercise
“Of all the substances of abuse including cocaine, heroin and marijuana, **alcohol** produces by far the most serious neurobehavioral effects in the fetus resulting in life-long permanent disorders of memory function, impulse control and judgment”

—**IOM** Report to Congress, 1996
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<td>Facial Malformation</td>
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<td>Intellectual &amp; Dev. Delays</td>
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<td>Hyperactivity, inattention</td>
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<td>Sleeping Problems</td>
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<td>Poor Feeding</td>
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<td>Higher risk of SIDS</td>
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<td>Organ Damage Birth Defects</td>
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<td>Respiratory problems</td>
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Brain Functioning
Most Affected Areas of the Brain

Frontal Lobes
Corpus Callosum
Hippocampus
Basal Ganglia
Hypothalamus
Cerebellum
FASD and the Brain

A. MRI of a 14-year-old control subject with a normal corpus callosum; B. 12-year-old with FAS and a thin corpus callosum; C. 14-year-old with FAS and agenesis (absence due to abnormal development) of the corpus callosum.

• Newborn baby’s brain damaged by alcohol
• Decreased size
• Not fully divided into left and right hemispheres
• Smooth surface and fewer folds indicate lack of development

Newborn baby’s brain
Normal Brain
Prenatal exposure to alcohol causes permanent brain injury that never goes away!
Frontal Lobes

- Perceptions, complex or abstract concepts
- Self awareness
- Emotional response
- Ability to delay gratification for long term goals
- Understanding connection between future consequences and current actions
Frontal Lobes

- Impulse control
- Decision making
- Judgment, problem solving
- Generalizing learning
- Attention, being “tuned in”
- Understanding social cues, nuance
Cerebellum

- Movement, motor control
- Balance & equilibrium
- Muscle tone
- Ability to judge distances
- Involved in some cognitive processes such as attention
Basal Ganglia

- Can affect spatial memory and behaviors like perseveration and inability to switch modes, work towards goals, and predict behavioral outcomes
- Time perception
Hippocampus

- Involved in connecting memory information in context - "I can remember what my keys look like, and I can remember where the coffee table is located, but the critical test of my memory is if I can remember that I left my keys on the coffee table."

~Ingrid Olson, Penn’s Center for Cognitive Neuroscience

- Navigation
- Connecting sensory information to motor output
- Damage may mean “out of sight, out of mind”
Hypothalamus / Brain Stem

• Receives input from all over the body and sends it to the cerebral cortex
• Controls appetite, emotions, temperature, pain sensation
• Organizes behavior related to survival-fighting, fleeing, feeding
• Ability to sleep is a brain stem function
Brain from Above ->

Right Side
- judging the position of things in space
- knowing body position
- understanding and remembering things we do and see
- putting bits of information together to make an entire picture
- Impulses, Creativity

Left Side
- understanding and use of language (listening, reading, speaking and writing)
- memory for spoken and written messages
- detailed analysis of information
- Facts, Rules, Order
Diagnosis Criteria
The FASD Umbrella

Fetal Alcohol Spectrum Disorders

- Fetal Alcohol Syndrome (FAS)
- Alcohol-Related Neurodevelopmental Disorder (ARND)
- Partial Fetal Alcohol Syndrome (pFAS)
- Alcohol-Related Birth Defects (ARBD)
- Fetal Alcohol Effects (FAE) replaced by ARBD & ARND in 1996
Fetal Alcohol Spectrum Disorders (FASD)

- **FAS**: Fetal Alcohol Syndrome - Symptoms include small head/body, facial characteristics, brain damage.

- **PFAS**: Partial Fetal Alcohol Syndrome - Some facial/growth characteristics but not all. Still has behavior and attention issues.
FASD

- **ARBD:** Alcohol Related Birth Defects - Anomalies such as heart defects, sight/hearing problems, joint anomalies, etc.
- **ARND:** Alcohol Related Neurodevelopmental Disorders - Disorders such as attention deficits, behavior disorders, obsessive/compulsive disorder, etc.
Diagnosing FAS (Fetal Alcohol Syndrome)

Person must have signs in each of these areas:

- Growth retardation
- Abnormalities in the central nervous system (CNS), deficits in some of the 10 brain domains
- Facial abnormalities: eyes, philtrum, upper lip
- History of maternal alcohol consumption when available
FAS Facial Characteristics

Thin upper lip

Palpebral fissures

Smooth, long philtrum

CDC 2004
Might also have: Low set ears, flat mid-face, up-turned nose, small chin, and epicanthal folds.

photo of John Kellerman, www.fasstar.com
Control Mouse not exposed to alcohol

Mouse exposed to doses of alcohol during gestation

Sulik, K. K., & Johnston, M. C. (1982).
Ethnicity and Characteristic FAS Facial Features

Source: American Family Physician Vol. 72/No. 2 (July 15, 2005)

MN Organization on Fetal Alcohol Syndrome
"People who don't have the facial features are truly discriminated against in terms of services. When they don't have a classic FAS face, the tendency is to act as though there's nothing wrong. They are expected to perform normally, but they're goofing up all the time. They get blamed for being lazy or careless, yet these people have functional brain impairments."

~Ann Streissguth
Minnesota Approach to FASD Evaluation

• FASD: Focus of Diagnosis
  – Growth Deficits
  – Central Nervous System Problems
  – Facial abnormalities

Standardized report form - *Understandable* FASD evaluation results and recommendations to families, caregivers, teachers and health professionals
Brain Domains
Brain Domains

- Cognition
- Attention
- Achievement
- Executive Function
- Memory
- Motor
- Sensory and Soft Neurological Signs
- Language
- Social Communication
- Adaptation
Cognition

• Cognition – Focuses on the general level of thinking ability
• Normal IQ but immature
• Limited skills and unrealistic goals
• “Not too bright”
• “Not trying”
• “Lazy”
Attention

- Focuses on processing capacity
- Poor impulse control
- Volatile behavior
- Short attention span
- Fidgety behavior
- For behavior of concentration, hyperactivity, and impulsivity
Achievement

- Focuses on core academic areas
- Poor reading comprehension
- Not well organized and poor study skills
- School is becoming increasingly difficult after 3rd, 4th, or 5th grade
- Tries hard but is often disappointed with their results
Executive Functioning

- Focuses on capacity for goal directed behavior
- Won’t accept responsibility
- Poor problem solving
- Has poor judgment
- Doesn’t understand laws, rules, codes of conduct
- Lacks understanding of safe sex and birth control
Executive Functioning

• Doesn’t understand right from wrong
• Doesn’t understand jokes or figurative speech
• “Doesn’t seem to learn from experiences”
• “Fearless”
• “So easy to tease”
• “Doesn’t know the difference between stealing, borrowed, or found”
Memory

- Focuses on capacity to consolidate, store, and retrieve information for long and short term application
- Incomplete knowledge
- Needs to relearn often
- Can’t remember rules to a game
- Trouble memorizing multiplication tables
- Trouble coming up with answer so just make one up
Motor

• Focuses on abilities to use large and small muscles
• Late and/or toe walking
• Babies have poor suck & swallow ability
• Clumsy, tends to upset or spill things more than others
• Messy homework
• Poor handwriting
Sensory integration & Soft Neurological Signs

- Focuses on making sense of sensory information
- Rocks back and forth
- Difficult Temperament
- Unpredictable sleep/wake cycles
- Either high or low hearing threshold
- Either high need for stimulation or is easily over stimulated
Language

- Focuses on all aspects of expressive and receptive language
- Late onset talking
- Can’t understand or follow multi-step directions
- Difficult to understand
- “Understands with pictures, but does not understand if I only tell”
Social Communication

- Focuses on appropriate communication in social settings
- Doesn’t understand personal boundaries or body language
- Individual prefers younger peers
- Acts much younger than age
- Socially isolated and emotionally disconnected
- Difficulty coping with change in social situations
Adaptive Functioning

- Focuses on meeting the challenges of daily living
- Poor grooming skills
- Poor Daily living skills
- Erratic sleeping pattern
- Loves to be center of attention
- Draws attention to self
Diagnosis and Co-morbidity in Diagnosis
Diagnostic and Statistical Manual (DSM-IV)

I. Clinical Mental Health Disorders
II. Personality Disorders and Mental Retardation
III. General Medical Conditions (FASD)
IV. Psychosocial and environmental concerns
V. Global Assessment of Functioning (GAF) rating
FASD Barrier: Limits of the DSM IV

- Children receive multiple diagnoses and interventions
- Interventions based on behavioral symptoms, rather than cause
- Exclusion of central factor of disability i.e. Brain dysfunction
- Confusion and fragmentation
DSM-IV T-R Diagnostic Codes

Category- Mental Disorders due to a General Medical Condition

- Mood Disorder due to general medical condition of prenatal alcohol exposure with evidence of FAS (293.83)
- Anxiety Disorder due to general medical condition of prenatal alcohol exposure with evidence of pFAS (293.84)
- Psychotic Disorder due to general medical condition of prenatal alcohol exposure with evidence of ARND (293.8x)
- Personality Change due to general medical condition of prenatal alcohol exposure with evidence of ARND (310.1) The personality changes include Labile, Disinhibited, or Paranoid.
## Overlapping Characteristics

### Overlapping Behavioral Characteristics of FASD & Related Mental Health Diagnoses in Children

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<td>Developmental Dysynchrony</td>
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<td>Feels different than other people</td>
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<td>Often does not follow through instructions</td>
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<td>Often engages in activities without considering possible consequences</td>
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<td>Often has difficulty organizing tasks &amp; activities</td>
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<td>Difficulty with transitions</td>
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<td>Lacks impulse control, semi hyperactive</td>
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<td>Sleep Disturbance</td>
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<td>Indifferently afflicts with strangers</td>
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<td>Lack of eye contact</td>
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<td>Joint crudity</td>
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<td>Lags about the average</td>
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<td>Limitless talk: &quot;Won’t stop, time can’t keep&quot;</td>
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<td>Speech: clutter, or abnormal speech pattern</td>
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<td>Increased motor response</td>
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<td>Functionally volatile, often exhibits wide range</td>
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<td>Depression, develops, often in ten years</td>
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<td>Problems with social interactions</td>
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<td>Deficit in speech and language, delays</td>
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<td>Overload, responsive to stimuli</td>
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<td>Poor problem solving</td>
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<td>Difficulty changing cues &amp; effect</td>
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<td>Low functional ability in one area</td>
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<td>Costs at what “normal” in</td>
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<td>Low weight, it would be easy to tell the truth</td>
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<td>Difficulty maintaining, following through</td>
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<td>Difficulty with maintenance</td>
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<td>Meaning time poorly: lack of comprehension of time</td>
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<td>Information processing difficulties</td>
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<td>Overload stress</td>
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<td>Often angry or uninvolved</td>
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<td>Often irritable</td>
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<td>Inconsistently</td>
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Cindy Brown, Therapist, Adoption Training Coordinator, Thespiee County, S.D. 605-543-0814 cindy.brown@thespiee-county.org  5/20/10
With much appreciation to the many who edited and contributed.
Sensory Processing

People with Fetal Alcohol Spectrum Disorders often have sensory processing disorder - or the inability to process information received through the senses.
SPD occurs when the brain “misreads” information from these senses:

- Sight
- Hearing
- Taste
- Touch
- Smell
- Tactile (sensations of our skin)
- Vestibular (balance)
- Proprioceptive (body position, muscles)
Sensory Processing Disorders

- Might have problems habituating
- May crave or retreat from sensory stimulation - sometimes both
- Clumsiness, emotional disregulation, distractibility, disorganization and hyperactivity can be associated with sensory processing disorders

*No cookbook approach - observe, change environment, meet sensory needs with calm space, weighted blankets, fidgets, music*
Sensory/Problems

Florescent lighting
• Over stimulated
• Does it have the “buzz”

Solution
• Have alternative lighting
• Dim the lights
• Headphones
Sensory/Problems

Smells

• Food smell
• Body odor

Solution

• Have a lavender or vanilla scented candle or air freshener
Strategies to help with Sensory Challenges

- Adapt the environment
- Provide a calm safe place
- Provide fidgets →
- Know trouble areas and prepare
  - Long lines
  - Crowded places
  - Unstructured areas
  - Busy places
Secondary Disabilities, Brain Damage & Red Flags
Secondary Disabilities

• Primary disabilities are those the child is born with.

• Secondary disabilities are those that develop as a result of failure to properly deal with the primary disabilities.
Secondary Behavioral Characteristics

- Fatigue, frustration
- Anxious, fearful
- Rigid, resistant
- Overwhelmed, shutdown
- Poor self concept
- Self aggrandizement (trying to ‘look good’)
- Few friends, isolated
Secondary Characteristics

- Acts out, aggressive
- Family and school problems
- Truancy, other forms of avoidance including substance abuse
- Unplanned pregnancy
- Depression, self destructive behaviors
Secondary Disability Study

- 90% Mental health problems
- 60% Disruptive school experience
- 60% Trouble with the law
- 50% Confinement
- 50% Inappropriate sexual behavior
- 30% Alcohol/Drug problems
- 80% Dependent living
- 80% Employment problems
## Developmental Skills Timeline

<table>
<thead>
<tr>
<th>SKILL</th>
<th>DEVELOPMENTAL AGE EQUIVALENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual age</td>
<td>18 yrs</td>
</tr>
<tr>
<td>Expressive language</td>
<td>20 yrs</td>
</tr>
<tr>
<td>Comprehension</td>
<td>6 yrs</td>
</tr>
<tr>
<td>Money and time concepts</td>
<td>8 yrs</td>
</tr>
<tr>
<td>Emotional maturity</td>
<td>6 yrs</td>
</tr>
<tr>
<td>Physical maturity</td>
<td>18 yrs</td>
</tr>
<tr>
<td>Reading ability</td>
<td>16 yrs</td>
</tr>
<tr>
<td>Social Skills</td>
<td>7 yrs</td>
</tr>
<tr>
<td>Living skills</td>
<td>11 yrs</td>
</tr>
</tbody>
</table>
Puberty and FASD

- Precocious puberty or delayed puberty
- May have anomalies to the genital organs
- Protect from victimization because of lack of stranger anxiety and improper boundaries
- Modesty
  - This is an abstract concept which needs to be taught
Sexuality and FASD

- Inability to predict or understand abstract processes
- Impulsive sexual behavior
- Do not understand “delayed gratification”
- Demonstrate sexual behavior “beyond their knowledge”
- Compromised internal value system
## Sexuality

**Typical Teen**  |  **Teen with FASD**
---|---
Gains skills leading to independence | Desires independence but needs supervision
Understands nuance and social cues | May interpret nice co-worker as “girlfriend”
Understands “private” – masturbation is discreet | Confuse public & private activities – bedroom rule
Consequences real – STDs, pregnancy | Might not connect actions w/consequences
Can distinguish between fantasy and reality | May believe they can date a celebrity
Affected Individuals and the Justice System
Red Flags

- In foster care or raised in adoptive home
- History of chemical dependency / child protection
- Immature & poor social behavior
- Adaptive behaviors lower than IQ indicates
- Easily distracted, hyperactive, inattentive, impulsive
- Truancy and school difficulties
More Red Flags

- Involvement with justice system, especially at a young age
- May give inconsistent answers to questions – or looked at as intentional lying.
- Unable to connect actions with consequences
- Does not seem affected by past punishments - show no remorse
FASD and the Juvenile Justice System

One of the few studies, 1997 Canadian study

- **287** youth (ages 12-18) who had committed a delinquent offense and were in a psychiatric/psychological assessment unit
- **78%** “red flagged”
- **23%** received a fetal alcohol related diagnosis (67 of those youth)  
  
# Juvenile Populations

<table>
<thead>
<tr>
<th>Category</th>
<th>General Population</th>
<th>Offender Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotionally Disturbed</td>
<td>2 – 5 percent</td>
<td>16 – 50 percent</td>
</tr>
<tr>
<td>Learning Disabled</td>
<td>3 – 6 percent</td>
<td>9 – 42 percent</td>
</tr>
<tr>
<td>Mentally Retarded</td>
<td>1 – 2 percent</td>
<td>3 – 30 percent</td>
</tr>
<tr>
<td>Other disabilities</td>
<td>4.1 percent</td>
<td>2.8 percent</td>
</tr>
</tbody>
</table>
Treatment in the Juvenile Justice System

- Those who are learning disabled are 200% more likely to be arrested because:
  - They lack avoidance strategies
  - They are used as scapegoats
  - They act defiantly, uncooperatively or evasively;
  - They lack the ability to predict or understand the consequences of the behavior
  - They are less capable of knowing how, when, and whom to talk.
Treatment in JJS

- Adjudication of delinquency is 220% more likely if the offender has a learning disability because:
  - They have less ability to understand the legal proceedings
  - They have less ability to self-advocate
  - They have poor social presentation
  - They do what other's tell them to do
Treatment in JJS

- Once adjudicated delinquent, the term of incarceration and/or probation averages two to three longer for those with disabilities as compared with non-disabled peers because:
  - They have less ability to understand and adhere to the terms of probation and/or release
  - They have less ability to comply with academic and other requirements as conditions for termination/release
  - They have more behavior and interpersonal problems with institutional staff and other students.
Strategies and Resources
To Improve Learning and Function for Youth with FASD

- Giving simple directions
- Identify and model language
- Create schedules
- Create rituals
- Be consistent in parenting/direct care
- Provide external motivation
- Encourage individualized programming
Communication

• Be Concrete!
  – Show me
  – It’s time to go when ... (provide a concrete specific example)
  – Can you draw it?
  – Let’s start here (demonstrate)
  – Be mindful of auditory processing issues
Communication

• Don’t use idioms

Use of common everyday idioms for those with FASD may not result in the intended outcome
  – “Bite Me”
  – “Over my dead body”
  – “You’re in hot water”

• Say what you mean

  – “Put the toys in the box” NOT “Pick up the living room”
Adapting Talk Therapy for Clients with FASD

• “The key is to link talk therapy to concrete, physical representations of the issues.” Susan L. Baxter *Fantastic Antone Grows Up*

• Concrete activities will, at the same time, help develop expressive language skills
Why Structure the Environment with Visual Supports?

- Organizing the environment with visual support can:
  - Create orderliness and predictability
  - Help child experience structure and stability
  - Help child function more independently
  - Encourage responsibility
  - Increase child reliability
  - Help child remember tasks
  - Visit www.do2learn.com
Teaching Time Concepts

• Time is an abstract concept
• Teach time-management skills
  – Create daily logs and calendars
• Show time in tangible, concrete ways
  – Pictures, charts, egg timer, growing plant to show time passage
  – Visual schedules to create predictability
<table>
<thead>
<tr>
<th>Behavior</th>
<th>Misinterpretation</th>
<th>Accurate Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Noncompliance</td>
<td>Willful misconduct</td>
<td>Difficulty translating verbal directions into action</td>
</tr>
<tr>
<td></td>
<td>Attention seeking</td>
<td></td>
</tr>
<tr>
<td></td>
<td>stubborn</td>
<td></td>
</tr>
<tr>
<td>Often Late</td>
<td>Lazy, slow</td>
<td>Can’t understand abstract concept of time</td>
</tr>
<tr>
<td></td>
<td>Poor parenting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Willful misconduct</td>
<td></td>
</tr>
<tr>
<td>Stealing</td>
<td>Deliberate dishonesty</td>
<td>Doesn’t understand ownership (abstract)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Immature thinking</td>
</tr>
<tr>
<td></td>
<td>Lack of conscience</td>
<td></td>
</tr>
<tr>
<td>Lying (confabulation)</td>
<td>Deliberate Sociopath behavior</td>
<td>Memory/sequencing problems</td>
</tr>
<tr>
<td></td>
<td>Lack of conscience</td>
<td>Trying to please</td>
</tr>
</tbody>
</table>

**Behavior**

- **Noncompliance**
  - Willful misconduct
  - Attention seeking
  - stubborn

- **Often Late**
  - Lazy, slow
  - Poor parenting
  - Willful misconduct

- **Stealing**
  - Deliberate dishonesty
  - Lack of conscience

- **Lying (confabulation)**
  - Deliberate Sociopath behavior
  - Lack of conscience
Rage Behavior Strategies

• Many individuals with a FASD diagnosis are $\frac{1}{2}$ their chronological age.

• Cannot force them into calming down.

• Back off, be calm, follow behavior plan

• Hovering, shouting, ordering, anything physical will produce fight or flight
8 Strategies

- Concrete
- Consistency
- Repetition
- Routine
- Simplicity
- Specific
- Structure
- Supervision

When a situation is confusing and an intervention is not working:

- STOP ACTION!
- OBSERVE
- LISTEN CAREFULLY
- ASK-WHAT IS HARD?
  …WHAT WOULD HELP?
  (Never ask WHY)

• developed by Deb Evensen and Jan Lutke 1997
Redirection Techniques

• Be consistent
• Redirect activity, offer another option, alter behavior
• Don’t debate rules or consequences.
• Reward completion of tasks and good behaviors
• Monitor their behavior
• Don’t try harder, CHANGE what you are doing
Shifting from Control to Structure for Improved Outcomes

- **Controlling**
  - Work *at* the person
  - Change the person
  - Dominate
  - Punish
  - Coerce
  - Rigid
  - Top down, power-driven
  - Limited options
  - Alienate

- **Structured**
  - Work *with* the person
  - Change the environment
  - Reciprocate
  - Prevent
  - Collaborate
  - Flexible
  - Mutual
  - Explore possibilities, expand options
  - Relate

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Online Resources

• General Information on FASD
  – Center for Disease Control and Prevention, FAS site
    • http://www.cdc.gov/ncbddd/fas

  – FASD Unit @ the Univ of Washington School of Medicine
    • http://depts.washington.edu/fadu/
Online Resources

• FASD Resources and Services
  • Listing by region of:
    – Medical (diagnostic clinics)
    – Mental health/chemical health
    – Advocacy & Education
    – Social Services Agencies
    – Informal and Community Support
Don’t Try Harder... Try Differently

If you’ve told a child a thousand times and he still does not understand, then it is not the child who is a slow learner

- Walter Barbee
Paradigm Shift

“We must move from viewing the individual as failing if she/he does not do well in a program to viewing the program as not providing what the individual needs in order to succeed.”

-Dubovsky 2000
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