DEVELOPMENTAL OVERVIEW OF FASD

Through the Eyes of Parents

TODDLERS (1 - 5)

Parents report that toddlers with FASD* are:

- sometimes medically fragile
- usually require high maintenance, keeping parents alert and on duty 24 hours a day
- often exhausted and irritable from uneven sleep patterns
- highly manipulative
- a danger to self and others because they do not grasp the universal laws of cause and effect
- void of the normal sequential learning abilities in reasoning, judgment and memory
- very difficult to manage when out in public
- no natural fear of danger, e.g., lacking in the normal abilities (of this age group) to distinguish between friend and enemy
- misunderstood by service providers because their IQ's appear to be developing normally

CHILDREN (6 - 11)

Parents report that children with FASD are:

- impulsive, unpredictable and mischievous, creating ongoing safety hazards, such as setting fires and running away
- often exhausted and irritable from uneven sleep patterns
- innately skilled in manipulative tactics
- void of normal sense of justice
- overlooked as permanently disabled because their IQ's are normal
- desperate for stimulation and excitement to keep them entertained and happy
- emotionally volatile and often exhibit wide mood swings throughout the day
- often disconnected from their own feelings and are unable to identify or express logical reasons behind their volatile outbursts
- isolated and lonely because the desire to be included remains intact while the reasoning skill to figure out why they are excluded is lacking
- angry and resentful toward more structure and supervision than their peers need
- limited in natural empathy for others because they are so egocentric

Note: These characteristics may appear to be typical behavior in a normal person, but in individuals who have been disabled by prenatal exposure to alcohol, these traits occur in grossly exaggerated form and do not respond to typical interventions.

* Fetal Alcohol Spectrum Disorder: umbrella term for all conditions/disabilities caused by prenatal alcohol exposure.

DEVELOPMENTAL OVERVIEW OF FASD

Through the Eyes of Parents

ADOLESCENTS (12 - 17)

Parents report that adolescents with FASD are:

- moral chameleons (despite consistent loving care, family values and even general rules of social behavior are not being internalized)
- often exhausted and irritable from uneven sleep pattern
- at high risk for being drawn into anti-social behavior: stealing, lying, running away, etc.
- continuing to be a safety menace to themselves and others
- still in need of limits and protection like a three year old
- often obsessed by primal impulses such as sexual activity and fire setting
- able to recognize and will submit to raw power, making them vulnerable to gangs
- seriously impaired when it comes to making decisions (not having the judgment or reasoning skills to actually "make" decisions)
- terrified of major transition or change, e.g., middle school, moving, etc.
- extremely vulnerable to ideas in movies, videos, music, TV and advertisements
- unaware of normal hygiene needs
- unable (not necessarily unwilling) to take responsibility for their actions

ADULTS (18 and over)

Parents report that their adult children with FASD are:

- moral chameleons
- often exhausted and irritable from uneven sleep patterns
- extremely vulnerable to anti-social behavior and at great risk for finding the structure and supervision they need in the criminal justice system
- unlikely to follow safety rules concerning fire hazards, safe meal preparation, vehicle operation, infectious diseases, basic life needs, etc.
- notably lacking in the ability to manage money
- volatile if pushed too far to do something they see as unreasonable, such as asking them for money to pay their rent or groceries.
- quite vulnerable to co-dependent relationships, which can turn violent
- incapable of taking daily medication or birth control pills on a regular and effective basis
- vulnerable to panic attacks, depression, suicide ideation, mental and emotional overload, and sometimes psychotic breaks
- very impaired as to entertaining themselves and keeping out of mischief
- not nearly as capable as they appear to be
- in desperate need of appropriate sheltered employment opportunities

Note: These characteristics may appear to be typical behavior in a normal person, but in individuals who have been disabled by prenatal exposure to alcohol, these traits occur in grossly exaggerated form and do not respond to typical interventions.

EPSDT Developmental Checklist

Many of us come into the parenting of affected children unprepared to communicate with pediatricians and medical doctors about the deficits we see in our children. Some of these deficits can be very subtle at first. But according to the Collective Family Experience if we had a vocabulary that would successfully convey our hunches and concerns to our primary care physicians and pediatricians, these deficits would be addressed much earlier. We believe this communication void is twofold. One, there is a lack of consistent vocabulary for parents. Two, there have not been enough phrases and terms developed and utilized to express the unique developmental deficits involved in FASD.

To meet these needs, we at FAS*FRI have developed two assessment tools. The first is the FASD Core Behavior Traits (see below, right) and the second is an **EPSDT Pocket Checklist** for children who are eligible for Medicare. The EPSDT Pocket Screen was developed by FAS*FRI staff based on the Well Child Exam forms used by the Washington State Department and Health Services. The Well Child Exam is a one-page form which the child's doctor fills out at the time of a medical examination. There are different forms for each developmental stage from 2 weeks of life through age 18. By understanding the age-appropriate developmental milestones assessed in the EPSDT program and comparing them to your child's progress, you will be better prepared to identify the deficits and developmental delays that may be surfacing in your child.

EPSDT Normal Developmental Signs

You can reasonably expect the following milestones to be met at these ages.

Infancy Checklist (4 - 6 months)
- ♦ Sleeps through the night
- ♦ Comfortable with his/her bedtime ritual
- ♦ Experiences stranger anxiety
- ♦ Mother feels rewarded when trying to comfort the child
- ♦ Communicates needs to caregiver

18-month Checklist:
- ♦ Follows simple directions
- ♦ Responds to "no"
- ♦ Hears normally–not tuning out during social interactions

Year 4 Checklist:
- ♦ Plays and gets along will with other children
- ♦ Understands limits and discipline
- ♦ Understands what happened yesterday and what's coming up tomorrow
- ♦ Plays games with other children
- ♦ Can join in and participate in pretend play

Year 5 Checklist:
- ♦ Enjoys make-believe play
- ♦ Gets adequate sleep
- ♦ Understands and accepts discipline/ limits
- ♦ Begins to take responsibility to pick up toys, setting the table, etc.
- ♦ Begins to learn the rules of games
- ♦ Practices eye contact with others

Year 6 Checklist:
- ♦ Plays well with other kids
- ♦ Seems rested when he/she awakens in the morning
- ♦ Gets adequate sleep
- ♦ Accepts discipline/limits
- ♦ Makes friends at school
- ♦ Does regular chores
- ♦ Helps care for pets

Teen Checklist:
- ♦ Seems rested when he/she awakens in the morning
- ♦ Has 1 or 2 close friends
- ♦ Can follow rules and be safe without after school supervision
- ♦ Handles stress, anger, frustration appropriately
- ♦ Has someone to talk to when frustrated
- ♦ Happy with his/her progress in school
- ♦ Sleeps appropriate amount (too much indicates depression and needs to be addressed)
- ♦ Consistent sleeping and eating patterns

EPSDT Defined

The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program is for children and young adults under 21 who are enrolled in Medicaid or in the Children's Health Insurance Program (CHIP). Regular well-child checkups are included to make sure preventive care is given and that any health problems are caught and treated at an early stage. These checkups (physical exams) can include vaccinations, comprehensive health and developmental history, labora-tory tests, and vision, hearing, dental/oral health, mental health and substance abuse screenings.

Core FASD Behaviors

We believe it is critically important to everyone's health and safety for parents and professionals to understand the core traits of this disability. According to the experiences of hundreds of families, six primary deficits have been identified in individuals with FASD:
- ♦ extreme vulnerability to peer influence (a moral chameleon quality);
- ♦ volatile and/or dangerous behavior without predatory intent;
- ♦ inability to see the need to follow rules;
- ♦ continuing childlike innocence regardless of age, I.Q., and experience;
- ♦ egocentric: living in the moment for immediate gratification;
- ♦ disrupted understanding of cause and effect in every life domain: physical, social, educational (mental), and moral

Some of these characteristics may appear to be due to immature or undisciplined behavior in a normal person; but in individuals with FASD, these traits occur in grossly exaggerated form and do not respond to typical treatment and intervention.

Preparing for a Diagnosis

Take some quiet time and think about each category shown on this page. Record your thoughts on paper and make copies of any written reports you may already have. Take all of this documentation and your child's pictures with you to your child's appointment.

I. History of Prenatal Alcohol Exposure

If you are a birth mother, self-reporting of alcohol use during pregnancy is ideal.

If you are a foster or adoptive parent, consider the following.

- If you have access to paternal or maternal relatives, ask them about prenatal exposure.
- Did your caseworker give you verbal or written information on prenatal alcohol exposure?
- Did a previous foster parent have maternal drinking information?
- Request written non-identifying, prenatal medical and mental health family history from your adoption agency. [If you are a foster or adoptive parent, with no prenatal history on your child, you have a right to request this information and "non-identifying" medical and mental health birth family history from your foster care or adoption agency.]

Verification of prenatal alcohol exposure can come from:

- A birth parent
- A paternal or maternal relative or friend
- A previous foster parent
- Your adoption caseworker (based on personal knowledge or written records)
- Written records from a hospital, doctor, treatment center, or adoption agency

II. History of Your Child's Growth Pattern

Was your child a "preemie" (born weeks before the due date)?
Did your child have "failure to thrive"?
Did your child have a low birth weight even though he/she was full term?
Do you have access to your child's hospital birth records?
Do you have medical and or school records documenting growth deficiencies?
If you do not have these types of records, you may request pre-adoption medical records from the adoption agency. It's the (federal) law –you are entitled to these records.

III. Physical Characteristics

1. Look for the "classic" facial features of FAS:
   - narrow eye openings which may cause the eyes to appear to be wide-set
   - a short nose with flat bridge
   - long flat (or curved out) space between the bottom of the nose and upper lip (phyltrum)
   - thin upper lip
   - flat mid-face

2. Think about your child's medical history. Has your child had any of the following?
   - ear infections/hearing problems
   - seeing/eye difficulties
   - teeth/jaw malformations and/or braces
   - seizures

3. Collect your child's school photos (or face shots, not smiling if possible) between 5 and 10 years old.

IV. Central Nervous System Damage (Behavioral Manifestations)

Does your child present most of the following behaviors?

- Difficulty concentrating or staying on task
- Problems connecting behavior to consequence
- Odd logic or reasoning
- Belief that rules are only for other people and do not apply to themselves
- Unpredictable and impulsive
- Inability (as opposed to unwillingness) to accept responsibility
- Habitual lying with a clear conscience
- Frequent manipulation of others
- Diagnosis of Attention Deficit/Hyperactivity Disorder
- Excessive vulnerability to peer pressure
- Multiple or pervasive developmental delays
- Volatile behavior (not necessarily violent or predatory which would indicate other factors)