



# The AAA's of FAS

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To most people in the U.S., AAA stands for American Automobile Association. I'm a faithful member and have utilized their services many times. They provide maps for journeys, pointing out the most efficient way to arrive at a destination, with potential delays and detours marked out for your convenience. They provide limited service, like jump-starting your battery or changing a flat tire. And if the problem is more serious, they can tow you to a service station or automotive facility of your choice. I drive an older, not-too-reliable car, so I keep my AAA card handy and their number is in my speed-dial of my cell phone. I love to travel and enjoy the anticipation of taking a road trip. And I enjoy making the journey as much as arriving at my destination.

Wouldn't it be nice to have an AAA for FAS? (For this article, FAS will mean **Fetal Alcohol Spectrum**, including Fetal Alcohol Syndrome and Fetal Alcohol Effects.) Well, maybe this article can serve as sort of an AAA for you to help you get where you want to go safely.

The AAA's of FAS are Awareness, Acceptance, and Action. These are the Three A's borrowed from Bill and Bob's 12-Step Program, Alcoholics Anonymous, are familiar to "program people." The process of "recovery" is similar for us "**Fasaholics**." If you find yourself on this journey of living life with FAS/E, whether as a parent or a caregiver or as an affected individual, the Three A's can help you on your way.

**Awareness  
Acceptance  
Action**

(continued from inside)

We must lead our own lives and lead the lost ones who might not want to follow, but must in order to survive. We need to learn to "navigate the system." This is a tough order for those of us who are quiet, maybe shy, on the passive side, who just want to "live and let live." We have a new role now, and it is an active role and a difficult one. We will make decisions, take initiative, change directions, face adversity, and keep on going. We take "one step at a time" and sometimes we have to start over. We might have to do things we don't want to do. Or we might have to give up doing things we really want. But it's sometimes a matter of life and death. What we are doing is saving a life. Sometimes it's our child's life we are saving, sometimes it's our own.

And if we get where we are going and achieve success, we just might save some other lives along the way. We can teach others the three A's through **education** and **awareness campaigns**. If we can't do that ourselves, we can **find others** to do it for us. If all those around us had the same level of education and awareness, the road would be so much safer to travel. The destination can be one of comfort and security, for all concerned. And the journey can be full of wonder and exploration. Life with FAS doesn't have to be hard all the time. We can laugh at ourselves, and we can even **laugh at FAS**. It can be exciting and fun and scary all at the same time, so fasten your seatbelts - you are about to take the ride of your life!



# The AAA's of FAS

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For parents of children who are diagnosed with or suspected of having Fetal Alcohol Syndrome or Fetal Alcohol Effects (FAS/FAE)

*"Where are you going, and how are you going to get there?"*

**A road map to help you on your journey:  
Awareness  
Acceptance  
Action**

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## Awareness

Awareness is always the first step in the recovery process, and in taking a journey. You need to know where you are, what you are dealing with, where you are heading, and where you want to go. This is the information gathering, eye opening, listening, getting past false assumptions, letting go of denial, facing the facts, and grasping the reality of FAS. This is more difficult than you would imagine, because you don't know what you don't know, and the barrier of denial takes many forms and is invisible until you can crash through.

These are the facts: **FAS is permanent brain damage**. There is no cure and it will never go away. Ouch. The root causes of the problems we encounter are neurological dysfunction. This is good news because it lifts the burden of blame from the individual. "It's not my fault, I'm not a bad person, it's just my brain not working right." And it's **not all Mom's fault**. The responsibility for the occurrence of FAS is far more complex than that, and we as a society can **all be held accountable** for the incidence of FAS. The **facts about FAS** and its possible causes and potential effects can be found on the Internet. The facts I want to focus on are the personal ones that are simple but not so obvious. Like the fact that life will never be normal again, for the individual or the family. Double ouch. **Grieving the loss of the dream** of having a normal life is one of the most difficult passages to maneuver. And this is chronic grief, so we will be crossing this pass many times on our journey.

What is our destination? Where do we want to go? Perhaps you have read the "**Welcome to Holland**" story for parents facing a new child's diagnosis of disability. Perhaps you have read the child-rearing books that encourage you to help your child achieve independence with discipline and "tough love." Other books stress accountability and responsibility. Although we can still hope for possible independence for our adult children with FAS, the reality is that this might not happen, or at least not the way we would like it to occur. And as much as we try to hold them

accountable, there are limits to this based on their ability to function. Our goals will be different from "normal" families. Our destination might not be the luxury of relaxed retirement that we dreamed of before we found out the meaning of FAS. We **redefine "success"** for ourselves and our children, and we alter our course to avoid construction on the unfinished road that lies ahead.

We learn to read the signs, to know what might lie ahead for us and our children. We learn to watch out for the danger signals. We learn to be vigilant and watchful. We hope that we don't run into too much trouble, but we're ready for it, just in case.

We could use some self-awareness as well. A good mirror helps. I look for people who can be good role models for me, who can give me feedback, who can be honest with me when I start to go in a direction that takes me away from my chosen destination. I look for parents who know how to cope with grace, who have a knack for quick problem solving, who are patient with themselves as well as their children, and who know how to **navigate the "system."** We will meet other parents along the way, but sometimes they are just as lost as we are. The place to find strong support might be on the Internet, where you can read about other **families stories**, or join **support group mail lists**. As certain and self-confident as I might feel, I still stop and check with fellow travelers to be sure I'm still on track. Isolation is like a giant rut in which we can easily get stuck. We don't have to travel this road alone; we can always use each other's wisdom and support when the going gets tough.

## Acceptance

Acceptance is one of the important steps in the grieving process I referred to. It's the step after knowing we are lost and before setting out in a new direction. It's absorbing those difficult facts. It's "getting it." It's stepping into that reality.

**"Normalcy is not an option."** The first time I heard my psychologist friend tell me this, it was like a slap in the face. But it was what I needed to wake up and

be alert to stay on this sometimes dangerous road in the "FAS lane." Acceptance is something that I have to grasp again and again, as I look in the mirror, read the articles, listen to the lectures, as I watch my child fail repeatedly. I don't want my child to fail, and I don't want others to set him up to fail, so I adjust my expectations based on the reality of FAS and how it affects my child's ability to succeed.

We learn to accept the less-than-perfect child who has been placed in our life. Actually, I accept my son John as perfect and accept the disorder as an obstacle. I accept John as a **person first**, who happens to have a disability that interferes with our original itinerary. I accept my child's limitations. And I accept my child's gifts and talents and celebrate them. I help my child accept himself as a good person, and I help him accept his limitations and abilities. I accept all the frustrations and restrictions and obstacles that are bound to be there in the middle of my winding road. And I accept that there are ways to get around those obstacles. I believe there is no problem that doesn't have at least one good solution. I try to accept "life on life's terms" – which is a real challenge for those of us who must accept FAS on FAS's terms. I accept that FAS changes my life in ways that I cannot control, but not ways that I cannot circumnavigate. I am going to make it. And so is my child. Just not exactly the way I had planned.

## Action

Action is taking the steps to get where we want to go. Once we know our destination and have our way mapped out, we are ready to GO. All we need is a vehicle. It would be nice to have a nice, new van for our trip. But with FAS, our vehicle is going to be more like a motorcycle with one of those side seats. We will be exposed to the elements of the Real World. It will be sometimes uncomfortable, but quite exhilarating, rather like a roller coaster ride. Taking action means we have to "just do it." We advocate, pass laws, gather groups, teach the teachers, and rouse the community.

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