# Fetal Alcohol Spectrum Disorders (part 2)

Presented by

Susan Astley, PhD and Christen Kishel, PhD October 6, 2014

With special thanks to Ruth Peters, PhD and Jeana Paul, MA, MFT for their contributions

## Neuropsychological Findings

- Global deficits
  - IQ scores range from 20 to 120, with average scores between 65 and 72
  - If no FAS facial features, IQ tends to be higher than if facial features present, but still lower than neurotypical peers

## More findings: ADHD Symptoms

- Visual sustained attention pervasively impaired
- Auditory sustained attention may relate to task demands
- Often does not present like typical ADHD
  - People with FAS have problems with shifting attention and encoding information, while children with primary ADHD typically display problems with sustained attention and focus
  - Can have "on" and "off" days instead of consistently exhibiting symptoms
  - Children with FAS similar in description of being easily distracted, having trouble with transitions, and trouble completing tasks
  - Hyperactivity symptoms typically described by parents:
    - "Busy"
    - Difficulty calming down
    - Overly active

## Neuropsychological findings cont'd

- Verbal learning and memory
  - Impaired unless children have an implicit memory strategy (like chunking)
  - Parents often report that their children seem to be able to perform a skill one day but not the next
- Nonverbal learning and memory
  - Results mixed: some suggest spatial recall is impaired; other don't.
- Speech and language
  - Some evidence of speech production problems- may be related to craniofacial structure
  - Expressive and receptive language problems, but typically consistent with IQ (consider that these two skills are often used as part of an IQ assessment)

## More neuropsych findings

- Executive functioning
  - Deficits in planning and organization
  - Poor utilization of feedback (failure to link cause and consequence, even when it's pointed out consistently)
  - Poor response inhibition (impulse control)
  - Poor verbal and nonverbal fluency
  - Concrete thinking
  - Difficulty following multi-step directions
  - Difficulty changing strategies or thinking of things in a different way
  - Inability to delay gratification
  - Inability to apply knowledge to new situations

## And even more findings...

- Visual-spatial ability
  - Impairments may be related to some extent to impaired motor ability:
    - Delayed motor milestones
    - Difficulty with writing or drawing
    - Clumsiness
    - Balance problems
    - Tremors
    - Poor dexterity
    - Poor sucking in infants often observed

## Social skills and Secondary disabilities

- Often described as:
  - Hyperactive
  - Disruptive
  - Impulsive
  - Delinquent
- And have elevated rates of anxiety and mood disorder diagnoses, ODD, adjustment disorders, and sleep disorders
- As well as deficits in adaptive behavior across the lifespan
  - Socialization
  - Communication
  - Daily living skills

## Social skills continued

- Often have social perception or social communication problems that make it difficult for them to grasp the subtle aspects of human interactions.
- Consistent difficulty understanding the consequences of behavior is a frequent problem.
- Other social concerns:
  - Lack of fear of strangers
  - Naïveté and gullibility
  - Being taken advantage of easily
  - Inappropriate choice of friends
  - Preferring younger friends
  - Immaturity
  - Superficial interactions
  - Inappropriate sexual behaviors
  - Fire setting

## Other possible problems

- Sensory
  - Tactile defensiveness, for example
- Pragmatic language problems
  - Trouble reading others' faces, nuances of conversation and interaction
- Memory deficits
  - Forgetting well-learned material
  - Needing many trials to remember
- Difficulty responding to common parenting practices
  - Not understanding cause-and-effect discipline

## Psychosocial Needs Associated with FAS Robin A. LaDue, PhD Fetal Alcohol and Drug Unit, University of Washington

#### Problems and Concerns during Latency Period, Ages 6-11

- Continued delays in physical and cognitive development.
- Temper tantrums, lying, stealing, disobedience, and defiance of authority
- Hyperactivity/distractibility
- Memory deficits
- Impulsivity
- Inappropriate sexual behavior, often with animals
- Difficulty separating fact from fantasy
- Easily influenced by others
- Difficulty predicting and/or understanding the consequences of their own or others' behavior
- Poor comprehension of social rules and expectations
- Difficulty in abstracting abilities

### Psychosocial Needs cont'

#### **Problems and Concerns for Adolescents Ages 12-17**

- Academic ceiling is often reached; usually 4<sup>th</sup> grade for Reading, 3<sup>rd</sup> grade Spelling and Math
- Increasing social difficulties and isolation
- Low motivation
- Egocentric, difficulty comprehending and/or responding to other's feelings, needs, and desires
- Lying, stealing, passivity in responding to requests
- Faulty logic
- Impulsive, aggressive, unpredictable, and violent behavior
- Involvement in vandalism, other criminal activity
- Pregnancy/fathering a child
- Loss of residential placement
- Low self esteem and mental health issues
  - Depression
  - Suicidal ideation and attempts
  - Substance abuse
  - Sexual/emotional abuse and trauma



## Psychosocial Needs cont'

#### **Recommendations for Ages 6-11**

- Continued monitoring of healthy issues
- Safe, stable, structured home or residential placement
- Help caretakers/teachers establish realistic goals and expectations
- Help the child make healthy choices appropriate to their emotional and cognitive level
- Use of clear, concrete, predictable, and immediate consequences
- Simple, clear, and concrete directions of daily chores and activities along with positive consequences for appropriate behavior, listed in writing
- Structuring of leisure times
  - Participation in organized sports, e.g., Special Olympics
  - Participation in clubs for handicapped children
- Psychological/academic/adaptive evaluations on a regular basis
- Education of parents and caretakers regarding age-appropriate sexual development\*
- Respite care for parents and caretakers
- Continued support for parent's sobriety, if needed
- Appropriate educational placement
  - Activity-based curriculum
  - Focus on communication skills
  - Focus on appropriate behavior
  - Basic academic skills embedded within functional skills
- Case manager's role expands to include schools, mental and physical health providers, and social service agency personnel
- Documentation of health impairment and deficits in adaptive behavior to aid in acquiring SSI and DD funding.

## Psychosocial Needs cont'

#### Recommendations for ages 12-17

- Change focus from academic skills to vocational and daily living skills
- Continued structuring and monitoring of leisure time and activities
- Involvement in structured social and sport group activities
- Anticipation of transition/crises situations along with appropriate planning and early interventions
- Help the patient to make healthy choices and to build on existing skills
- Education of parents, caretakers, and patients regarding sexual development, birth control options, and protection against sexually transmitted diseases (STDs)
- Education of parents, caretakers, and patients to help protect against sexual exploitation
- Implementation planning for future residential placement, financial needs, and vocational/educational training
- Case manager role expands to include acting as a liaison between patient, family, schools, vocational programs, health care providers, and court services, if necessary
- Continued listing of daily chores with increasing responsibility
- Respite care for families
- Caretakers support group

### Protective Factors

#### **Early diagnosis**

\*A child who is diagnosed at a young age can be placed in appropriate educational classes and get the social services needed to help the child and his or her family.

\*Early diagnosis also helps families and school staff to understand why the child might act or react differently from other children sometimes.

#### Involvement in special education and social services

\*Children who receive special education geared towards their specific needs and learning style are more likely to reach their full potential.

\*Children with FASDs have a wide range of behaviors and challenges that might need to be addressed.

\*Special education programs can better meet each child's needs.

\*In addition, families of children with FASDs who receive social services, such as counseling and respite care, have more positive experiences than families who do not receive such services.

## DDA Eligibility Requirements

- FAS falls under the category "Other condition similar to Intellectual Disability"
- FAS with unknown exposure and PFAS both fall under this category
- Static Encephalopathy does NOT, even with confirmed alcohol exposure
  - Why? A number of MD's give this diagnosis without the rigorous evaluation process undertaken by the FAS DPN, and it can be very non-specific
  - This is an area in which ongoing advocacy is needed
- In addition to the FAS/PFAS diagnosis, there needs to be evidence of a FSIQ below 78 and adaptive functioning below 70.

## Accepted measures of IQ & AF

## **Accepted Intelligence Tests**

- Wechsler Intelligence Testsfull (WISC or WAIS, not WASI)
- Kaufmann Assessment Battery for Children (not KBIT)
- Stanford-Binet
- Differential Abilities Scale
- Das-Naglieri Cognitive Assessment System
- Woodcock-Johnson Test of Cognitive Abilities
- If nonverbal:
  - NV portions of WISC, WAIS, or KABC
  - Leiter-R
  - K-ABC

## Accepted Measures of Adaptive Functioning

- Vineland Adaptive Behavior Scales
- Scales of Independent Behavior-Revised
- Adaptive Behavior Assessment System-II
- Inventory for Client and Agency Planning (DDA only)

## After DDA Eligibility...

- A case manager will come to the home to conduct an assessment of needs (called the CARE assessment
- Depending on the needs identified in the CARE, services may range from MPC (Medicaid Personal Care) to financial assistance for needed services and equipment, payment to contracted providers for specialized services, and outof-home residential placements

#### Loving, nurturing, and stable home environment

\*Children with FASDs can be more sensitive than other children to disruptions, changes in lifestyle or routines, and harmful relationships.

\*Therefore, having a loving, stable home life is very important\_
for a child with an FASD.

\*In addition, community and family support can help prevent secondary conditions, such as criminal behavior, unemployment, and incomplete education.

#### Absence of violence

\*People with FASDs who live in stable, non-abusive households or who do not become involved in youth violence are much less likely to develop secondary conditions than children who have been exposed to violence in their lives.

\*Children with FASDs need to be taught other ways of showing their anger or frustration.

#### **Medical Care**

People with FASDs have the same health and medical needs as people without FASDs. But, for people with FASDs, concerns specific to the disorder must also be monitored and addressed either by a current doctor or through referral to a specialist.

Types of medical specialists might include:

Pediatrician Primary care provider Dysmorphologist Otolaryngologist Audiologist **Immunologist** Neurologist Mental health professionals Opthalmologist Plastic surgeon Endocrinologist Gastroenterologist **Nutritionist** Geneticist Speech-language pathologist Occupational therapist Physical therapist

#### Medication

No medications have been approved specifically to treat FASDs. But, several medications can help improve some of the symptoms of FASDs. Following are some examples of medications used to treat FASD symptoms:

#### **Stimulants**

This type of medication is used to treat symptoms such as hyperactivity, problems paying attention, and poor impulse control, as well as other behavior issues.

#### **Antidepressants**

This type of medication is used to treat symptoms such as sad mood, loss of interest, sleep problems, school disruption, negativity, irritability, aggression, and anti-social behaviors.

#### **Neuroleptics**

This type of medication is used to treat symptoms such as aggression, anxiety, and certain other behavior problems.

#### **Anti-anxiety drugs**

This type of medication is used to treat symptoms of anxiety.

Medications can affect each child differently. One medication might work well for one child, but not for another. To find the right treatment, the doctor might try different medications and doses. It is important to work with your child's doctor to find the treatment plan that works best for your child.

## **Behavior and Education Therapy**

#### Friendship training

\*Many children with FASDs have a hard time making friends, keeping friends, and socializing with others.

\*Friendship training teaches children with FASDs how to interact with friends, how to enter a group of children already playing, how to arrange and handle in-home play dates, and how to avoid and work out conflicts.

\*A research study found that this type of training could significantly improve children's social skills and reduce problem behaviors.

#### Specialized math tutoring

A research study found that special teaching methods and tools can help improve math knowledge and skills in children with FASDs.

#### **Executive functioning training**

This type of training teaches behavioral awareness and selfcontrol and improves executive functioning skills, such as memory, cause and effect, reasoning, planning, and problem solving.

#### Parent-child interaction therapy

\*This type of therapy aims to improve parent-child relationships, create a positive discipline program, and reduce behavior problems in children with FASDs.

\*Parents learn new skills from a coach.

\*A research study found significant decrease in parent distress and child behavior problems.

## **Parent Training**

## \*Children with FASDs might not respond to the usual parenting practices.

\*Parent training has been successful in educating parents about their child's disability and about ways to teach their child many skills and help them cope with their FASD-related symptoms.

\*Parent training can be done in groups or with individual families.

\*Such programs are offered by therapists or in special classes.

## Parent Training Specifics

Although each child is unique, the following parenting tips can be helpful:

- Concentrate on your child's strengths and talents
- Accept your child's limitations
- Be consistent with everything (discipline, school, behaviors)
- Use concrete language and examples
- Use stable routines that do not change daily
- Keep it simple
- Be specific-say exactly what you mean
- Structure your child's world to provide a foundation for daily living
- Use visual aides, music, and hands-on activities to help your child learn
- Use positive reinforcement often (praise, incentives)
- Supervise: friends, visits, routines
- Repeat, repeat, repeat

## Alternative Treatments

Before starting such a treatment, check it out carefully, and talk to your child's doctor.

Your child's doctor will help you weigh the risks and benefits of these therapies.

Some of the alternative treatments used for people with FASDs include:

#### Eight Keys to Remember in the Classroom

#### Vicky McKinney ◆ Reprinted from FAS Times, Fall 97

- We have found that our children benefit from early specific motor and mental stimulation.
- Programs for early intervention, with realistic expectations adjusted to their specific strengths and weaknesses, work well.
- Structure! Structure! Structure!
- Classrooms should have as little stimuli as possible. Our children have trouble filtering out unnecessary stimuli, which we find very easy to do everyday.
- Use concrete learning methods. Abstract thinking is very difficult. Most children with FAS/E will learn from something they can see, feel or touch.
- Only one command or task should be given at a time. Talk over any change in the schedule ahead of time, as transitions are very difficult. Our children find security in knowing what to expect next. They do not adjust easily to change.
- Don't be disappointed if what you teach them today is not with them tomorrow. It is not a reflection of your ability, but it is a reflection of their disability.
- Be practical. Help them learn vocational and life skills. Teach math with a calculator and time with a digital watch. Use a timer to help set the boundaries for activities.
- The reward system works wonders, but the rewards need to be immediate. A sticker or positive recognition means more to our children than the promise of \$500 at the end of a good semester.

#### FASD web sites

- http://www.depts.washington.edu/fasdpn/
  - FAS diagnostic and prevention program at The University of Washington.
- http://www.fascenter.samhsa.gov/
  - FASD Center for Excellence. US department of Health and Human Services site.
- http://www.cdc.gov/ncbddd/fas/default.htm
  - CDC Government site. Most recent national news on FAS

## My contact information

- Christen.kishel@dshs.wa.gov;
- 509-329-2859