



Take Another Look

A Guide on Fetal Alcohol Spectrum Disorders
for School Psychologists and Counselors

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.

Revised as of 5/1020

School psychologists and school counselors are key players in the success of students who are experiencing learning challenges. With connections to classroom teachers, 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 students.

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.

JOSH, 10, is currently in 4th grade and lives with his adoptive parents John and Linda. He was diagnosed with fetal alcohol effects (FAE) at age 2 ½ years of age. He entered the Early Intervention program at age 7 months due to physical issues. He started a school based program at 2 years of age and continued in the program until he transitioned to kindergarten as a student with special educational needs in speech and language along with physical and occupational therapy.

Josh is helpful and friendly. He is well liked by his teachers and peers. He is a sensitive child who needs encourage-

ment to take risks. He has begun having problems getting both his class work and homework completed, and his teacher is noticing that Josh looks flustered much of the time in class. In previous years he has made slow but steady gains in most areas of academics, including math, but he is falling behind this year. Josh's mother reports that Josh has shown no behavior problems at home until recently. He has become difficult at home when ask to do his homework, stating he doesn't like school. Many times he is unable to remember what he needs to do or forgets the materials he needs to complete his homework.

JANET, a pretty, petite 16 year old, lives with her adopted parents, Jack and Ann, along with her biological sister. Janet received a diagnosis of fetal alcohol syndrome (FAS) when she was 5 years old. She is currently identified by the CSE with an Emotional Disturbance. She has been hospitalized twice for dangerous behaviors. Janet is medically managed for a variety of psychiatric disorders.

Janet attends a remedial math class, where she receives one-on-one assistance as needed, however she is easily discouraged when she doesn't

understand the material. Janet has some difficulty when transitioning between classes, and she has been seen on multiple occasions facing her locker with her eyes closed and her hands over her ears between classes. The principal has been notified that Janet instigates fights on the bus on the way home. She meets with the school psychologist every other week for individual counseling. Yesterday, Janet burst into the psychologist's office and reported that she wanted to file sexual harassment charges against her science teacher.

Fetal Alcohol Spectrum Disorders

In 1973, United States researchers first recognized and named fetal alcohol syndrome (FAS).¹ 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.²**

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.³
- **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.⁴ 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.⁵
- **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, 1996*

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.

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“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.

“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.”⁹

Source: Chasnoff⁹

Recognizing FASD

Because the 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.

Area of Dysfunction	Symptoms
Central Nervous System Impairments	<ul style="list-style-type: none"> Below average intelligence Delayed milestones Motor abnormalities Neurobehavioral disorders Perceptual problems
Motor Abnormalities	<ul style="list-style-type: none"> Poor gross motor skills Delays in fine motor skills Hand tremors
Neurobehavioral Disorders	<ul style="list-style-type: none"> Hyperactivity Poor attention span Perceptual problems Poor impulse control
Language Disabilities	<ul style="list-style-type: none"> Late onset Delayed use of sentences Uneven expressive and receptive skills Low quality masked by high fluency
Behavioral Manifestations	<ul style="list-style-type: none"> Social inappropriateness Persistent temper tantrums Excessive friendliness Fearlessness Poor response inhibition Processing deficits Input-output, integration deficits Short-term memory loss Sensory hypersensitivity Perseveration

Source: FASD Center for Excellence¹⁰

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.

- | | |
|--|---|
| <ol style="list-style-type: none"> 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 students 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. | <hr/> <p>“THESE BEHAVIORS
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TIONAL—THEY ARE
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|--|---|

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: Malbin¹¹

Secondary Behaviors

When 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: Malbin¹²

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.**¹³

“WHEN 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.”

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.

Diagnosing a Fetal Alcohol Spectrum Disorder

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.

Benefits of Diagnosis

It is likely that there are children with FASD in every school system. While it is difficult to give a precise estimate, a school system with 10,000 students might have 80 to 100 students with learning problems related to FASD. Some of these children will have problems severe enough that they are best served in self-contained special education classes. The majority, however, will be enrolled in regular classrooms. Within this majority, some students with FASD will have resource room support, but many others will be unidentified and may be struggling to learn.¹⁴

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.¹⁵ 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.¹⁶ 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.

“AT SOME TIME BETWEEN THE AGES OF 6 AND 12 YEARS, 94% OF CHILDREN WITH FASD ARE DIAGNOSED WITH A MENTAL HEALTH DISORDER.”

Behavior: Takes risks	Core Cause of Behavior	Intervention
FASD	Does not perceive danger	Provide mentor; utilize a lot of repeated role play
ADHD	Acts impulsively	Utilize behavioral approaches (e.g., stop and count to 10)
ODD	Pushes the envelope; feels omnipotent	Psychotherapy to address issues; protect from harm
Behavior: Does not complete tasks	Core cause of behavior	Intervention
FASD	May or may not take in information; cannot recall information when needed; cannot remember what to do	Provide one direction at a time
ADHD	Takes in information; can recall information when needed; gets distracted	Limit stimuli and provide cues
ODD	Takes in information; can recall information when needed; choose not to do what they are told	Provide positive sense of control; limits and consequences
Behavior: Hits others	Core cause of behavior	Intervention
FASD	Someone told them to; misinterprets intentions of others; may sense bump as attack; may respond from history of abuse	Deal with misinterpretations at the time; one-to-one support
ADHD	Frequently an impulsive act	Behavioral approaches to address impulsivity
ODD	Plans to hurt others; misinterprets intentions of others as attack or impending attack	Consequences; cognitive behavioral approaches

Source: Dubovsky¹⁷

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 school 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 and school 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 the school's 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.

“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 team or during a Committee on Special Education (CSE) meeting. There is no place for blame or stigma. Once the disability is understood, it is time to move on and identify appropriate interventions so the child can succeed academically and socially. When a mother can move from guilt and pain to “Warrior Mom”, she will be her child's best advocate and a valuable partner with the school.¹⁸

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 school 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).¹⁹**
- **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.

Examples of recommended tools:

Ages and Stages Questionnaires (pre-school)

Infant Toddler Sensory Profile

Adaptive Behavior Assessment System (ABAS-II, 2003)

Wechsler Memory Scale

WISC-IV

Delis-Kaplan Executive Function System (D-KEFS)

Trail Making Test

Wisconsin Card Sorting Test

Stroop Color-Word Test

Controlled Oral Word Association Test

NEPSY-II (NEuro-PSYchological)

Sensory Integration and Praxis Test (SIPT)

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.

JOSH (age 10)—Because of Josh's current difficulties and his history of FAE, the school decided to complete a functional behavioral assessment (FBA) and consultation with the occupational therapist who worked with Josh last year. The school psychologist also talked with Josh, who said he's having a hard time understanding the work, and the teacher expects him to get things done very quickly. He forgets what the homework assignment is, and then the next day he has to stay inside during recess to make up the work.

Josh has an average IQ score of 95. The occupational therapist reports that in a one-to-one setting, his handwriting is functional but pacing is slow. Handwriting becomes illegible when he tries to rush to keep up the pace of the regular classroom. His expression is good, but the writing mechanics are weak. Josh has difficulty following along with reading from the text. Josh's math skills are inconsistent, with a below average rate of progress due to weak recall of previously learned concepts. Josh becomes very restless in the afternoon. Directions needed to be explained and repeated. Josh was not writing down his homework assignments.

JANET'S (age 16) IQ falls in the low average range with a full score of 87. Janet's Mathematic Composite score is in the below average range and her reading comprehension fell within the average range, although she began to exhibit difficulties when the reading passage required sequencing, predicting events and outcomes, recognizing implied cause and effect and drawing conclusions. Adaptive scales showed the highest level of maladjustment in the areas of somatization, social stress, interpersonal relations, and self reliance. The school psychologist and homeroom teacher spent some time reviewing Janet's earlier records and Individualized Education Programs (IEPs). They noted that she had been diagnosed with an FASD at age 5.

The principal interviewed several other students and an aide who were present in the science class when Janet alleged sexual harassment. They recalled that the teacher told Janet she looked very nice that day, and that Janet recoiled when the teacher accidentally brushed her as he walked down the aisle later that during the class.

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 educational 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.

Functional Behavioral Assessments

A functional behavioral assessment (FBA) is a key element in designing behavioral strategies and supports for a student with FASD. It provides information on why the student engages in the behavior; when the student 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 “wobble 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.²¹

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.²²

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. 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.

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:²³

- **Maintain a positive, non-judgmental approach, even if the response seems negative.**
- **Continue to invite parents to come to 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.**
- **Provide a single contact person at school, even if there are siblings in different classes.**
- **Try to partner parents with other parents.**

“ALL ADULTS WORKING WITH THE CHILD NEED TO UNDERSTAND THAT THE CHILD’S BEHAVIORS ARE A SYMPTOM OF BRAIN DYSFUNCTION, NOT WILLFUL NONCOMPLIANCE.”

Interventions

The interventions identified for a child are individualized in accordance with the type and severity of difficulties displayed. Some students’ needs can be fully addressed through accommodations provided as part of a Section 504 plan. Others may require a detailed 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 child is different, and much of what works with students with FASD may be learned through trial and error. Here are some general tips:²⁴

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 student 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 students 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.
6. Be specific. Say exactly what you mean. Give directions step-by-step. Break large tasks into smaller tasks. Use pictures, charts, or other visual aids. Show the student what to do.
 - Touch and count objects.

- Cut worksheets into smaller strips so the student can work on a few problems at a time.
 - Highlight important points in textbooks for students.
 - 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 student 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.

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 AA meetings to encourage women to abstain from alcohol use during pregnancy.

JOSH (age 10) is at the age when challenges for students with FASD become more evident. Language is more complex, problem-solving skills are emphasized more than the rote learning that applied in earlier grades. Learning by reading is difficult for many children with FASD. To assist Josh at this critical point in his education, he now attends special math and English classes. These classes are smaller in size, and co-taught by a special education teacher and a regular teacher. Josh receives one-on-one instruction, directions are given one at a time, and instructors break projects down into manageable steps.

The occupational therapist (OT) advised his classroom teacher to allow him to attend recess. Josh was not able to complete last night’s homework during recess any better than he could complete it last night, and he needed the physical activity to help settle into afternoon classes. The OT also spends time with Josh outside of the classroom working on

handwriting and keyboarding. To assist in writing assignments, Josh is allowed to use a computer to type rather than write if more than four sentences are involved. His teachers now write out all homework assignments on one sheet of paper for him to bring home. His homeroom teacher identified one of Josh’s peers, who likes Josh, to assist him in gathering the appropriate materials to bring home for homework assignments. Josh’s mother has also obtained a set of books for home use.

Because Josh will be entering the middle school in September, the school is beginning to write down the strategies that work for him so his new teachers can accommodate his needs. They are also planning opportunities for Josh to visit the middle school with his parents to become familiar with the layout prior to the planned orientation for all entering students. He will be provided with his schedule and be able to practice finding classrooms, restrooms, library and cafeteria.

JANET (age 16)—The CSE decided to again provide Janet with a one-on-one aide, a strategy that had proved successful when Janet was younger. The aide, a mother of a special needs child, was instructed by the team on helping Janet interpret non-verbal cues, identifying when she is becoming upset, keeping her on task, helping her organize her materials and time, and assisting her in the transition time between classes. Janet and her aide organized materials for each class into separate, color-coded bags in her locker so she can grab them easily. Janet's IEP specifies that she is allowed to leave the classroom with her aide for up to 5 minutes, once per period if she needs to regroup. A peer mentor was also identified to talk with Janet in a friendly way about socially acceptable behavior.

For the last period of the day, Janet was assigned to a study hall. She is

encouraged to use headphones to block out sound or listen to quiet music. This allows her to decompress from the day and quietly begin her homework. Complaints from the school bus driver have ceased.

Because students with FASD have permanent difficulty with the input, integration, storage and retrieval of information, abstract concepts such as social behavior are particularly difficult to grasp. The school psychologist began using her time with Janet to role play social interactions in a variety of settings, sometimes with the assistance of her aide or peer mentor. The school also discussed the accommodations that were made for Janet with all of her teachers. This has led to an educational initiative on FASD for all school employees, from the superintendent to the lunchroom staff.

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 than 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 students need to be challenged to reach as high as they can.

Transition planning

Because the brain damage is permanent, the student 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).²⁵

Avoiding these secondary disabilities may be considered success for some children and their families. A positive and supportive school environment will help. Independent living skills should be taught using the learning strategies that have proven effective in other areas.

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 student 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

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 students will do well in the military, where rules are clear and the environment is extremely structured.

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 process of the brain organizing and interpreting this information is called sensory integration. It is the organization of sensory information for on-going use. 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 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 ²⁶

A Final Word

FASD is a condition that can have profound impact on a child's success in school, 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 school community about FASD.**

Endnotes

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Resources

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“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>

Making a Difference – Working with students who have Fetal Alcohol Spectrum Disorders. 2006. Yukon Department of Education.

http://www.education.gov.yk.ca/pdf/fasd_manual_2007.pdf

Reach to Teach: Educating Elementary and Middle-School Children with Fetal Alcohol Spectrum Disorders.

<http://www.fasdcenter.samhsa.gov/publications/reachToTeach.cfm>

“Essentials of School Neuropsychological Assessment.” Daniel C. Miller. ISBN: 978-0-471-78372-5. February 2007.

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“Fantastic Antone Grows Up: Adolescents and Adults with Fetal Alcohol Syndrome.” Judith Kleinfeld and Siobhan Wescott (Eds). 2000.

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<http://www.center4familydevelop.com/sensorychecklist.htm>

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“Finding Perspective... Raising Successful Children Affected by Fetal Alcohol Spectrum Disorder”. 2005. Liz Lawryk and Parents Everywhere. ISBN 0-9737739-0-1.

Fetal Alcohol Spectrum Disorders Center for Excellence.

<http://www.fasdcenter.samhsa.gov/>

National Organization of Fetal Alcohol Syndrome. <http://www.nofas.org/>. NOFAS has developed a K-12 FASD Education and Prevention Curriculum:

<http://www.nofas.org/about/K-12Curriculum.htm>

FASLink Fetal Alcohol Disorders Society. <http://www.faslink.org/>

New York State FASD Resources as of May 2010

INFANTS AND TODDLERS

(AGES BIRTH TO 2 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.

PRESCHOOL 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 learning in a preschool setting or processing information.

CHILDREN AND YOUTH

(5 – 17 YEARS OLD)

The screening and evaluations would be conducted also 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 learning in an educational setting or in processing information.

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.

WESTERN REGION

Luther K. Robinson, MD

Director, Special Diagnostic Clinic
Women and Children's Hospital of Buffalo
140 Hodge Street
Buffalo, NY 14222
716-878-7530

Sandra H. Jee, MD MPH

Department of Pediatrics
Golisano Children's Hospital at Strong
601 Elmwood Avenue Box 777
Rochester, NY 14642
585-275-7813

NEW YORK CITY AND SURROUNDING METRO AREA

Robert Marion, MD

Paul Levy, MD and Dr. Samanich

Montefiore Center for Congenital Disorders-
Division of Genetics
3415 Bainbridge Avenue
Bronx, NY 10467

(Accept Medicaid and see children, teens, adults)

Dr. Sultan and Dr. Turner, Attending Physicians

Child Psychiatry Clinic
Harlem Hospital
506 Lenox Avenue
New York City, NY 10037
212-939-3129 (Medicaid accepted)

Kwame Yebua, MD, FAS Specialist

Columbia-Presbyterian Medical Center
Milstein 9 Garden N. Room 421
177 Fort Washington Avenue
New York City, NY 10032
212-305-6731 (Accepts Medicaid)

Dr. John Pappas, Geneticist

NYU Director of Clinical Genetic Services
 NYU School of Medicine
 212-263-5746
 e-mail: J.Pappas@med.nyu.edu

Children's Evaluation & Rehabilitation Center (CERC)

Rose F. Kennedy Center/Albert Einstein
 College of Medicine
 1410 Pelham Parkway South
 Bronx, NY 10461

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

**Dr. Lisa Shulman (developmental
 pediatrician)** 718-430-3901

HUDSON VALLEY REGION/NYC METRO AREA**Lawrence Shapiro, MD**

Regional Medical Genetics Center, Inc.
 19 Bradhurst Avenue
 Hawthorne, NY 10532
 914-593-8938 fax
 Capital Region Behavioral Evaluations

Tara Lane

Behavioral Health Intake
 Harvey Scherer, M.D.
 Behavioral Evaluations
 Center for the Disabled
 314 South Manning Boulevard
 Albany, NY 12208
 518-437-5732

NEUROPSYCHOLOGICAL EVALUATIONS**CAPITAL REGION****Paula Zuffante, Ph.D.**

Children's Neuropsychological Services, PLLC
 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, Ph.D.**

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
 1090 Amsterdam Avenue, 13 Floor
 New York, NY 10024
 917-539-6424

HUDSON VALLEY REGION**Nelson J. Dorta, Ph.D.**

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

**CAPITAL REGION
DEVELOPMENTAL PEDIATRICS**

Anthony Malone, MD
Developmental Pediatrics
7B Johnson Road
Latham, NY 12110
518-782-7733

Gary Griffith, MD
Developmental Pediatrician
CapitalCare Pediatrics Clifton Park
942A Route 146
Clifton Park, NY
518-371-8000
Dr. Griffith is an attending physician at The
Ellis-Bellevue Hospital complex in
Schenectady.

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. Felixbrod
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
516-528-4209

Vincent Guarrera, DSW & LCSW
20 Canterbury Rd. Suite 2000
Great Neck, New York 11021
516-829-9362

CAPITAL REGION

Jeanette Scotland, LCSW-R
10 McKown Road
Albany, NY 12203
518-229-4387
(Se Habla Espanol)

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 helenw@eccpasa.info
Operates Western NY Family Support Group

PARENTS AVAILABLE FOR SUPPORT & EXPERT GUIDANCE**Dianne O'Connor**

doconno2@nycap.rr.com
518-376-1546 cell

Cindy Whitcomb

tctwhit@juno.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.

Post-adoption Services: A Factsheet for Families. http://www.childwelfare.gov/pubs/f_postadoption.cfm, Child Welfare Information Gateway. (2005). *Postadoption Services: A Factsheet for Families*. Washington, DC: US Department of Health and Human Services.

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

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: 914-997-4488
 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.nacersano.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 1-877846-7369
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
 866-946-9733 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 518-402-7769 fax
 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 518-473-1733 fax
 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.orphan.doctor.com

The Children's Advisory Group (Educational Consultants for Special Education Students-private)

Susan Lugar, C.S.W.

155 West 72nd Street Suite 201

New York, NY 10023

212-769-4644 (Ext. 103)

Pius XI 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