Take A First Look

A Guide on Fetal Alcohol Spectrum Disorders for Early Childhood Professionals
About the NYS FASD Interagency Workgroup Logo

Our logo was designed by Jason, a 12-year old sixth-grader with ARND (Alcohol-Related Neurodevelopmental Disorder).

When asked to describe himself, Jason told us the following:

I am a cute, wavy-haired boy who loves art and gym.
I live with my mom and dad and have eight brothers and sisters.
I love my school and I love my cat Pepper.
I will be a teenager on my next birthday.

Jason put a lot of effort and consideration into the development of this logo and we thank him for all of his hard work and for the creation of this logo which we have adopted to represent the work of the FASD Interagency Workgroup.

Disclaimer

The resources presented in this publication are not all inclusive and do not imply endorsement of any particular methodology or approach.

May 2010
Early learning professionals are key players in the success of infants and young children who are experiencing developmental challenges. With connections to parents and other primary caregivers; evaluative tools and skills; and influence on the child’s educational programming, you are in a unique position to put solutions into place.

This booklet addresses Fetal Alcohol Spectrum Disorders (FASD). FASD is an umbrella term that encompasses several conditions resulting from maternal alcohol use during pregnancy. Children with FASD often test with normal intelligence, appear normal, and speak fluently. Yet, they have permanent brain damage that impacts their social interactions and ability to learn. Individualized interventions and strategies that accommodate their differences are vital to the success of these infants and young children.

To better illustrate the range and complexity of children with an FASD, we will use three case examples, described below. We will revisit these children while they undergo evaluation and testing, and again when appropriate strategies have been identified and implemented.

**JAY** is an adorable, petite 5 year old boy who lives with his mother, Sandi. Jay was born 2 months premature. Sandi admitted to using alcohol and crack cocaine during her pregnancy. At age 7 months, Jay had a grand mal seizure which resulted in a 4 day hospital stay, where they found evidence of brain damage.

Jay qualified for Early Intervention (EI) services and received occupational and physical therapy, and special education teacher services in a home based program. At age 2 he moved to a school based integrated program where he received more intense services. He has made slow but steady gains in his program. Jay just started speaking at 4 years of age, but has continued to use sign language to support his newly found skills. At this time he is still not potty trained. Jay takes medication for a seizure disorder. He was also started on a low dose of a stimulant medication due to concerns with attention deficit. This has helped with his progress in school. Sandi has been sober for more than two years now and reports that Jay is a joy to have at home. He is a fussy eater and doesn’t like certain clothing, but she has found ways to help him with the support from the occupational therapists at the EI program. Jay is curious about his surroundings and will get into things he shouldn’t. Jay becomes anxious when leaving the house and this has limited the amount of things she is able to do with him when he is not in school. Sandi will be attending the Committee on Special Education (CSE) meeting to find appropriate resources for Jay as he enters kindergarten.
**Miranda**, a sweet curly haired 18 month old toddler, is the middle child of a professor father and stay at home mother, who has just given birth to her third child. Miranda has been enrolled in a nearby day care/nursery school.

After the initial assessment, the lead teacher mentioned several items that she wanted to work on with Miranda and her parents. The teacher noticed Miranda doesn’t verbalize many words and was quickly overwhelmed by easy instructions.

Miranda’s parents report that Miranda’s older sibling, Chris, is doing remarkably well in school and that Miranda does not seem to enjoy the same activities that Chris did as a toddler.

Miranda has wide set eyes and a smooth philtrum. She is a smiley child, very affectionate and inquisitive of her surroundings.

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**Jack**, an infant, was recently adopted by Bob and Ann an older couple with no other children. Bob and Ann have reached out to their pediatrician because Jack seems inconsolable, crying often and does not drink regularly from the bottles of formula they fix for him. They are still quite excited about the adoption and wonder what they are doing wrong as first time parents.

Dr. Sherman has read extensively on the psychological and social-emotional needs and development of adopted children and recently viewed the movie, Broken Cord. Broken Cord tells the story of a single man who adopts a young boy who then begins to show signs of mental illness but which are in fact, symptoms and behaviors of fetal alcohol syndrome. Dr. Sherman is quick to notice unique facial features such as wide set eyes, smooth philtrum and low nasal bridge coupled with Jack’s poor feeding and crying as Fetal Alcohol Syndrome.

The diagnosis is both a relief and a shock to Bob and Ann, a shock because they never thought they weren’t adopting a perfectly healthy boy and a relief in that now they can move forward and address Jack’s development within the context of fetal alcohol syndrome.
In 1973, United States researchers first recognized and named fetal alcohol syndrome (FAS). Since that time, scientists have learned that any amount of alcohol consumed at any time during pregnancy can be harmful to the developing fetus. In 2005, the U.S. Surgeon General issued an Advisory on Alcohol Use in Pregnancy, stating in part:

- Alcohol consumed during pregnancy increases the risk of alcohol-related birth defects, including growth deficiencies, facial abnormalities, central nervous system impairment, behavioral disorders, and impaired intellectual development.
- No amount of alcohol consumption can be considered safe during pregnancy.
- Alcohol can damage a fetus at any stage of pregnancy. Damage can occur in the earliest weeks of pregnancy, even before a woman knows that she is pregnant.
- The cognitive deficits and behavioral problems resulting from prenatal exposure are lifelong.
- Alcohol-related birth defects are completely preventable.

Different diagnoses have been formulated for prenatal alcohol exposure. These include:

- **Fetal Alcohol Syndrome (FAS)**, recognized by growth deficiency, central nervous system damage, and a unique cluster of minor facial abnormalities. FAS may be diagnosed when prenatal alcohol exposure is unknown.
- **Partial FAS (pFAS)**, includes central nervous system damage, prenatal alcohol exposure, and some but not all of the growth deficiency and/or facial features of FAS.
- **Fetal alcohol effects (FAE)**, a term introduced in 1978 to describe abnormalities seen in individuals that were compatible with those caused by prenatal alcohol exposure, but the pattern was not sufficiently complete to render a diagnosis of FAS. Some clinicians use the term ARND (see below) rather than FAE.
- **Alcohol-related neurodevelopmental disorder (ARND)**, diagnosed when the child has central nervous system damage and prenatal alcohol exposure.
- **Static encephalopathy – alcohol exposed**, defined as any significant abnormal condition of the structure or function of brain tissues that is unchanging.
- **Alcohol-related birth defects (ARBD)**
The previous diagnoses are all Fetal Alcohol Spectrum Disorders. In 2004, several federal agencies and experts in the field convened at a summit sponsored by the National Organization on FAS (NOFAS) to develop a consensus definition of FASD. That definition is:

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.6

Note: Canadian scientists have identified diagnostic criteria for FASD. Keep this in mind when reviewing materials on FASD from Canada.

The Science

“Of all the substances of abuse, including cocaine, heroin and marijuana, alcohol produces, by far, the most serious neurobehavioral effects in the fetus.” Institute of Medicine, 19967

Alcohol is a teratogen, i.e., a birth-defect-inducing substance. Alcohol in the mother’s blood crosses the placenta freely and enters the embryo or fetus through the umbilical cord. Defects caused by prenatal exposure to alcohol have been identified in virtually every part of the body, including the brain, face, eyes, ears, heart, kidneys, and bones. No single mechanism can account for all the problems that alcohol causes. Rather, alcohol sets in motion many processes at different sites in the developing fetus:

- Alcohol can trigger cell death in a number of ways, causing different parts of the fetus to develop abnormally.
- Alcohol can disrupt the way nerve cells develop, travel to form different parts of the brain, and function.
- By constricting the blood vessels, alcohol interferes with blood flow in the placenta, which hinders the delivery of nutrients and oxygen to the fetus.
- Toxic byproducts of alcohol metabolism may become concentrated in the fetal brain and contribute to the development of an FASD.8

“DEFECTS CAUSED BY PRENATAL EXPOSURE TO ALCOHOL HAVE BEEN IDENTIFIED IN VIRTUALLY EVERY PART OF THE BODY, INCLUDING THE BRAIN, FACE, EYES, EARS, HEART, KIDNEYS, AND BONES.”
The pattern and severity of structural and functional effects on the developing fetus depend on the dose, timing, pattern, and duration of the alcohol exposure as well as maternal and genetic factors. Vulnerability to alcohol-induced damage varies across cell types and tissues as well as across stages of fetal development. Anytime a woman drinks, the alcohol can influence whatever is developing in the baby at the time.

Because the central nervous system (CNS) and brain develop continuously throughout gestation, damage to these structures is the most disabling, though often the hardest to detect, feature of FASD. Damage to the brain structure impacts the brain’s ability to relay and integrate information within the brain.

The effects of prenatal alcohol exposure on brain development are as follows:

The behavioral, emotional, and learning difficulties of children with FASDs can best be understood as a deficit in processing information; recording information (bringing it in to the brain), interpreting the information, storing the information in memory for later use, and using the information to guide language and movement.

The damage to the brain caused by prenatal alcohol exposure mainly occurs in the parts of the brain that affect information processing. The hippocampus connects sensory and motor information from different parts of the brain. Damage to the hippocampus interferes with the child’s using sensory information (such as hearing) and connecting that information to a motor activity. This causes learning and memory problems. For example, asking a child to take a note to the teacher often will result in her taking the note to school, but she cannot remember what to do with it when she gets there.

Other alcohol-induced structural changes in the brain can occur in the corpus callosum, the section of the brain that permits the two major halves of the brain to share information. If this communication is interrupted, as it is in alcohol-exposed children, then some types of information can never reach consciousness. For example, a child can recite the rules for good behavior in the school lunchroom, but then cannot understand or follow them.

"OF ALL THE SUBSTANCES OF ABUSE, INCLUDING COCAINE, HEROIN AND MAJUANA, ALCOHOL PRODUCES, BY FAR, THE MOST SERIOUS NEUROBEHAVIORAL EFFECTS IN THE FETUS."
Finally, the thalamus receives input from all over the body and sends it to the cerebral cortex, the area of the brain responsible for cognition and learning. The thalamus helps organize behavior related to survival—fighting, feeding, and fleeing. This is why children with FASD often get a look of panic in their eyes when faced with a sudden change or threat or when they are overloaded with information. Parents describe the children as ‘not there.’ Also, the child does not learn from experience. Parents describe the child as “stubborn,” but the connections between past instructions or experience and current behavior just don’t exist.

It therefore can be seen that the behaviors demonstrated by children with FAS are a result of brain damage, not willful misconduct. When a child knows all his spelling words one day, and cannot spell a single word the next day, he often is accused of having “selective memory.” Instead, the child is having difficulty recording information and storing it for later use. This child will need special, often multi-sensory, clues to be able to remember the spelling words. The child who runs out into the street is not being disobedient. She simply has not made the connections between the words, “Do not run out into the street,” and the literal motor action. Thus, she will need clear structure (‘This is the boundary of our yard.’) to ensure her safety.

Source: Chasnoff

How FASD Affects Young Children

Because the central nervous system (CNS) and brain are developing throughout each trimester of pregnancy, deficits resulting from prenatal alcohol exposure are broad-ranging. Both brain structure and brain function are affected. Children may experience central nervous system impairments, motor abnormalities, neurobehavioral disorders, language disabilities, and behavioral manifestations.
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Source: FASD Center for Excellence
Primary Behaviors

The behaviors listed below, known as “primary,” are those that most clearly reflect underlying changes in brain structure and function. These behaviors are not intentional—they are the result of permanent brain damage. Note that the occurrence and severity of these behaviors will vary, and they are not exclusive to children with FASD.

1. **Compromised executive functioning**; may have difficulty planning, predicting, organizing, prioritizing, sequencing, initiating, and following through. Difficulty setting goals, complying with contractual expectations, being on time, or adhering to a schedule.

2. **Difficulty with memory**; information input, integration, forming associations, retrieval, and output. Difficulty learning from past experiences. Often repeats the same mistake over and over again in spite of increasingly severe punishment.

3. **Inconsistent memory or performance**; may remember on Monday but forget by Tuesday.

4. **Difficulty with abstract concepts** such as time, math, or money.

5. **Impaired judgment**; often unable to make decisions. Difficulty understanding safety and danger, friend from stranger; or differentiating fantasy from reality.

6. **Inability to generalize information**; difficulty forming links and associations, unable to apply a learned rule in new setting.

7. **Communication challenges**; appears to understand instructions, nods and agrees, but is not able to comprehend. Often repeats rules verbatim, then fails to apply them.

8. **Language problems**; difficulty comprehending the meaning of language and accurately answering questions. May agree or confabulate—comply or fill in the blanks. May talk excessively, yet be unable to engage in a meaningful exchange. The sheer volume of words may create the impression of competence.

9. **Slow cognitive pace**; may think more slowly, say “I don’t know,” shut down, or require minutes to generate an answer rather than seconds. Those with FASD are “ten-second people in a one-second world.”

10. **Slow auditory pace**; central auditory delays means language is processed more slowly, requiring more time to comprehend. Many children only grasp every third word of normally paced speech.

11. **Perseveration**; may be rigid, get stuck, have difficulty switching gears, stopping an activity, or transitioning to a new one. Often reacts strongly to changes in setting, program, or personnel.

12. **Dysmaturity**; often functions socially, emotionally, and cognitively at a much younger level developmentally than chronological age. A five-year-old may be
developmentally more like a two-year-old, a twelve-year old more like a six-year-old. Note: Dysmaturity is distinct from immaturity. Dysmaturity means a person is functioning at a younger developmental level where immaturity suggests the capacity to catch up with chronological age.

13. Impulsivity coupled with inability to abstract and predict outcomes; acts first and then is able to see the problem after the fact.

14. Sensory systems dysfunctions; may be over-reactive to stimuli—e.g., tactile defensiveness, may be easily overwhelmed by sensory input, may be unable to filter out extraneous stimuli, symptoms of which appear as increased agitation, irritability, or aggression. May be under-reactive to pain, may not complain of earaches, broken bones, and may be unable to experience painful stimuli.

Source: Malbin

Sensory Integration

The senses work together. Each sense works with the others to form a composite picture of who we are physically, where we are, and what is going on around us. Sensory experiences include touch, movement, body awareness, sight, sound, and the pull of gravity. The brain organizes the information the senses take in to make the information useful. The process of the brain organizing and interpreting this information is called sensory integration. Sensory integration provides a crucial foundation for later, more complex learning and behavior.

For most children, sensory integration develops in the course of ordinary childhood activities. Motor planning (e.g., what we would need to catch a ball) ability is a natural outcome of the process, as is the ability to adapt to incoming sensations. But for some children, sensory integration does not develop as efficiently as it should. When the process is disordered, a number of problems in learning, development, or behavior may become evident.

Signs of Sensory Integrative Dysfunction, also called sensory processing disorder, include hypersensitivity and/or hyposensitivity to touch, sound, smell, movement, visual stimuli; problems with muscle tone, coordination, motor planning; difficulty making transitions from one situation to another; may tire easily; complaining about how clothing feels (tags, socks); unusually high or low activity level.

The concept of sensory integration comes from a body of work developed over decades by psychologist and occupational therapist A. Jean Ayres. It is research supported, and literature from the fields of neuropsychology, neurology, physiology, child development, and psychology has contributed to theory development and intervention strategies.

In addition to FASD, sensory integration treatment assists persons with autism spectrum disorders, premature births, learning disabilities, brain injury and strokes. Parent to Parent
Secondary Behaviors

There is a poor fit between the child with an FASD and the environment, the child may develop defensive behaviors as a reaction to his or her frustration. These secondary behaviors can be prevented if the child is provided with interventions and environment that accommodate the brain based impairment of FASD. As with primary behaviors, this list is not unique to FASD.

1. Inappropriate humor; class clown.
2. Pseudo-sophistication; may echo words, phrases, manners, and dress in order to “pass” as competent beyond their actual ability, often to their detriment.
3. Fatigued, irritable, resistant, argumentative.
4. Anxious, fearful, chronically overwhelmed.
5. Frustrated, angry, defensive, destructive.
6. Poor self concept, often masked by unrealistic goals or self-aggrandizement.
7. Isolated, few friends, picked-on.
8. Family or school problems including fighting, suspension, or expulsion.
9. May run away or use other methods of avoidance.
10. Trouble with the law, addictions.
11. Depressed, may be self-destructive, suicidal.

Source: Malbin

Protective Factors

The prevalence of secondary behaviors, as well as secondary disabilities such as mental health problems, repeated school failures, and inappropriate sexual behavior, can be lessened or eliminated through protective factors. Five universal protective factors have been identified by a leading researcher in this field, Ann Streissguth:

- Living in a stable and nurturing home of good quality;
- Not having frequent changes of household;
- Not being a victim of violence;
- Having received developmental disability services; and
- Having been diagnosed before age six.

Early identification of the effects of prenatal alcohol exposure will result in effective assistance for the child and may prevent secondary behaviors. Early intervention services may enable the brain to build new connections that work around the damaged parts of the brain. As the child ages, the brain loses this plasticity.
Role of Early Childhood Professional in Identifying FASD

Parents are always a child’s first teacher. They may have recognized behavioral and learning issues much before any early childhood professionals are involved. Earliest signs may be poor feeding, poor sleeping, and difficulty calming the baby or a feeling of poor bonding with the parent. Parents may have any number of unanswered questions, and having a diagnosis may come as somewhat of a relief.

It is important that parents be fully engaged and able to grasp the issues and potential interventions for their child. Their feedback must be actively sought throughout the process of figuring out what works best with an individual child.

Usual Development

Every child is different. This chart gives general milestones in a child’s development. The information below lets you know what to expect. It will help you distinguish moments of usual development and areas where you may have a concern about an infant or young child’s progress.

At 1 month, most children...
- Lift head a little when lying on stomach
- Watch objects for a short time
- Make "noise in throat" sounds
- Stay away from annoying sensations such as cloth or blanket on the face

At 2 months, most children...
- Hold their head up (bobbing when supported in sitting position)
- Sometimes copy or respond to a smiling person
- Roll part way to side
- Make sounds of discomfort

At 3 months, most children...
- Lift head and chest when lying on stomach
- Recognize bottle or breast
- Smile when talked to
- Show active body movement
- Follow moving things with their eyes
At 4 months, most children...

- Hold head up for a long time without bobbing
- Laugh out loud
- Roll from front to back
- Like to play
- Grab an object held near their hand
- Make sounds when talked to

At 6 months, most children...

- Sit with little support
- Respond to a friendly voice with a smile or coo
- Roll from back to stomach
- Turn and look at sounds
- Change object from hand to hand and from hand to mouth

** when a 6 month old infant doesn’t do these usual development movements and you have concern about a child in your care…talk with parents and recommend that parents talk with their child’s pediatrician about their child’s development. It is possible at this time to recommend that parents call the New York State Growing Up Healthy Hotline (1-800-522-5006) and parents in New York City can call 1-800-577-2229.

At 9 months, most children...

- Sit alone and change position
- Say “mama” and “dada”
- Crawl
- Respond to people they know
- Respond to their name

** when a 9 month old infant doesn’t do these usual development movements and you have concern about a child in your care…talk with parents and recommend that parents talk with their child’s pediatrician about their child’s development. It is possible at this time to recommend that parents call the New York State Growing Up Healthy Hotline (1-800-522-5006) and parents in New York City can call 1-800-577-2229.
At 12 months, most children...
- Pull themselves to stand and may step with support
- Can nod their head to signal "yes"
- Give love
- Pick things up with thumb and one finger
- Say two or three words

** when a 12 month old infant doesn’t do these usual development movements and you have concern about a child in your care…talk with parents and recommend that parents talk with their child’s pediatrician about their child’s development. It is possible at this time to recommend that parents call the New York State Growing Up Healthy Hotline (1-800-522-5006) and parents in New York City can call 1-800-577-2229.

At 15 months, most children...
- Walk without support
- Do some self-feeding
- Speak and make their voice go up and down
- Drink from a cup held by someone
- Use four or five words

** when a 15 month old child doesn’t do these usual development movements and you have concern about a child in your classroom…talk with parents and recommend that parents talk with their child’s pediatrician about their child’s development. It is possible at this time to recommend that parents call the New York State Growing Up Healthy Hotline (1-800-522-5006) and parents in New York City can call 1-800-577-2229.

At 18 months, most children...
- Walk (may run a bit)
- Use five to ten words
- Climb up or down one stair
- Pull toys that have wheels
- Mark on paper with crayons
- Understand easy directions
**when a 18 month old toddler doesn’t do these usual development movements and you have concern about a child in your classroom...talk with parents and recommend that parents talk with their child’s pediatrician about their child’s development. It is possible at this time to recommend that parents call the New York State Growing Up Healthy Hotline (1-800-522-5006) and parents in New York City can call 1-800-577-2229.

At 2 years, most children...
- Give toys when asked
- Recognize a familiar picture and know if it is upside down
- Kick large ball
- Turn pages in a book (two or three at a time)
- Use two or three words together, such as "more juice"

**when a 2 year old child doesn’t do these usual development movements and you have concern about a child in your classroom...talk with parents and recommend that parents talk with their child’s pediatrician about their child’s development. It is possible at this time to recommend that parents call the New York State Growing Up Healthy Hotline (1-800-522-5006) and parents in New York City can call 1-800-577-2229.

At 3 years, most children...
- Walk up stairs holding railing
- Unbutton large buttons
- Stand for a moment on one foot
- Talk of toilet needs
- Open doors
- Stack objects by size
- Ask and answer simple questions
- Speak clearly and are understood by family members

**when a 3 year old child doesn’t do these usual development movements and you have concern about a child in your classroom...talk with parents and recommend that parents talk with their child’s pediatrician about their child’s development. It is possible at this time to recommend that parents call their local school district for an assessment.
At 4 years, most children...

- Can hop in place
- Throw a ball above their head
- Wash hands without help
- Copy a circle
- Begin to play with other children
- Know their own sex, age, last name
- Answer out loud to "Hi" and "How are you?"
- Point to six basic colors when asked

** when a 4 year old child doesn’t do these usual development movements and you have concern about a child in your classroom…talk with parents and recommend that parents talk with their child’s pediatrician about their child’s development. It is possible at this time to recommend that parents call their local school district for an assessment.

At 5 years, most children...

- Run on tiptoe
- Understand "yesterday" and "tomorrow"
- Print a few capital letters
- Know their name in print
- Use sentences with correct grammar, such as, "May I go to the store?" or "I want a big cookie."
- Play together with others
- Put their shoes on the correct feet

** when a 5 year old child doesn’t do these usual development movements and you have concern about a child in your classroom…talk with parents and recommend that parents talk with their child’s pediatrician about their child’s development. It is possible at this time to recommend that parents call their local school district for an assessment.

IITinois Child Find
What to do if You Suspect FASD and How to Approach Parents.

As child serving organizations, early care and learning programs recognize the importance of the first years of a child’s life. In the first three years, particularly, children grow very quickly and have so much to learn. Clearly, getting help early can make a major difference!

If program staff suspect that a child is not performing at the same level as his or her peers, the parents may have also noticed the delays. Parents can be advised to talk to their health care provider or to call (if the child is under age three) the local Early Intervention Program (EIP) or the local school district (for children over age three). The New York State Growing Up Healthy Hotline (1-800-522-5006) is open twenty-four hours-a-day and seven days-a-week and can help direct parents. Parents in New York City can call 1-800-577-2229.

Here are some other hints that can be given to parents:

• When calling their pediatrician or health care provider to schedule a visit, they should tell the receptionist that there are concerns about the child’s development. Early childhood professionals can talk with the parent about how to make a phone call to their provider to get the child checked and can practice with the parent what to say about their concerns.

• If the child is under age three, the parents may elect to call Early Intervention (EI) directly. The Early Intervention Program is located within their local Department of Health (for your local EI program, contact: bei@health.state.ny.us / 518-473-7016). They can request that EI screen the child at day care or preschool or at home.

• Once the child has turned three, he/she is eligible for care from the local school district. In that case, parents will be asked to request a formal evaluation to get started.

Reaching the diagnosis of FASD can be devastating for a family, especially for the mother. Staff should remain sensitive to the mother’s feelings and not contribute to the guilt she may carry. One reason often given for under-diagnosis of FASD is the stigma attached to this disability for the mother and for the child. It might be helpful to staff to remember that even if a mother stopped drinking as soon as she learned she was pregnant, damage may have occurred before that time. Initial conversations should occur one-on-one, so that the mother does not feel confronted or overwhelmed by a committee.

Reaching a diagnosis can often be very helpful to the family. It can reduce the frustration that occurs when the parents or caretakers don’t have a good understanding of the child’s behavior. The diagnosis can bring them hope and understanding. They can then become more active partners in their child’s education and develop-
ment, which can increase the likelihood of positive outcomes. If there are siblings, these other children may benefit from the family’s new understanding of the effect of alcohol.

*Suggested Tools and Websites for More Information*

Ages and Stages Questionnaires (pre-school)
http://www.agesandstages.com/

Infant Toddler Sensory Profile

Wechsler Memory Scale
http://psychology.wikia.com/wiki/Wechsler_Memory_Scale

WISC-IV
http://psychology.wikia.com/wiki/Wechsler_Intelligence_Scale_for_Children

Delis-Kaplan Executive Function System (D-KEFS)
http://psychology.wikia.com/wiki/Delis-Kaplan_Executive_Function_System

Trail Making Test

Wisconsin Card Sorting Test
http://en.wikipedia.org/wiki/Wisconsin_card_sort

Stroop Color-Word Test
http://www.snre.umich.edu/eplab/demos/st0/stroopdesc.html

Controlled Oral Word Association Test
http://en.wikipedia.org/wiki/Verbal_fluency_test

NEPSY-II (NEuro-PSYchological)
http://en.wikipedia.org/wiki/NEPSY

Sensory Integration and Praxis Test (SIPT)

*inclusion of these tools and websites does not constitute formal recommendations but only to make early childhood professionals aware of the range of assessment tools that can be utilized in these situations.
Maternal Alcohol Use

Because a diagnosis of Fetal Alcohol Syndrome (FAS) requires the presence of measurable facial abnormalities, it is the only alcohol-related diagnosis that can be made in the absence of a confirmed maternal alcohol history. For diagnoses such as ARND, the clinician needs to confirm that the child was exposed to alcohol in utero.

Addressing alcohol use during pregnancy with the mother of a child who is experiencing difficulties can be uncomfortable. There may be situations where this conversation simply cannot happen. However, there can be many benefits if the parents understand the nature of their child’s disability:

- The parents may move from frustration and hopelessness to understanding and hope.
- The parents, program and/or doctor/pediatrician can effectively partner, eliminating any power struggles or blaming that may have occurred.
- Identified strategies can be implemented at home, reducing stress for the family.
- The child will experience a more positive learning experience, reducing secondary behaviors.
- The child’s future challenges can be better anticipated and managed, increasing positive outcomes in many life areas.
- Both current and future siblings of this child will benefit from the mother’s new knowledge about alcohol use during pregnancy.

In the initial discussion with the mother, focus on your desire to truly understand and help the child. Acknowledge that there is misinformation out there about the safety of alcohol use during pregnancy; some doctors still believe that small amounts are harmless. Even if the mother did not drink once she learned that she was pregnant, alcohol use can damage the developing embryo before the pregnancy is detected. Even small amounts are harmful—the mother need not be an alcoholic or “problem drinker” for her child to have an FASD. Keep in mind that the prevalence of FASD is not associated with the mother’s ethnicity, socio-economic, or educational level.

As FASD is the result of maternal alcohol use during pregnancy and is completely preventable, recognizing that she has caused her child’s disability can be devastating for a mother. Discussion should be one-on-one between the mother a school staff person that she knows and trusts. She should not be “confronted” by a
Red Flags and Recommended Tools

It may not be feasible, or even desirable, to address prenatal alcohol use with the mother and/or obtain a multi-disciplinary evaluation for FASD. Most children with an FASD have no visual signs of alcohol exposure and may have normal or above-average IQs. If the child has not been evaluated and maternal alcohol use is unknown, the program can still consider whether the child has an FASD when these red flags are present:

- Problems applying what has been learned, e.g., moving from rote recitation to problem-solving.
- Concrete thinking, e.g., doesn’t understand similes, metaphors, jokes.
- Responds to immediate feedback rather than distant consequences such as point or reward systems.
- Visual and “hands-on” learner rather than auditory.
- Multiple diagnoses and history of failed interventions (including medications and treatment).\(^\text{17}\)
- Diagnosed with a mental health disorder (such as ADHD, ODD, bi-polar) before grade school.
- Excluded from preschool or nursery school program because of behavior.

In choosing tools that will identify the types of issues experienced by children with FASD, remember many standard measures for academic achievement will only address cognitive functioning. The limbic system must also be addressed. For best results, work closely with an occupational therapist to implement assessments that measure adaptive behaviors, memory, executive functioning, and sensory integration.

To illustrate the evaluation process, here are the assessments and tests administered to the children we met earlier, and the results.
JAY (age 5) — During the CSE meeting, the team decides to place Jay in the least restrictive setting to see how he will do, and enrolls him in a regular full-day kindergarten. Sandi reluctantly agrees. The school psychologist has reviewed his records from Early Intervention and notes that Sandi is a recovering alcoholic. She makes an appointment to meet with Sandi alone the next week. They discuss the possibility that Jay’s problems may be connected to prenatal alcohol exposure. Sandi agrees to comprehensive neuropsychological testing for Jay, and arrangements are made.

The testing is completed and several issues are identified. Jay’s expressive language is at a 3 year-old level. He is easily fatigued and overwhelmed by environmental stimuli. He has difficulty comprehending multi-step directions. Jay does respond well to music, moving along with the beat and singing. In the meantime, Jay has not been doing well in kindergarten. He doesn’t participate in activities, and can’t stay awake in the afternoon.

JACK (infant) — The infant was seen by a FASD specialist in Buffalo who confirmed the pediatrician’s suspicions of a diagnosis of Fetal Alcohol Syndrome or FAS. Jack will be followed by Dr. Sherman, the pediatrician, and enrolled in early intervention services for sensory integration therapy with an occupational therapist. During Jack’s early intervention evaluation, the staff utilized the Infant-Toddler Sensory Profile, Brazelton Neonatal Behavioral Assessment Scale and the Bayley Scales of Infant Development to gauge Jack’s strengths and weaknesses. Together these assessments provided the early intervention team, and later Dr Sherman, a comprehensive picture of how Jack’s brain and body are developing and his reactions to several stimuli, which can help in formulating a treatment plan for Jack.

Jack is experiencing sensory integration problems that results in crying and waking himself up from naps, causing irritability. Bob and Ann have learned by experimentation what consoles Jack and are beginning to prevent such episodes of irritability. Some efforts that have calmed Jack down are decreasing the light in his bedroom when he is awake. Bob and Ann do not have the radio tuned to the oldies station as they have found that Jack is sensitive to the loud sounds in many commercials. They have also learned to wash Jack’s clothes twice with fabric softener in order to decrease the tactile contrast. Also, if the clothing has tags, they are careful to cut them out before putting them on him. They are also careful about what they choose for clothing and bedding—it has to be very soft.
**MIRANDA** has been attending her preschool for several months now and seems to thrive in the daily routine. She laughs often and is very affectionate with her teachers. She loves to play outside and dance to music at music time. However, Miranda has had several disruptive episodes during class transitions and she hit another child while playing with blocks.

Miranda’s lead teacher has recommended an assessment with the Early Intervention (EI) team of the local health department. She is concerned about Miranda’s delayed language development and continued disruptive behavior. Miranda’s parents are reluctant to call Department of Health for the testing and her mother seems overwhelmed with caring for the new baby, twice arriving late to pick Miranda up from preschool.

An early intervention testing session was scheduled for Miranda at morning drop off time so both parents could attend. The preschool arranged for a teacher to watch Miranda’s infant brother so her parents could concentrate on Miranda and the evaluation. The early intervention team consisted of a speech pathologist, a pediatric public health nurse, and an occupational therapist. They worked together and evaluated Miranda on a variety of gross and fine motor skills, language retention and pronunciation, and attention span. The EI team recommended speech therapy to help with Miranda’s language development and occupational therapy to help with transitions and positive social behaviors. These services could happen at preschool during regularly scheduled class time so Miranda would keep her same daily schedule of coming to and going from school.

This situation was beneficial to Miranda’s parents who did not have to re-arrange their schedules at this time. Miranda’s parents seemed more engaged in Miranda’s development and successes at school after the EI assessment. They continue to report mini-tantrums from Miranda but with less intensity and her mother mentioned that using techniques from the EI team discussions helped her a lot at home.

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**Planning for Success**

The child with FASD has brain damage. This is a physical disability with behavioral symptoms. The child’s behaviors are a symptom of brain dysfunction, not willful noncompliance. Understanding the reason for the behavior will help you to focus on accommodating the child, rather than trying to change or “fix” him or her. This approach has a greater likelihood of success.
This will be a paradigm shift in some early childhood settings. The student with FASD will not understand distant consequences of a reward system. Punishment for agitated behavior will be ineffective if the behavior is caused by over-stimulation. The child’s behavior is due to a lack of understanding, rather than non-compliance. All adults involved with the child must link the idea of brain dysfunction with presenting behaviors, reframe perceptions, and move from punishment to support.

**Partnering With Parents**

Families are experts when it comes to their own children. Educators and parents must work together and learn from each other to develop consistent support for students with FASD. Even if FASD has not been identified, the parents can provide valuable information on strategies that do and don’t work and help you to understand their child better. Discuss physical, behavioral, social, and learning strengths as well as concerns.

Create a family-centered, rather than professionally-centered partnership. In the former, parental decision-making and capabilities are promoted. In the latter, families are seen from a deficit perspective and needing help from the professionals. In a family-centered partnership, the educator might say to the parents “Your son has an aptitude for video games. How could we use this at school?” In a professionally-centered partnership, the educator says, “I don’t think you should let him play video games; he should do homework.”

Try these strategies if parents are reluctant to work with you:

- Maintain a positive, non-judgmental approach, even if the response seems negative.
- Continue to invite parents to come to pre-school.
- Ask for assistance from an agency that is involved with the family, such as social services.
- Offer to meet with the parents at a location of their choosing.
- Suggest parents invite someone to come to the meeting with them, such as a family member or parent advocate.

Research shows that most children are not diagnosed until ages eight to ten. This is unfortunate, because the years of maximum brain growth have preceded the diagnosis. We have to do better. Earlier diagnosis gives the child the best chance for positive outcomes.
Diagnosis can be made on the basis of:

- Facial abnormalities.
- Impaired prenatal or postnatal growth.
- Central nervous system (CNS) disorders.
- Behavioral disorders.
- Confirmed maternal alcohol use.

Misclassification often leads to inappropriate treatments and increased risk of secondary disorders. This can also lead to increased family frustration.

**Functional Behavioral Assessments**

A functional behavioral assessment (FBA) is a key element in designing behavioral strategies and supports for a child with FASD. It provides information on why the child engages in the behavior; when the child is most likely to demonstrate the behavior; and situations in which the behavior is least likely to occur.

A functional behavioral assessment should minimally include the following components:

- Identification of the problem behavior.
- Definition of the behavior in concrete terms.
- Identification of the contextual factors that contribute to the behavior (including affective and cognitive factors).
- Formulation of a hypothesis regarding the general conditions under which a behavior usually occurs and probable consequences that serve to maintain it.\(^{20}\)

In observing the child,

- Set aside judgment (e.g., she could do that if she tried harder).
- Consider all environmental influences. Take note of input from all senses – what the child hears, sees, and feels. See the world through the child's eyes.
- Consider the child’s feelings of fatigue, hunger, anxiety, or fear.
- Note on-off task behavior, task antecedents and consequences.
All FBAs need not be conducted with the same set of resources and procedures. The assessment should be individualized. For a student with FASD, it is critical that the FBA be comprehensive and is completed over several days and at various times in the day. The child’s functional status will vary—most children do better earlier in the day.

The FBA should identify the time of day, the task being completed, and what is happening in the environment at the point that the student experiences difficulty. This type of careful analysis pinpoints triggers for reactive behaviors. When there is recognition of exactly what sets off a problem, interventions can be found to ameliorate that trigger, hopefully before it even occurs. The focus is on ascertaining what environmental accommodation is needed to keep the child on task, and when it must be put into place.

FBAs should be conducted on a regular basis to assess the effectiveness of interventions and understand new behaviors.

**Occupational Therapy**

Sensory issues are present in virtually all children with FASD. At a minimum, a consultation with an occupational therapist (OT) is in order. An evaluation usually consists of both standardized testing and structured observations of responses to sensory stimulation, posture, balance, coordination and eye movement.

The OT can assist in identifying environmental factors that impact the child’s ability to succeed, and suggesting modifications. These may include changes such as providing a “wiggle cushion” to sit on or sound-blocking headphones. If sensory therapy is recommended, the child will be guided through activities (sometimes called a sensory diet) that challenge his or her ability to respond appropriately to sensory input. This active involvement and exploration enables the child to become a more mature, efficient organizer of sensory information.20

More information on sensory integration can be found on page 28.

**Neuropsychological Assessment**

Neuropsychological assessment is an evaluation of cognition, mood, personality, and behavior that is conducted by licensed, clinical neuropsychologists. The assessment process quantifies the patient’s higher cortical functioning that may include various aspects of attention, memory, speed of information processing, language, visuospatial ability, sensory processing, motor ability, higher-order executive functioning, and intelligence.21
When a comprehensive evaluation for FASD is conducted by a team of medical professionals, neuropsychological testing will be included. If the child has not received such an evaluation, you should consider obtaining a neuropsychological assessment, particularly if strategies already in place have proven ineffective. The assessment will determine if the child has a brain dysfunction that prevents the acquisition of learning material through traditional means, and provides a roadmap of this individual’s strengths and deficits. A neuropsychological evaluation provides a comprehensive view guiding medication management, behavior intervention and educational services. Though the cost for such an assessment can be high, this investment may ultimately save school resources that would be spent on ineffective, inappropriate interventions or placements.

Reaching a Diagnosis

As previously noted, FASD is not itself a clinical diagnosis—it is an umbrella term that describes the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.

An FASD can only be diagnosed by a licensed medical practitioner. Because the child’s presentation may meet the diagnostic criteria for a variety of physical and mental health disorders, a multi-disciplinary approach is recommended. The evaluation team should include a pediatrician, clinical psychologist, occupational therapist, and educational specialist. Assessments should include each body system that may have been impacted by prenatal exposure:

- Cortical – impacts cognitive and executive functioning.
- Limbic – involved with emotional reactivity, sensory input, motor regulation, attachment.
- Diencephalic – regulation of internal homeostasis, including sleep and appetite, and relay of sensory signals to other parts of the brain.
- Brainstem – autonomic functions such as heartbeat and respiration.

This thorough evaluation will identify the child’s strengths as well as underlying neurocognitive challenges.
It is likely that there are children with FASD in every community. While it is difficult to give a precise estimate, a community with 10,000 children might have 80 to 100 with learning problems related to FASD.

Getting a diagnosis is one of the key protective factors in preventing secondary behaviors and disabilities. A diagnosis identifies the disability and begins the process of developing appropriate, individually tailored interventions. Knowledge and understanding of FASD helps make sense of the challenges facing students with the disability.

Absent the physical characteristics associated with FAS, children with alcohol-related, organically-based brain problems are often never identified as having an FASD. The cognitive, behavioral, and language manifestations of alcohol’s effects are often attributed to disabilities such as attention deficit or general developmental delays.

At some time between the ages of 6 and 12 years, 94 percent of children with FASD are diagnosed with a mental health disorder.\textsuperscript{22} This is because there is considerable overlap between neurobehavioral symptoms of FASD and the symptoms of other diagnoses. The problem is that most mental health diagnoses describe behaviors and interventions target those behaviors. Treatments that attempt to change behaviors that are actually symptoms of FASD, rather than a mental health disorder, are inappropriate and ineffective.\textsuperscript{23} It is important to note that a child may have co-occurring FASD and mental health disorders.

The following chart gives examples of appropriate interventions for a child with FASD, compared to a child with attention deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD).
<table>
<thead>
<tr>
<th>Behavior Takes Risks</th>
<th>Core Cause of Behavior</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>FASD</td>
<td>Does not perceive danger</td>
<td>Provide mentor; utilize a lot of repeated role play</td>
</tr>
<tr>
<td>ADHD</td>
<td>Acts impulsively</td>
<td>Utilize behavioral approaches (e.g., stop and count to 10)</td>
</tr>
<tr>
<td>ODD</td>
<td>Pushes the envelope; feels omnipotent</td>
<td>Psychotherapy to address issues; protect from harm</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behavior Does Not Complete Tasks</th>
<th>Core Cause of Behavior</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>FASD</td>
<td>May or may not take in information; cannot recall information when needed; cannot remember what to do</td>
<td>Provide one direction at a time</td>
</tr>
<tr>
<td>ADHD</td>
<td>Takes in information; can recall information when needed; gets distracted</td>
<td>Limit stimuli and provide cues</td>
</tr>
<tr>
<td>ODD</td>
<td>Takes in information; can recall information when needed; choose not to do what they are told</td>
<td>Provide positive sense of control; limits and consequences</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Behavior Hits Others</th>
<th>Core Cause of Behavior</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>FASD</td>
<td>Someone told them to; misinterprets intentions of others; may sense bump as attack; may respond from history of abuse</td>
<td>Deal with misinterpretations at the time; one-to-one support</td>
</tr>
<tr>
<td>ADHD</td>
<td>Frequently an impulsive act</td>
<td>Behavioral approaches to address impulsivity</td>
</tr>
<tr>
<td>ODD</td>
<td>Plans to hurt others: misinterprets intentions of others as attack or impending attack</td>
<td>Consequences; cognitive behavioral approaches</td>
</tr>
</tbody>
</table>

Source: Dubovsky 24
The interventions identified for a child are individualized in accordance with the type and severity of difficulties displayed. Some children’s needs can be fully addressed through accommodations provided as part of a Section 504 plan. Others may require a detailed Individualized Family Services Plan (IFSP) or an Individualized Education Plan (IEP) that incorporates occupational therapy, environmental modifications, and special education services. If an IEP is developed, the disability classification used for a child with FASD is “Other Health Impaired.”

Every infant is different and the brain damage is unique to each situation and child. The “caregiver dance” with an infant is one of listening and responding to the baby’s cues. Easily overwhelmed infants may need to be swaddled and laid down in their crib in a darkened room without being rocked to sleep. Another infant may respond to soothing music as he is falling asleep. You will learn by trial and error with each child and it is helpful to take notes and compare with other caregivers, especially parents, what has worked well with each infant.

These are interventions that have been shown to work with fetal alcohol exposed infants:

1. Poor sleeping does occur with infants who have not been exposed in-utero and there are many techniques available for parents to try and strategies for taking turns while adult partners get some sleep and rest. How to swaddle—place the infant with his head in the corner of a square blanket, wrap the blanket securely around the infant with hands and feet inside. This snug blanket covering or swaddling can calm an infant and prevent flailing of arms and legs which may wake him up from a sleep.

STRATEGIES for parent and early childhood professional to work as team:

- Swaddle infant, hold infant and rock softly, walk gently around darkened room.
- Swaddle infant, sing lullaby or play soft music, begin soothing routine that parent/caregiver can follow.
- Swaddle infant and leave in crib in darkened room and minimize noise (perhaps with ‘white’ noise machine).
- Ask parents what has worked at home to sooth infant.
2. Poor feeding can occur with malformation of the mouth and chin and each infant may need unique intervention to improve the sucking movements for daily intake of milk. Infants are learning to comfort themselves and the self-regulation mechanism for an infant exposed to alcohol is off-kilter and must be helped in order for infants to learn to self-regulate. This is to be a theme among children exposed to alcohol during pregnancy, recognizing and learning self-regulation and self-awareness of bodily functions.

STRATEGIES for parent and early adulthood professional to work as a team:

- Wet fingers with milk, let infant suck fingers, continue offering nipple/bottle, wet cloth and drip into infant's mouth.
- Offer pacifier shaped like nipple or bottle nipple, continue offering nipple/bottle.
- Signs of dehydration are dry mouth, sunken eyes, reluctance to drink, cold hands and feet, high fever, and/or inability to cry or urinate. Call for emergency help or go to the doctor immediately when any of these signs appear.
- Ask parents what has worked at home to soothe infant.

3. Poor attachment may be seen in infants with poor feeding and poor sleeping habits due to the lack of positive feedback that parents receive from the infant, there may be less hugging and affection because of these deficiencies and internalized negative parental thoughts. However, poor attachment can occur with the best of parenting intentions and its origins remain a mystery as attachment improves and parents are able to realize smiles and recognition from their infant.

STRATEGIES for parent and early childhood professional to work as a team:

- Hold infant for periods of time and let infant sleep, awake and feed in arms.
- Swaddle infant and keep calm, rock gently.
- Spend time with infant with calm, safe and secure movements.
- Offer affection, routine and calmness to reassure infant and provide for his or her needs (food, safety & love).
- Ask parents what has worked at home to soothe infant.
The next set of interventions are general tips for how to work with an alcohol exposed toddler and/or older preschool age child. Each child may need an individualized plan in accordance with the type and severity of difficulties presented. Working with parents and other caregivers is essential for success and often includes practical improvements in daily lives of children. Transitions from preschool to another school or educational setting can be disruptive and challenging for child and parents, any information and guidance that you, an early childhood professional, can offer by writing up successful strategies and the child’s daily routines would be very helpful for the child’s next transition.

Every child is different, and much of what works with students with FASD may be learned through trial and error. Here are some general tips:

1. **Use literal terms.** Avoid words with double meanings, slang, and idioms (e.g., “school of hard knocks”).
   - “Think younger” when providing assistance, giving instructions, etc.
   - Teach abstract concepts with concrete materials (e.g., stopwatches, measuring cups, coins).
   - Use sensory stimulation, (e.g., to teach the color orange, wear orange clothes, paint with orange paint, cut orange paper).

2. **Be consistent.** Use the same words for key phrases and oral directions.
   - Keep symbols consistent, (e.g., a red circle with a line through it to designate what not to do).
   - Make sure all teachers and aides that work with the child are using the same words.
   - Use the same language for review and testing, (e.g., if you review using the question, “How are these things alike and how they are different?” don’t change the test question to “Compare and contrast these things.”)

3. **Repeat, repeat, repeat.** You may need to re-teach information multiple times.
   - Better yet, show, tell and repeat—quietly and patiently.
   - Give lots of response time between repetitions.
   - When you repeat, be sure to use the same language.
   - If the student forgets on Thursday what was learned on Monday, reassure him that it’s ok, and re-teach.
4. Follow a routine. Routine helps children with FASD know what to expect and decrease their anxiety.
   - If there will be a change in routine, such as a fire drill, discuss it ahead of time and practice the activity.
   - Post schedules using words and pictures.
   - Color code subjects in notebooks for organization.

5. Keep it simple. Students with FASD learn better in a simple environment with few distractions. One-to-one or small groups work best.
   - Set up an area where the child can go if he becomes overwhelmed. This area, sometimes called a comfort corner, should be soothing and quiet. It is never used for punishment.
   - Keep bulletin board decorations to a minimum.
   - Seat students so that they do not distract each other.
   - Ask a mature student to be a lunchroom buddy for a student with FASD.

   - Touch and count objects.
   - Cut worksheets into smaller strips so the child can work on a few problems at a time.
   - Highlight important points in textbooks for children.
   - Teach a new skill in the setting in which it will be used.

7. Provide structure. Structure helps students with FASD make sense of their world.
   - Use visual, musical, or physical cues to signal transitions.
   - Establish a pre-arranged signal with the child for you to know when he or she is upset.
   - Give notice at 10 minutes, then 5 minutes that the activity will be ending.
8. **Supervise.** Students with FASD can be naïve and gullible and lack social skills. They need constant supervision to develop patterns of appropriate behavior.

- Provide immediate feedback on behavior—distant consequences don’t work.
- Establish a resource room or other safe space for students to go before school or during recess if they have difficulty managing free time.
- Use role plays and skits to explore appropriate behavior.
- Have an adult close by on the playground to keep the student “grounded.”

Devising effective strategies often means thinking outside the box. An IEP may state that the child is allowed to chew gum to assist in maintaining focus. Instead of writing down the words during spelling tests, allow the child to recite the letters to the teacher. Schedule academic classes in the morning and hands-on classes (art, music, physical education) in the afternoon.

Some of the strategies that are effective for children with autism spectrum or developmental disorders will work for children with FASD, and vice versa.

To illustrate how accommodations are implemented, let’s look at the plans for our three students.

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**JAY (age 5)**—The CSE team meets again in November to review the results of Jay’s testing and his classroom adjustment. It’s clear that he is not learning in his current setting. A small class setting is identified at BOCES, and Sandi observes the program. Everyone agrees to try Jay there. In the BOCES class, the teachers quickly become attuned to his energy peaks and valleys.

When he has good energy, he receives instruction using manipulatives for math concepts, and sensory activities such as cutting numbers out of sandpaper and writing on the chalkboard. When he does not have energy, the teacher reads to him or he is or allowed to rest. The room is set up with different stations for instruction, quiet time, and projects. The teachers often talk to Jay in rhymes or with a sing-song voice that makes him perk right up and pay attention. Jay now enjoys school and is learning his letters and numbers. When the class went outside and dug up earthworms, he was related what he learned to his mom in great detail.

Sandi has joined an online support group, and is learning more about FASD all the time. She has shared information about FASD at her Alcoholics Anonymous meetings to encourage women to abstain from alcohol use during pregnancy.
**JACK (infant)**—Bob and Ann have put on hold their plans for another adoption to devote their time and energy to taking care of Jack. Ann has taken a leave of absence from her job to care full-time for Jack. Bob has concerns about how other children will treat Jack and is not sure he should plan on attending a big family reunion during the summer for fear the stimulation will set off Jack’s irritability for the whole weekend. Bob and Ann have discussed preschool options and decided to enter him in preschool, where he will be with other children and learn to socialize more. They have selected a Head Start instead of a local preschool, where they believe the staff is sensitive to Jack’s special needs.

This decision was not without some stress, Bob and Ann worry about how Jack reacts to other children and how other children react to Jack, and that Jack tend to believe that other children are being hostile when they are not. Bob & Ann recently found out that they would be exempt from the income guidelines because Jack is considered handicapped. Ann has joined a mothers’ group at church for support and both Bob and Ann have attended the adoption center’s post-adoption support group.

**MIRANDA** has not been diagnosed with an FASD but is receiving necessary supportive services during her preschool day. She is a playful and affectionate little girl. Miranda delights in looking at books with animals that are learning their ABCs just like she is in her classroom.

Her preschool teacher is concerned that Miranda will not qualify for these same supportive services when she turns three years old and has written up the successful strategies for the transition meeting. She also plans to talk with Miranda’s parents about changes and strategies to use at home.
INFANTS AND TODDLERS (AGES BIRTH TO TWO YEARS, ELEVEN MONTHS)
New York State Early Intervention Program is run by your local Health Department, usually part of the county government structure. Parents can call the New York State Growing Up Healthy Hotline (1-800-522-5006) and parents in New York City can call 1-800-577-2229. The screening and evaluation through the early intervention program would be free, offered at no cost to the parents, and can occur at home, at day care or at the health dept.

PRE-SCHOOL AGED CHILDREN (3 – 5 YEARS OLD)
The screening and evaluations would be conducted through the local school district. The screening and evaluation through the school district would be free, offered at no cost to the parents, and based on any difficulties or challenges that a child may have in learning in a preschool setting or processing information.

FASD SPECIALISTS
The doctors and professionals listed below would be able to add to these initial assessments or be able to provide more extensive evaluation with a FAS or ARND diagnosis and/or rule out of FAS, ARND for children being referred. It is common for a child to see more than one provider to get a comprehensive view of strengths and challenges that child will encounter in his or her life.

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Dr. Robert Marion (clinical geneticist) 718-430-8521
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**CAPITAL REGION**

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834 Kenwood Ave. Suite 3  
Slingerlands, NY 12159  
518-439-1641 / fax 518-439-1625  
www.childrensneuroservices.com

**NEW YORK CITY REGION**

Nelson J. Dorta, PhD  
Senior Attending Neuropsychologist @ St. Luke’s Roosevelt Hospital  
Director Neurodevelopmental Evaluation Service  
Assistant Professor of Medical Psychology & Child Psychiatry  
Columbia University College of Physicians & Surgeons  
1000 Amsterdam Avenue, 13 fl.  
New York, NY 10024  
917-539-6424

**HUDSON VALLEY REGION**

Also has an office in Mt Kisco (Hudson Valley)  
Neurodevelopmental Evaluation Service  
49 Smith Avenue  
Mt Kisco, NY 10549  
917-539-6424

**LONG ISLAND REGION**

**NORTH SHORE UNIVERSITY HOSPITAL**  
Center for Neuropsychological Services  
Dr. Barbara Wilson, (also with Dr. Prena Shah, Dr. William Matos)  
300 Community Drive  
Manhasset, NY 11030  
516-978-2886  
(Medicaid accepted)

**Dr. Paul Mattis**  
North Shore University Hospital  
Department of Neurology, Children/Adult Evaluations  
Great Neck, NY  
516-570-4455  
(Medicaid accepted)

**Dr. Keena Gyato, Neuropsychologist**  
Office in Northport, NY  
631-574-2284

**THERAPISTS**

**NEW YORK CITY**

Steven Alter, P.H.D. Psychologist  
110-45 Queens Blvd. Suite A2  
Forest Hills, New York 11375  
718-261-3363  
(also has Manhattan location)

**LONG ISLAND**

Dr. Jeffrey J. Felichrood  
Behavior Therapy Associates  
175 Jericho Turnpike, Syosset NY and  
228 Birch Drive, Manhasset Hills NY  
516-294-5000

Dr. Jennifer Ratas, Psychologist  
100 Manetto Hill Road  
Plainview, NY 11803  
516-528-4299
PARENTS & FAMILY SUPPORTS

Parents and extended family members are a child’s first teachers and mentors. It is important to get support for yourselves and talk about parenting and coping issues in safe, non-judgmental space with other parents and caring, well-trained therapists. It is common for parents of children with challenges to give and get support from other parents with challenges. Parent to Parent is one such organization that is available statewide in NY. There are similar organizations across the state. The resources list here are specifically related to support for families dealing with children with an FASD but you may find support in a different parent support group near you. Parents who understand what you’re going through can provide expert referrals and advice, as well as offer a sympathetic ear.

Fetal Alcohol Syndrome Support Network of NYC and Long Island (FASSN)
33-33 164 Street
Flushing, New York 11358
www.fassn.org

Jennifer Faringer, MS.Ed, CPP
Director, DePaul’s NCADD-Ra
1931 Buffalo Avenue
Rochester, NY 14624
(585) 719-3480 Fax (585) 423-1908
jfaringer@depaul.org or www.nydas.org
Provides community & professional education, resources and information, and hosts a Rochester-area Parent Networking Support Group

Helen Weinstein
Erie County Council for the Prevention of Alcohol & Substance Abuse (ECCPASA)
1625 Hertel Avenue
Buffalo NY 14216
716-831-2298 helwen@eccpasa.info
Operates Western NY Family Support Group

PARENTS AVAILABLE FOR SUPPORT & EXPERT GUIDANCE

Dianne O’Connor
dcoonno2@nycap.rr.com
518-376-1546 cell

Cindy Whitcomb
tcwht@鞍山.com
585-924-2444

POST-ADOPTION SUPPORT SERVICES AND REFERRALS

It is common for adoptive families to need support and services after adoption. Post-adoption services can help families with a wide range of issues. They are available for everything from learning how to explain adoption to a preschooler, to helping a child who experienced early childhood abuse, to helping with an adopted teen’s search for identity.

Experience with adoptive families has shown that all family members can benefit from some type of post-adoption support. Families of children who have experienced trauma, neglect, or institutionalization may require more intensive services.

POST-ADOPTION RESOURCE CENTER OF THE CAPITAL REGION

Parsons Child & Family Center
60 Academy Road
Albany, NY 12208
518-426-2888 / fax 518-447-5234
Provides post-adoption services as well as FASD support groups for families, including families with FASD.
Postadoption Services: A Factsheet for Families. 


Jane Aronson (International adoptions only) 
Director of International Pediatric Health Services 
151 East 62nd Street, Suite 1A 
New York City, NY 10021 
212-207-6666 / 212-207-6665 
www.orphanndoctor.com

NON-PROFIT ORGANIZATIONS
Susan Rose, Director 
The Fetal Alcohol Syndrome Support Network of New York City and Long Island 
33-33 164th Street Flushing, NY 11358 
Email: fassn_2@yahoo.com or www.fassn.org 
NOFAS Affiliate for NYC Metropolitan Area

Jennifer Faringer, MS.Ed, CPP 
Director, DePaul’s NCADD-Ra 
1931 Buffalo Avenue 
Rochester, NY 14624 
585-719-3480 / Fax 585-423-1908 
jfaringer@depaul.org or www.nydas.org

Helen Weinstein 
FADE Program 
Erie County Council for the Prevention of Alcohol & Substance Abuse (ECCPASA) 
1625 Hertel Avenue 
Buffalo NY 14216 
helenw@eccpasa.info 
716-831-2298

NYSARC, Inc. 
393 Delaware Ave 
Delmar, NY 12054 
www.nysarc.org 
518-439-8311 
A family-based organization working with and for people who have a developmental disability.

March of Dimes NYS Chapter 
Empire State home office 
212-353-8353 
March of Dimes 
1275 Mamaroneck Avenue 
White Plains, NY 10605 
National Office Phone: 914-997-5488 
Nationally recognized maternal and child health advocacy and educational organization. MOD seeks to improve the health of babies, by preventing birth defects, premature birth, and infant mortality through volunteer and peer-to-peer educational campaigns. 
There are six local divisions in NYS, to find a chapter office near you, go to: www.marchofdimes.com or Spanish language version: www.nacerosano.org.

NEW YORK STATE AGENCIES

NYS Office of Alcoholism & Substance Abuse Services (NYS OASAS) 
1450 Western Avenue 
Albany, NY 12203 
518-473-3460 
1-877-8-HOPENY or 1-877-786-7369 
www.oasas.state.ny.us/fasd 
OASAS has staff who provides information, resources, and trainings on FASD. Toll-free hotline can make referrals for adults & children to chemical dependency programs across NYS.

NYS Developmental Disabilities Planning Council (NYS DDPC) 
155 Washington Avenue, 2nd floor 
Albany, NY 12210 
www.ddpc.state.ny.us 
518-486-7505 
Assists New Yorkers with developmental disabilities receive the necessary services and supports.

NYS Office of Mental Retardation & Developmental Disabilities (NYS OMRDD) 
44 Holland Avenue 
Albany, NY 12229-0001 
(866) 966-9733 or TTY: (866) 933-4889 
OMRDD and its network of 800 not-for-profit agencies provide high quality, person-centered services, supports and advocacy to individuals with developmental disabilities and their families.
NYS Department of Health (NYS DOH) operates several programs that can be helpful:

**Early Intervention Program**
Corning Tower Building Room 208
Albany, NY 12237
bei@health.state.ny.us
518-473-7016
Contact information on local early intervention services across NYS.

**Congenital Malformations Registry**
547 River Street, Room 200
Troy, NY 12180
518-402-7990 / fax 518-402-7769
Maintains New York State's Birth Defects Registry for up to age 2.

**NYS Laboratory of Newborn Screening and Genetic Services**
Wadsworth Center, Room E-299
Albany, NY 12201
kbh02@health.state.ny.us
518-474-7148 / fax 518-473-1733
Contact information for genetic service providers/clinics across New York State.

**SPECIALIZED RESOURCES**

**Pregnancy Risk Network/The Ferre Institute**
A NYS Teratology Information Service
Toll Free: 1-800-724-2454
http://www.pregnancyrisknetwork.org/index.htm
The purpose of the Pregnancy Risk Network (PRN) is to increase healthy habits during pregnancy and decrease fetal risk. A Teratogen Information Specialist will answer questions about prenatal exposure and the impact on your pregnancy.

**Jane Aronson** (International adoptions only)
Director of International Pediatric Health Services
151 East 62nd Street, Suite 1A
New York City, NY 10021
212-207-6666 / 212-207-6665
www.orphandoctor.com

**The Children's Advisory Group** (Educational Consultants for Special Education Students-private)
Susan Lagar, C.S.W.
155 West 72nd Street Suite 201
New York, NY 10023
212-769-4644 (Ext. 103)

**Pius XII Youth and Family Services- Foster Boarding Home Program/Adoptions**
Robert Martinez, Program Director
188 W 230th Street
Bronx, New York 10463
718-562-7855 (main number) Camps also available.

**BOOKS**

**Fetal Alcohol Syndrome**
by Ann Streissguth

**The Out-Of-Sync Child: Recognizing and Coping With Sensory Processing Disorder**
by Carol Stock Kranowitz

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**Measuring Success**

Defining success for a child with FASD goes beyond academic measures. When a child is able to rise above a challenge caused by FASD, there is cause for celebration. In a younger child, success could be making a friend or engaging in interactive rather than parallel play. For an adolescent, developing an appropriate sense of humor or asking for help rather bursting into tears are signs of success.
Expectations and interventions for children with FASD must be geared to their developmental age, rather than their school grade or chronological age—but don’t let lowered expectations translate into assumptions that the child cannot learn or achieve goals. All children need to be challenged to reach as high as they can.

**Transition to School and Adulthood**

Because the brain damage is permanent, the child will not age out of the primary behaviors. Several studies have demonstrated the continuing adverse effects of prenatal alcohol exposure into adolescence and adulthood. Rates of secondary disabilities have been identified in a study of patients with FAS and FAE:

- **Mental health disorders** (over 90% of patients age 6 and over).
- **Disrupted school experience** (suspended, expelled or dropped out of school - 60% of patients age 12 and over).
- **Trouble with the law** (60% of patients age 12 and over).
- **Confinement** (includes inpatient treatment for mental health or alcohol/drug use as well as incarceration - 50% of patients age 12 and over).
- **Inappropriate sexual behavior** (50% of patients age 12 and over).
- **Alcohol/Drug misuse** (30% of patients age 12 and over).  

Avoiding these secondary disabilities may be considered success for some children and their families. A smooth transition from an early childhood program to a positive and supportive school environment will help.

Some children with an FASD may need to transition into supported living and employment settings. Others can go on to college or a trade school. Careful planning, support, and research of appropriate programs will be needed. The child will need a GED diploma—an IEP diploma is insufficient for higher education. Strong advocacy from the school and parents may be necessary to enroll young adults in higher education programs with the supports they need for success. Try this link for more information: [www.thinkcollege.net](http://www.thinkcollege.net)

Understanding the challenges that these children face, we sometimes forget that they also may have wonderful talents and skills. Adults with FASD have found success as artists, art teachers, chefs, and plumbers. Strengths such as empathy and understanding can lead to a career working with young children. Some children will do well in the military, where rules are clear and the environment is extremely structured.
Lifespan continuum and service transitions
Pregnancy

Non-pregnant and pregnant women are seen most commonly in the reproductive health clinics by medical personnel. Women planning for pregnancy and those who are not planning to be pregnant soon, require different clinical services yet many of the same health messages for keeping healthy and clinical screenings for protecting themselves from disease, both sexually transmitted and breast or uterine cancer are available.

Both groups of women, pregnant and those non-pregnant should receive education regarding the no safe use of alcohol during pregnancy. Pregnant women should receive additional education and screening for current use of alcohol and referrals to support services, if needed.

Labor and Delivery – one of the first transitions in our lives is when an infant is born. This transition is significant for the parents and provides an opportunity for clinicians to ensure appropriate services and support is given to mother and infant dyad. Mothers will receive education and support regarding breastfeeding and infants undergo several newborn screenings for birth defects and disabilities that modern science is able to detect at such an early age.

Infants and Toddlers - Birth to 2 Years, 11 Months

Infants grow steadily and there are routine doctor’s visits and immunizations to receive in the first year. Parents are offered assistance during this first year with parenting classes offering support on how to comfort, swaddle and handle poor sleeping patterns.

As young children grow and develop, parents may have certain concerns about their child’s growth and development. The local health department operates the Early Intervention program which offers a multi-disciplinary childhood assessment. This multi-disciplinary childhood assessment covers speech and language development, growth status, muscle tone and hearing and vision screens. This assessment can occur at any time before a child is three years old. Referral to services may mean that a speech therapist would come to the early learning center and work with the toddler one-on-one and/or with a small group of children experiencing speech and language delays.

Strategies for preparing the child and family for transition to the local school district system and potentially different services and service providers are important to ensure continuity of services, to bolster self-confidence of child and guide parents through this transition.
Children 3 – 5 Years

When a child turns three and there are parental concerns about growth or development, the local school district is the responsible party. This age, three years old, marks another transition on the lifespan continuum. Society expects three year olds to be in nursery or preschool, learning social skills along with the alphabet and colors. Teachers and early learning specialists form a team with the parents to monitor and support a child’s growth and development. When a teacher or parent has a concern about a child’s growth or development, a referral is made to the local school district, the jurisdiction where the family lives not where preschool is located, if located within another school district.

Services might include a part-time aide to help the child in the classroom to offer help for focusing on tasks and building individual skills. Each child’s individualized service plan will look different depending on the child’s needs and strengths. The child serving systems most likely to be involved in addition to those within the education system such as special education and BOCES are the Office for Mental Retardation and Development Disabilities (OMRDD) and Office of Mental Health Services (OMH).

Early Childhood Professionals view the span of birth to five years as extremely important in providing a solid foundation for future growth and development. These five years are crucial in that brain growth continues during this time as well as the visible body growth manifestations as an infant grows into a toddler and than a young child.

Children and Youth Ages 6 – 17 Years, 11 Months

As with younger children, the transition out of early childhood brings more growth and development and regular school attendance. Nursery school may be part-time, three days a week and kindergarten may be half days Monday through Friday. However, with the advent of first grade, the child is spending the majority of his and her day at school with teachers and peers. This transition is not highlighted on the continuum as it is not referring to a service system transition as the other transitions are signifying for the families. This age span from six years old to almost eighteen years old is the time that children and youth spend in elementary, middle and high school with experiences common to most US students yet unique to their communities. Children with a Fetal Alcohol Spectrum Disorder may require daily assistance and guidance to succeed in school. Vocational and Educational Services for Individuals with Disabilities (VESID) offers access to a full range of services (special education, vocational rehabilitation and independent living) programs that may be needed by persons with disabilities through their lives.
Adulthood – 18 Years Old and Older

The eighteenth birthday presents another transition in the service world; it is a sign for moving from the child and youth system to the adult system and to adulthood. The adult serving systems most likely to be involved are the Office for Mental Retardation and Development Disabilities (OMRDD) and Office of Mental Health Services (OMH). The office of Vocational and Educational Services for Individuals with Disabilities (VESID) offers access to a full range of services (special education, vocational rehabilitation and independent living) programs that may be needed by persons with disabilities through their lives. The preparation for transition to adult services should begin at 15 years of age.

Promising Approaches

There is some promising research that may lead to earlier detection of FASD in very young children. Researchers from Queens University found that measurement of children’s eye movements may be helpful in early detection of FASD before the appearance of symptoms. The measurement of eye movements appears to have many benefits, among them being that the tool is objective and less susceptible to cultural bias. Researchers found that children with FASD have specific eye movements that can be measured with eye movement testing. The movements are tracked with a video-based, head-mounted, infrared eye tracker. The data from the tracker is then analyzed with special software. The test has not yet been integrated into clinical assessment and screening protocols for FASD, but may be integrated after further testing validates the selectivity and sensitivity of the tool. Eye movement tracking has been tested in various geographic locations across Canada, and researchers are hopeful that this testing will soon be integrated into clinical determination of FASD and ADHD. The test is able to distinguish FASD from Autism Spectrum Disorders.27

A researcher in Canada has discovered that prenatal exposure of the unborn to alcohol can be detected by testing the meconium (first stool) of infants. Researchers found that 3.7 percent of infants had detectable evidence of maternal alcohol use.28

FASD children may attribute a hostile intent to the behavior of others. A three month course of teaching social skills to children may lead to improved developmental outcomes. Research shows that as children learn to read better and develop more social skills, they were less likely to believe people around them were hostile or negative, and less likely to lash out at others.29

A technique called Rehearsal Training has been shown to successfully improve the working memory span of children with FASD. This has potential for helping to ameliorate working memory difficulties and for supporting academic and developmental growth.30
Prevention is still the most promising strategy. Because we know that damage can take place prior to the woman even knowing she is pregnant, it is important to keep repeating the message and reminding women that 1.) women should stop drinking alcohol if they are thinking of getting pregnant; and 2.) no amount of alcohol, no matter how small, is considered safe while pregnant.

While we have attempted to gather evidence-based interventions and provide these above examples of emergent research and promising practices in the classroom geared to children with FASD, as an early childhood professional, you can stay engaged and educate colleagues and families through your center’s staff development and parent education campaigns.

Here are several websites to help you keep in touch with the FASD research and practice.

Resources

Provincial Outreach Program for Fetal Alcohol Spectrum Disorder. British Columbia Ministry of Education. Available at http://www.fasdoutreach.ca/

FASD Toolbox for Teachers http://www.dotolearn.com/disabilities/FASDtoolbox/index.htm


Reach to Teach: Educating Elementary and Middle-School Children with Fetal Alcohol Spectrum Disorders. http://www.fasdcenter.samhsa.gov/publications/reachToTeach.cfm


Sensory Integration Screening Questionnaire:
http://www.center4familydevelop.com/sensorychecklist.htm

The Centers for Disease Control and Prevention have FASD Fact Sheets available in English and Spanish.
http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/FASD_english_spanish.pdf. They also have information for pregnant women

The Early Childhood Learning Knowledge Center:
http://eclkc.ohs.acf.hhs.gov/hslc/ecdh/Health/HealthandWellness/HealthandWellnessFamilies/GettinganEarlyStartonFetalAlcoholSpectrumDisorders.htm


The ARC of the United States (A National Organization on Mental Retardation)
http://www.thearc.org

The Fetal Alcohol and Drug Unit (University of Washington)
http://depts.washington.edu/fadu

The Centers for Disease Control FAS Prevention Branch
http://www.cdc.gov/ncbddd/fas

Kleinfeld, J & Westcott, S. Anchorage AK: University of Alaska Press: These readable books give poignant, instructive and often positive experiences of parents, teachers, therapists and researchers with alcohol effected children, adolescents and adults. These stories give hope and intervention ideas.
ASD is a condition that can have profound impact on a child’s success in life, yet it is difficult to recognize, particularly when it co-occurs with mental health disorders. Even children with average intelligence scores seem to function at a lower level than would be expected, and inconsistent performance is common. The education system can do tremendous good by identifying these children and giving them the tools to succeed.

Remember:

• Children with an FASD can learn, but the process will be different.
• Use a skills-based approach.
• Use your imagination and creativity.
• If a strategy isn’t working, try something different. Don’t try harder, try smarter.
• Engage and empower the parents.
• Educate your pre-school community about FASD.

A Final Word

This booklet was created from the template of Take Another Look: a guide on fetal alcohol spectrum disorders for school psychologist and counselors developed by the Fetal Alcohol Spectrum Disorders Interagency Workgroup and previously published by the Council on Children and Families with funding from the US Department of Health and Human Service, Health Resource and Services Administration Early Childhood Comprehensive Systems Initiative.

The Fetal Alcohol Spectrum Disorders Interagency Workgroup collaborated with the New York State Head Start Training and Technical Assistance Network to produce Take a First Look: a guide on fetal alcohol spectrum disorders for Early Childhood Professionals.

Take a First Look: a guide on fetal alcohol spectrum disorders for early childhood professionals is published by the Council on Children and Families with Early Childhood Comprehensive Systems funding.

Please address all comments about this booklet to council@cef.state.ny.us.
Endnotes


5 Ibid.


9 Dr. Ira Chasnoff. Children's Research Triangle. Used with permission.


13 Ibid. p56.


16 Personal communication with Dianne O’Connor. October 2008.


22 Reach to Teach: Educating Elementary and Middle School Children with Fetal Alcohol Spectrum Disorders, DHHS Pub. No. SMA-4222. Rockville, MD: Center for Substance Abuse Prevention, Substance Abuse and Mental Health Services Administration, 2007.

23 Dr. Ira Chasnoff. October 18, 2007, Albany, NY.


25 Dan Dubovsky, SAMHSA FASD Center for Excellence. Used with permission.


27 Streissguth A, Barr H, Kogan J, Bookstein F. Primary and Secondary Disabilities in Fetal Alcohol Syndrome. 1996.


References

