

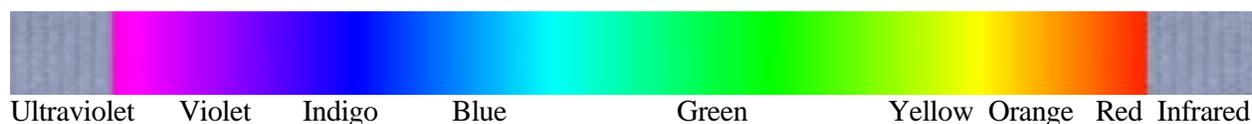
The ABC's of FASD

© 2003 Teresa Kellerman

This is an article that looks at **Fetal Alcohol Spectrum Disorders** on a basic level to help people learn and understand all the causes and consequences of **FASD**.

“ABC” usually makes people think of the alphabet and children in the early school years. But this article covers FASD during the early years before school and the teen and adult years as well as childhood. From beginning to end, from A to Z. It covers the whole spectrum of FASD. And the first idea I am going to look at is “spectrum.”

The easiest way to explain spectrum is to think of a rainbow, which is a spectrum of color made up of rays of light. When you look in the sky right after the rain stops and the sun starts to shine, if the rain is still coming down some other place, you might see a rainbow. At first glance it will look like just three or four colors, but if you look carefully, and if the rainbow is especially clear, you will see seven colors: Red, Orange, Yellow, Green, Blue, Indigo and Violet. And that’s just the visible spectrum of light, the colors we can see with our eyes.



But there are colors that we can't see, that are invisible – ultraviolet and infrared can only be seen by special instruments. Ultraviolet light is lighter than the lightest color that we can see, violet, and it comes from the sun. We cannot see ultraviolet light, but those are the light rays that can give us a sunburn if we stay out in the sun too long. Infrared light is at the end of the red end of the spectrum, beyond the red light that we humans can see. But special infrared glasses or goggles can let you see infrared light, because it is warmer than visible light. You cannot see infrared light, but you can feel it.

FASD is a spectrum because there are many types or “looks” of FAS, from full FAS with the “FAS look” and all the symptoms that will get the person an FAS diagnosis from a doctor, to partial FAS where the person may have some of the looks but not enough to get a diagnosis, to the invisible types of FAS that are not seen as FAS and are not called FAS, but they still are FAS because these persons have all the same problems as the other types. FASD covers the whole spectrum of Fetal Alcohol disorders because it includes all types, whether they are visible (recognized as FASD) or not. I think of full FAS as the red-yellow-green types of FAS, fairly easy to recognize and understand. I think of FAS combined with disabilities like cerebral palsy as Infrared, beyond FAS, more severe than typical FAS, that is not seen as FAS because the severe symptoms of paralysis or blindness cover up the symptoms of FAS. I think of FAE as Ultraviolet because the symptoms are not visible, it is thought to be either not serious or non-existent by some, just because it cannot be seen. But just like Ultraviolet light today can cause sunburn tomorrow or even cause cancer after years of exposure, FAE can cause serious secondary disabilities later, and can cause more problems for the individual than FAS does. This is how I see the spectrum of FASD:

Invisible types FAE or ARND	FAE or ARND with mental illness	FAS with normal looks and IQ	FAS with some facial features, normal IQ	FAS with some facial features, retardation	FAS with face but with normal IQ	FAS with face and mental retardation	FAS with other serious physical disorders
-----------------------------------	---	--	---	--	---	---	--

The alphabet is a spectrum - it goes from ABC to DEF all the way to XYZ. When you hear the letters “ABC” you automatically think of “ABCDEFGH...” and so on. You only hear three letters, but you know that means all 26 letters of the alphabet.

ABCDEF GHIJKLMNOPQRSTU VWXYZ

When most people see the letters FAS, they are thinking of the full FAS with facial features, mental retardation, short height, and so on. But FAS really should be thought of as the full spectrum of FASD, which includes what some people call the “alphabet soup” collection of disorders: FAS/E, FAE, pFAS, ARND, ARBD, plus “alphabet soup” of all the possible mental health (MH) disorders like ADHD, ADD, ODD, RAD, SID, CAPD, OCD, and other related disabilities like MR and CP. (See FASD glossary)

ABCDEF GHIJKLMNOPQRSTU VWXYZ

FASD Glossary of Acronyms
(Terms abbreviated or shortened by using just the initial or first letter):

- ADD = Attention Deficit Disorder
- ADHD = Attention Deficit Hyperactive Disorder
- ARBD = Alcohol Related Birth Defects
- ARND = Alcohol Related Neurodevelopmental Disorders
- CAPD = Central Auditory Processing Disorder
- CP = Cerebral Palsy
- FAE = Fetal Alcohol Effects
- FAS/E = Fetal Alcohol Syndrome and Effects
- FAS = Fetal Alcohol Syndrome
- MH = Mental Health
- MI = Mental Illness
- MR = Mental Retardation
- OCD = Obsessive Compulsive Disorder
- ODD = Oppositional Defiant Disorder
- PEA = Prenatally Exposed to Alcohol
- SID = Sensory Integration Disorder

The ABC’s of FAS can be seen in another way. Sometimes the **ABC** can stand for **Always Be Careful** – which is good advice for individuals with FASD and their parents. The reason that individuals with FASD need to be even more careful than people who are not affected is that the ability to make decisions is messed up, and they are more likely to make decisions that could get them into trouble or cause someone to be hurt, including themselves. That is why we say that people with FASD are at high risk. The ability to make decisions is called “judgment” and poor judgment is something that is sometimes seen in people with FASD. There are lots of difficulties, but this one, poor judgment, might be the most important, because it is not always seen or understood, and is likely to cause a lot of problems. This is one of many problems with FASD and is one that can have really awful consequences. It is important to understand causes and consequences of actions and behaviors, if we are to help the person with FASD.

The ABC's of FASD Behavior

© 2003 Teresa Kellerman

ABC can stand for Antecedent-Behavior-Consequence. This is a term used by child psychologists for a method of solving behavior problems. I think this can be used to understand many problems with FASD. What does the term mean? Let's analyze it (look closely at the details).

A is for Antecedent, which means something that happens before the behavior. This gives us clues as to the possible causes of the behavior or problem, to the reasons why the behavior or problem occurs in the first place. When we see a child suddenly jump up and scream "Ahh!!!" every few minutes, we want to figure out why that is happening. If we look at the antecedents (events that happen before) of this behavior, we might find that the child's playmate is clobbering him over the head with a toy, or that he ate extra helpings of snack and might now have a tummy ache with pains every few minutes, or that no one is paying attention to him until he hollers. But we cannot assume it is any one of these factors, because it could mean more causes are behind the behavior than what we see. When we perceive a behavior (see, hear, or feel something happening), sometimes we assume we know the cause (take a good guess), but there is usually many causes behind the behavior that we need to look at to really understand the problem.

B is for Behavior, whatever it is the person is doing that is causing a problem. This is the first thing we notice, before we look at the before and after. We just see the behavior. Sometimes the behavior is perceived (seen) as a problem. But sometimes we have to ask ourselves, "Whose problem is it anyway?" Is it the child's problem? Only if it is causing discomfort or stress for the child. Maybe yelling suddenly doesn't bother the child, and might even relieve some stress for the child. But the behavior might cause discomfort or stress for others, like parents or teachers. So it can actually be the other person's problem, not the child. It does become the child's problem if he has to suffer a consequence like being put in detention, or losing friends, or having a parent yell or take away toys or give some other consequence. Which brings us to the last part of the term.

C is for Consequence, which in this case means whatever happens afterwards as a result of the behavior. It could be an imposed consequence (done on purpose by someone), like being sent to the bedroom, or having toys or privileges taken away. Or it could be a natural consequence, like having a parent or teacher get angry, or having friends choose to stay away, or getting hurt or feeling pain, or any number of consequences that will happen naturally, without anyone intending to make it happen.

Antecedent >>>>>>>>>>	Behavior >>>>>>>>>>>	Consequence
Lisa runs and jumps too much>>>>	Lisa falls down and gets hurt>>>>	Mom hugs and holds Lisa
Tommy bops Johnny on the head>>>>	Johnny hollers and yells>>>>	Teacher scolds Johnny
Mandy eats too many sweets>>>>	Mandy throws up at the table>>>>	Mom sends Mandy to bed

These are very simple examples, and sometimes it is a good idea to look at more antecedents (causes) than the obvious ones. In the examples above, if we know that these children have FASD, we might look at the disorders associated with FASD as possible additional causes. In Lisa's case, her excessive activity could be caused by ADHD (Attention Deficit Hyperactive Disorder) that causes her to be hyper sometimes. She may also have poor motor skills that keep her from being coordinated well enough to avoid getting hurt. After getting hurt over and over, and getting her mother's affection and attention over and over, Lisa might learn (without really being aware of learning) that the more often she gets hurt, the more affection she will get from her mother. The mother might be more aware of her poor motor skills as the cause, and a psychologist or teacher might be more aware of the attention-getting factor, when it really is a combination of these two factors, and probably other factors too. It's important for everyone to remember that there are many factors (reasons) that could be connected to the behavior or problem.

Sometimes a consequence for one behavior can be an antecedent for another behavior. In the case of Lisa getting hurt frequently, the consequence is that her mother gives her loving attention and soothes her. This can be the cause of another problem, if Lisa starts to pretend to be hurt or gets hurt on purpose just in order to get attention from her mother. This can lead to another consequence. If the mother is interrupted from other work too often, she might become frustrated and get angry with Lisa, especially if she learns that Lisa is only pretending to be hurt. It can also lead to a consequence for the mother if another person criticizes her for being overprotective with her child or spoiling her child with too much attention. When we follow one behavior to see the consequence, and then follow that action to see a possible consequence, and keep doing that, we can understand better how one action can have many consequences, and that consequences in the future might not even seem to be connected to the behavior that started the first consequence.

And we can also look at the antecedent (cause) of the behavior and see if we can find the cause of that factor, and the factor behind that factor, and so on. I took a class one time that taught how to find the basic cause of a problem. The instructor said to write down the problem, then ask “Why?” Write down the reason, then ask “Why?” for that reason. Then write down that reason, and ask “Why?” again, and again, and eventually the same reason will begin to show up several times.

In the first example above, what is the behavior we see? Lisa is always getting hurt. She falls down a lot, bumps into things, is always crying and complaining that something hurts. When we use the ABC analysis, we first ask “Why?” Because she is hyperactive. Because she has poor coordination. Because she tends to get out of control on the playground. Because she wants to get her mother’s attention. Because she gets pushed down or bumped into by other kids. Ask “Why” for each of these antecedents. She is hyperactive because she has ADHD, she is not on medications for ADHD, she has a diet that includes too many artificial additives. She has poor coordination because the connections from her brain to her hands and feet don’t work very well. She gets out of control on the playground because she gets overwhelmed easily, she is very sensitive to noise and touch, and because there is not very much supervision. She wants to get her mother’s attention because there are not too many ways to get positive attention from a busy mother and there are not very many positive behaviors that get positive attention. She gets pushed and bumped by other children because she is not as physically mature and not as socially mature, the other kids are bigger and act older and are not patient with a playmate that acts like a little kid. See how many reasons are behind the reasons? The antecedents have antecedents. Let’s take it a step further. Ask “Why?” Lisa has ADHD because she is alcohol affected. Lisa has poor coordination because she is alcohol affected. Lisa gets overwhelmed and is over sensitive because she is alcohol affected. Lisa has immature social development because she is alcohol affected. After analyzing this one behavior of falling down and getting hurt, we see many causes that all point to FASD, and we see many consequences that cause more and more problems for many people, that are often not thought of as having anything to do with the FASD. But they do!

Antecedent	Antecedent	Behavior	Consequence	Consequence
Lisa was exposed to alcohol before birth	Lisa has poor physical and social skills	Lisa falls down and gets hurt often	Lisa gets extra attention from her mother	Lisa’s mother is thought to be over-protective

Why is it important to understand all the causes of a problem? Because this kind of analysis can help us find solutions. If we can identify the antecedent (cause), then maybe we can make changes in the child’s life that can prevent the problem from happening in the future, or at least help it to not occur so often. We can start to think about intervention strategies – a plan to prevent problems or solve problems in the best way possible.

The ABC's of Intervention Strategies

When we look at the spectrum of different disorders that make up the full range of Fetal Alcohol Spectrum Disorders (FASD), we see that there are different factors or parts that make up the disorder, and that not all persons have all the symptoms. Some affected persons might have the FAS face, others do not. Some might have mental retardation, others have normal intelligence. Some might have mental health disorders, others do not. Some might have short statures, others do not. Some might have had an early diagnosis, others do not. These factors all affect the outcome of the person's life. Each person has a different set of symptoms and problems that are unique to that one person. So it is difficult to put together a set of intervention strategies that would apply to all persons with FASD. Even when a parent or an adult with FASD reads everything they can about the disorder, it will still be hard to figure out what is the best thing to do when there are problems. I have found the easy, simple answer is this:

WHATEVER WORKS!

It's almost too easy, but it's not as simple as it looks. But it is a good rule to follow. Keep in mind that this rule means "Whatever Works" if it is safe, has good results, and does not make more problems for the person or for others, and is based on good common sense. When the person with FASD is trying to figure out a solution to their problems, it is better to check with a wise parent or teacher or mentor for help in making these decisions, because common sense isn't always there and poor judgment is an area where many people with FASD have a problem, and sometimes they don't even know that, until later when their decision leads to more problems, then it's too late. So it's better to check it out with someone else first.

This leads me to the three simple rules that I have made for John to follow to help him find success in what he does and to help him prevent problems. These are the ABC Rules of Success for Individuals with FASD, which can be helpful to all persons with any of the types of disorders along the spectrum:

ABC Rules of Success for FASD

Ask for help

Be respectful

Communicate your needs

Ask for help. This is easy to agree with, but it is hard to do. People with FASD often do not have as many freedoms and privileges as non-disabled people. They want to be independent as much as anyone else, but they don't have the ability to make good decisions sometimes, so the people who love them often put many restrictions in place. This can be frustrating for everyone, and can cause the person with FASD to feel like there are no freedoms or privileges. Persons with FASD will want to do things by themselves, and will think they can manage things on their own. Sometimes they are successful, and sometimes they aren't. Too often, when they make the wrong decision, and get hurt or get into trouble, the person loses even more privileges and has even less freedom than before. So in order to get as much freedom as possible and to stay out of trouble as much as possible, to avoid making too many mistakes, it is a good idea to ask for help before the mistake is made. Even people who are very smart and talented will ask for help when they are not sure. It is good for individuals with FASD to ask for help, whether they are children, teens or adults. It is good for parents and teachers and professionals to ask for help. It is a sign of wisdom and maturity to ask for help when help might be needed. The trick is to know when to ask for help. With FASD this is even more tricky, because the person with FASD might think they know what they are doing and might want to think they can handle things themselves. But if a person is honest and looks at how many mistakes they have made and how much trouble those mistakes have caused, it makes

more sense to ask for help to avoid making a mess of things. So, if you are not sure, ask for help. If it's the first time you are trying something, ask for help. If you have had problems with this situation in the past, ask for help. If you are confused, ask for help. If you are scared, ask for help. If you are feeling stressed, ask for help. If a voice in your head says, "I can handle this by myself, I don't need help," then you probably need to ask for help. If there is a split moment between the idea and the action where you wonder if you should do something or not, ask for help. I simplify this for Johnny by telling him, "Always ask for help." That takes all the guessing out of the decision. He will never get in trouble, or get criticized or teased or get a consequence for asking for help. He will get praised, because this is a sign of maturity and responsibility and wisdom. John might not always have good judgment, but he is often wise, and shows how smart he is when he asks for help.

Be respectful. The number one rule in our house is **RESPECT**. This is important for many reasons. But first, let's talk about what respect is. Respect is good manners when you are talking to others, when you are playing, when you are working, when you are at home with your family, when you are at school or work, when you are in public. Respect is more than good manners and being polite. Respect is listening when someone is talking. Respect means expressing your anger or frustration without using bad words or calling names or putting people down. Respect means not being mean back when people are mean to us first. Respect means not getting too close to someone. Respect means taking turns and being patient when you have to wait for others. Respect means trying to not have an "attitude" – especially with parents and other authority figures (teacher, boss, police officer). Sometimes it is hard for the person with an "attitude" to know when they have an "attitude." A good way to know if you have an "attitude" is if someone tells you that you have one. And they usually will tell you. And they usually will be right. That is the time to try to act and speak in a respectful way. If you are having a hard time being respectful, then you might want to take a personal "time out." This applies to everyone, not just the person with FASD. When a person feels out of control, and is no longer able to be respectful, then it might be helpful to go to a room or area that is quiet and safe, where you can calm down and talk yourself through the situation. Sometimes it takes more than a quiet time out. When Johnny becomes disrespectful and is not able to act respectfully, it is usually due to his meds wearing off or something in his diet that makes him feel off balance. When a person is feeling out of control, it is easy for disrespect to turn into abuse, and then there is a risk of losing consequences, or even getting hurt or arrested. When Johnny takes his meds or sleeps off the effects of a poor diet, he is able to apologize for his disrespect, and we start all over again. The nice thing about respect is that if you are respectful to others, they are more likely to be respectful to you. And it is a good feeling to get respect from others. Johnny tries to always be respectful.

Communicate your needs. And your feelings, and ideas, and opinions. I read some good advice by a wise person once that said that most arguments are started because of miscommunication or misunderstanding. When I observed arguments that I was part of, this seemed to be true almost all of the time. Individuals with FASD have good expressive language skills, but they have poor communication skills. This means that the person with FASD might talk a lot and be very sociable, but they might not always get the right message across, and cannot always get the right message from others, because of how their thoughts get mixed up, they forget, and they see things differently sometimes. If you have needs and tell someone, those needs are more likely to be met. If you have feelings and tell someone, you are more likely to be understood. If you have opinions or thoughts or ideas and tell someone, you might have discussions that can lead to a better quality of life. Good communication can help prevent problems and arguments and can help living with FASD go a little more smoothly. And that's a good thing, because life in the FASD Lane has too many bumps and turns and obstacles.

Always Ask for Help

Always Be Respectful

Always Communicate Your Needs