

# Common Cycles of Individuals with Fetal Alcohol Spectrum Disorder (FASD)

- In the Absence of Identification of FASD
  - With Early Identification of FASD
  - Recommendations for Supporting Individuals with FASD
- Adolescents and Young Adults with FASD
  - Sexuality and FASD

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## **Common Cycles In The Absence of Identification:**

1. Poor Bonding, failure to thrive, interrupted sleep patterns. Difficulty feeding, withdrawal.
2. Possible physical and emotional issues, abuses and neglect. Early removal from home is common, multiple residences, inconsistent parenting and abrupt transitions exacerbate early developmental problems.
3. Early indicators of inconsistent memory, poor sequencing, distractibility, hyperactivity.
4. Developmental delay (may be mild or masked by some skills): delayed walking, speech and language, toilet training. Vision and auditory processing deficits may not be obvious; evidence of processing deficits may appear in the form of not following series of directions, or randomly doing so.
5. Partial diagnosis = incomplete intervention: vision, hearing, cognition, behavior etc.
6. Early school failure: attention deficit disorder/hyperactive. Majority are "gray area children," unidentified, ineligible for services. May be easily influenced, unable to understand or predict consequences of behavior although they present the illusion of competency.
7. Function at levels lower than indicated by testing (performance, verbal). FAS and FAE are often functionally the same. Individuals appear to be able to work at levels that are actually beyond their abilities.
8. Differential interpretation of behaviors by parents and school, compounds the problem, i.e. seeing willful misconduct rather than organicity = punishment rather than support. Cumulative internal frustration without ability to access and resolve development of defense systems, i.e. enormous anger responses to apparently minor stimuli.
9. Difficulty with abstractions: math scores typically lowest, communication nuances lost. Inability to "link" cognitively.
10. Not competitive by 4th grade academically. School refusals start at 4th grade when called upon to use higher cognitive processes.
11. Socially isolated; intrusive, inappropriate, few friends. Poor comprehension of social rules and expectations.

12. Early school refusal (4th grade), problems with family.
13. Early first use of alcohol/drugs, other behavior problems; shoplifting, arson, aggressiveness, lying, defiance of authority, temper tantrums, destructiveness.
14. Sexual difficulties, victimization/acting out, easily exploited. Experimentation, other inappropriate behavior. Discrepancy between physical maturity and emotional immaturity may lead to exploration with younger children. Need for mastery, autonomy, pleasure and predictable responses may be attempted to be met through sexuality.
15. Alcoholism/chemical dependency; early first use, rapid deterioration. Traditional interventions, difficult for adolescents in general, are compromised by organicity. In treatment, they 'talk the talk' but don't 'walk the walk'.
16. Traditional attempts at intervention ineffective, end up 'blaming the victim' (i.e. insight therapy does not work well for individuals with FAS/FAE). Treatment for substance abuse currently fails to incorporate functional processing deficits.
17. Pregnancy: latter births of former teen parents at greatest risk for giving birth to infants with FAS. AIDS and other sexually transmitted diseases pose a major risk. High rate of male, female prostitution, topless dancing, etc.
18. Involvement with the legal system; truancy, shoplifting, arson, run aways, prostitution -- both male and female.
19. Termination of parental rights may occur early or with adolescence.
20. High rates of depression, suicide, incarceration.
21. Highly suggestible, 'unrealistic', impulsive tendencies continue, appears to modify at approximately age 25. Expanded timelines for achieving independence appear appropriate for some individuals.
22. Often have difficulty managing money, time. Forget appointments, over spend.
23. May get jobs, but unable to keep them.
24. Persistent narrow repertoire of behaviors, i.e. anger, withdrawal. Apparent inability to modify behaviors on past experiences.
25. Unstable relationships with significant others, abuses, abandonment.

## **Common Cycles With Early Identification:**

1. Intervention in parental alcoholism/chemical dependency; the home is stabilized, parenting improves. Subsequent impaired births are prevented. Abuses are prevented.
2. Full range of assessments (vision, hearing, speech, motor skills) determine deficiencies at an early age.
3. Infant stimulation programs and specific ameliorative work is implemented. Often, little remedial work is necessary.
4. Environments are structured to enhance development. Early failures, frustrations, deterioration are prevented.
5. Parental supports for recovery and parenting skills continue. Rates of relapse decline with appropriate support.
6. Conscious integration of implications of 'organicity' or brain differences, continues. Environments are evaluated for their appropriateness, and appropriate modifications continue to be made.
7. Care is coordinated; smooth transitions are accomplished between infancy, toddlerhood, school, and eventually adulthood.
8. Headstart and other appropriate programs are accessed. The home-to-school continuum is established.
9. 'Preventative parenting' techniques are taught, i.e. conscious problem solving, structure rather than control. Trying "differently" not "harder".
10. Identification of strengths, inclinations and interests are reinforced. Experiences of success occur.
11. Optimal learning modes are identified.
12. 'Preventative parenting' continues; advocating and educating to prevent the erosion of self-esteem which results from inappropriate levels of expectation and unresolved frustration.
13. Prevention of alcoholism and chemical dependency through early identification of FAS/FAE occurs through intervening in the cycle of early school failure, poor peer and family environments, unstable homes, and unaddressed impulsivity.

# **Recommendations for Supporting Individuals with FAS/E**

**The statement in BOLD type is the guideline.**

*The statement(s) in italics provide specific details.*

(The statement(s) in parentheses refer to the general characteristic it addresses.)

## **Evaluate elements of environments and modify appropriately.**

*Individuals with FAS/FAE have organic brain differences. Environments are modified to support other handicapping conditions. Environments need to be modified to support individuals with FAS/FAE.*

(FAS/FAE is an invisible handicapping condition. Changing elements of environment improves outcomes.)

## **Observe patterns of behaviors.**

*Identify patterns which reflect developmental stages and tasks which may be independent of chronological age.*

(Individual may be delayed in some areas; work with them at *their* level.)

## **Recognize and modify expectations regarding timelines.**

*Revise timelines for milestones as appropriate, i.e., toilet training, learning to read, leaving home. Individuals may require more time to achieve goals.*

(There seems to be a gradual 'catch up' process for individuals with FAS/FAE over time.)

## **Identify strengths, skill and interests.**

*Work to individual's strengths; prevent chronic failures; help build self-esteem.*

(Individuals learn and relate through their own strengths.)

## **Identify 'stuck' patterns, and frustrations; learn to detach.**

*Use observational techniques to maintain neutrality, defuse. Random reinforcement of parenting techniques is normal.*

(Inconsistent performance and spotty retention contribute to illusion of competency.)

## **Reframe the interpretation of behaviors: from won't to can't.**

*Move from seeing behaviors as willful misconduct to understanding the underlying organicity, from lazy to unmotivated to frustrated. See beneath secondary symptoms, and view behavior as form of communication.*

(Patterns of behavior which may be distressing are often manifestations of the underlying organicity.)

**Provide structure rather than control.**

*Recognize power struggles. Disengage, de-escalate, re-evaluate, and create.*

(Structure enhances respect, involves the individual in developing an internal structure, and empowers the individual. Involvement in the process increases retention.)

**Establish routines.**

*Modify gradually, as developmentally appropriate.*

(Individual may be unable to learn 'incidentally'.)

**Build transitions into the routine.**

*Use four steps: forewarn, anticipate, state, act. Individual's difficulty with 'switching gears' may reflect perseveration or stimulus overload.*

(Perseveration may dictate lengthy transition.)

**Limit television viewing time; be selective.**

**Choose non-violent, informative programs, and monitor closely.**

(There may be an inability to distinguish reality from fantasy; the individual may see violence as 'real', especially younger children.)

**Model appropriate behaviors.**

**Demonstrate, articulate, communicate and reinforce the range of emotions, corresponding resolution, and other behaviors, i.e. grooming.**

(Indirect learning, by implication, may be unattainable by individuals with FAS/E.)

**Provide simple instructions or cues.**

*Use simple words, and only one or two directions at one time.*

(Individual's ability to process information may not allow for retention of instructions or ability to follow long sequences.)

**Identify 'shut down' cues; behaviors which indicate the internalization and accumulation of frustrations. Examples include persistence, irritating behaviors, a flat affect, anger disproportionate to stimulus, use of simple defense mechanisms such as lying, avoiding or playing 'dumb'.**

*Help to develop skills for resolution of frustrations: keep it concrete, as in, "What does this make you want to DO?". Think about hunger, fatigue, sadness as a part of the equation.*

(Individual may not recognize physical or emotional indicators of distress, or be able to access them.)

**Help to develop skills for expressing feelings.**

*Help individuals learn to communicate through the use of metaphor, art, play, anger reduction techniques which are safe, and which provide a bridge to verbalization of issues.*

(Linking words with internal state of feeling may be difficult; apparent verbal skills may mask lack of depth or congruence with internal state of feeling.)

**Provide specific support for social skills development.**

*Supervise friends and play. Specifically teach social skills in context. Verbalize actions which are usually taken for granted. Monitor social ostracism.*

(Individuals with FAS/FAE typically miss social cues.)

**Understand the various forms of communication.**

*Identify the range of behaviors which may reflect attempts by the individual to communicate.*

(Individual may attempt to communicate through increased movement, subtle verbal or nonverbal cues, aggression, withdrawal, and/or apparent 'off the wall' comments.)

**Encourage safe multi-sensory exploration.**

*Provide a range of media to explore. Allow adequate time for exploration.*

(Individual may need time to thoroughly process an activity.)

**Include as many sensory modalities as possible to facilitate integration of information and experience.**

*Include sight, sound, touch, taste, smell, emotion and action.*

(Individuals learn best from multi-sensory, concrete approach.)

**Integrate awareness of the components of information processing deficits and how they manifest. (Morse, 1991)**

*\* Inability to translate information into appropriate action.*

*\* Failure to generalize information.*

*\* Difficulty perceiving similarities and differences. Recognize spotty learning and retrieval as normal, work with the individual to devise strategies to compensate for deficits.*

(Individuals with FAS/FAE may require specific cues to access previously stored information. Note: Redoubling efforts to teach to the deficits may be exercises in futility.)

**Re-evaluate expectations and goals for the individual; clarify whose needs are being met by the goals.**

*Work to revise and expand as indicated through observations. Appropriately modify goals with out compromising or limiting potential. Include social skills in goals.*

(Remember that there is no 'norm' for FAS/FAE. There is a broad range of degree and type of effects. IQ's may range from 20 - 110+.)

**Clarify goals and values for education and independence.**

*\* Advocate*

*\* Anticipate*

*\* Participate*

*\* Coordinate*

**Identify environments which enhance and support the individual.**

*Remove the individual from or revise erosive environments to help prevent the development of secondary symptoms. Access environments in which FAS/FAE is non-focal, where individuality flourishes and individual strengths are identified and supported.*

(Prevention of secondary symptoms includes helping the individual to experience successes on a consistent basis.)

**Assure integration of culturally relevant values, traditions, art, music, and stories.**

*Teach skills in context of students' natural environment. Integrate experience, relevancy and good teaching. Use visualization techniques to help clarify.*

(Individuals with FAS/FAE tend to learn through action or experience. Since their ability to integrate information is impaired, it is important to link information with internal structure.)

**Form integral partnerships.**

*Establish continuity between home, school, and community. Include academic, social, emotional, and vocational components.*

(Continuity is vital to provide adequate levels of support, clarity, and consistency for individuals with FAS/FAE.)

## **Common FAS/FAE Cycle: Adolescents and Young Adults with FAS/FAE**

The wide variability of effects and needs, cultures and resources precludes a simplistic set of recommendations for an entire diverse population. The following are general considerations.

1. Prevent deterioration associated with chronic failure. Assure opportunities for significant, sustained success in all spheres.
2. Evaluate expectations for appropriateness; continue to 'think younger' with adolescents and young adults, identifying their actual, rather than apparent, maturational level and abilities.
3. Prepare for expanded timelines and gradual 'catch-up' potential; individuals with FAS/FAE may experience significant integration between the ages of 25-30 rather than 18-22. Identify potential stressors related to this (emotional, financial, social) for individuals with FAS/FAE and their family systems.
4. Identify or develop resources for families and individuals with FAS/FAE to support gradual transition into adulthood.
5. Identify a case manager who is knowledgeable about FAS/E (identify receptive professional(s) to whom to provide information about FAS/FAE and facilitate coordination of services, as needed.
6. Provide specific social, vocational, and life skills training
7. Continue to teach pragmatic life, vocational, and academic topics in an appropriate manner (concrete, contextual, relevant).
8. Monitor for early behavioral indicators of frustration or deterioration. Evaluate for use of alcohol and/or other drugs and intervene appropriately. Should treatment be indicated, choose a program which recognizes and addresses the needs of individuals with FAS/FAE.
9. Maintain predictable, safe structure. Avoid control and power struggles. Invite participation and problem solving of person with FAS/FAE as appropriate. Reinforce successes; expect the necessity of reteaching skill periodically.
10. Involve individual with FAS/FAE in their own advocacy efforts. Support increased awareness of and communication about strengths and areas of weakness.

## Common FAS/FAE Cycle: Sexuality and FAS/FAE

1. May be 'on time' for physiological development, but delayed maturationally.  
Think: 'fully sexually mature six year old.'
2. Individuals with FAS/FAE are at tremendous risk for sexual abuse due to friendliness, fearlessness, lack of ability to appreciate consequences, suggestibility.
3. Normal sexual exploration, appropriate for a five year old, becomes abuse when a 16 year old engages in sexual exploration with an emotional developmental peer (a six year old, for example). These individuals are at risk for inappropriate sexual behavior due to powerful hormonal imperatives and impulsivity, therefore preventive measures (safe settings and circumstances) are important.
4. Where FAS/E has not been identified, and the person has experienced isolation, failure, pain, loneliness and chronic incompetency, sexuality may assume a disproportionate role in the person's life (this is not unique to people with FAS/E).
5. Sexuality provides:
  - Acceptance
  - Adequacy, relative normalcy
  - Pleasure
  - Power, mastery
  - Predictability
  - Connectedness with another human being, relationship
  - Few requirements to abstract, perform intellectually
  - Is concrete, immediate, available
6. Sexuality in adolescents with FAS/E often elicits fear in parents and caregivers.
7. Very real fears include:
  - AIDS, other sexually transmitted diseases
  - Pregnancy or paternity (may not understand contraception)
  - Premature parenthood
  - Where there is a history of abuse, early sexualization:
  - Aggressive sexually: rape, molestation, incest.
8. **Reactive** responses include:
  - Various attempts to control the individual, including monitoring all behavior, sterilization, or implantation.
9. **Proactive** responses include:
  - Prevention of deterioration, sustained supports as appropriate; good training about relationships, sexuality, and reproduction; good role models for relationships, and friendships; healthy physical, productive vocational activities; and, successful social interactions with peers.