

Introduction

Instead of calling the disorder Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE) it is now called Fetal Alcohol Spectrum Disorder (FASD). The other two terms are still used as a classification of the disorder.

I work part time as a Parent Liaison for MNASAP (Minnesota Adoption Support and Preservation). Part of my job is answering crisis phone calls. Once I had a phone call from a lady who blurted out, “How long does God expect me to do this?” She went on to say that she did not like her adopted child and did not want to live with him anymore.

I explained to her that what she was feeling was common, and what her child needed was a correct diagnosis, services, and for her to be calm. What she needed was respite, hope, a support group, to be calm, knowledge about FASD and parenting techniques specific to FASD.

Parenting children with FASD is mentally, emotionally, and physically draining. We have set up goals for parenting children with this disorder. I will list each goal with an explanation, and they are not given in order of importance. Following each goal is a short list of some of the most important knowledge we have gained from others and from raising our 10 diagnosed FASD children. Then, I will briefly explain our vision for “HaysKids,” a FASD assisted living center, for the purpose of presenting a model.

Goal 1: Learn parenting techniques specific to FASD

First, understand that normal parenting techniques will not work. Persons with FASD have organic brain damage. The three most common characteristics of children with FASD are impulsiveness, lack of self- control, and confusion.

Be calm: As one parent/professional once told me, “The less I say and the calmer I say it, the more effective it is.” Not only is this true, but it is unhealthy for your child and it is unhealthy for you to yell very often. It creates an emotional gap between both of you. You want them to feel you are on their side. Being calm is more important than almost any issue.

De-escalation: All too often when a child with FASD thinks they are in trouble, their already fragile connectors in their brains go down. At that point, all they can do is deny and escalate. Use a time out before you ever talk to them about what happened; this will give them time to calm down and let their brain stabilize. This is important with older kids too.

Look at “what frustrates you.” Sometimes you have to just accept it. Most of the time you can find a solution if you can remain calm long enough to keep trying different ideas. If you are seeking a solution, then there is hope, which is something you need.

If you think they are going to change on their own, then you have a problem. You change their circumstances. You change their environment. Don’t set them up. They may not ever change, but if they do: be thankful.

Telling the truth and not stealing are often very hard issues. They are issues that you need to teach too often. At the same time you need to understand that because of their FASD confusion, at times, they do not know the truth. In the FASD world we do not call it stealing, we call it “ownership issues.” It is often because of their impulsiveness that they take things. Often they do not even want what they take. Lock things up, and remove the temptation.

You need to understand the difference between “won’t vs. can’t.” “Can’t” means they either do not have the ability, the drive, or the understanding to do something. “Won’t” is defiance. Keep in mind, knowledge or skills gained one day does not automatically mean they will know it the next.

Goal 2: Feel good about your parenting

All too often when I say this, parents think, “I’m just trying to survive.” We need to reach beyond surviving so we can feel good inside about our parenting.

Tell your child that you are on their side, and then prove it to them. Tell them that you are not out to get them, but that you are out to teach them. Strive to feel good about yourself and about your parenting.

There is a difference between equality vs. fairness. Our goal is not to be equal but to be fair. A child with FASD may not be able to ride their bike on the road when another child can, but the child with FASD maybe just told to stop throwing a fit where the other child would have consequences for the same action.

Goal 3: Protecting them

They need protection from society and from themselves, and society often needs protection from them. As they get older, protecting them not only becomes more important but it is more difficult to do. They need even more external structures and controls.

You need to be a control freak. You will be judged for being too hard on the kid, and then when the kid blows it, it is your fault because you didn't have control over your kid. You can't win.

As our children are getting older, we are locking more and more things up. This is to protect them from getting into trouble, breaking, stealing, or ruining things.

If they can't deal with 6 year old issues then how are they going to deal with teen and then adult issues? Our children are not getting worse as they are getting older, they are dealing with more complicated issues and they do not have the skills to handle them. Think about this when making their "Life Plan."

Teach them to trust you and the people you say to trust.

Because they can understand the words it does not mean they understand the meaning. For example, "Don't talk to strangers." So you go to the park and your child meets Jane, and your child will tell you Jane is not a stranger because he knows Jane's name.

Teach them not to let someone set them up. Don't let them set you up.

Notify the police that you have a child at risk, and teach the police about de-escalation.

Make them want to stay home as a young adult, or at least stay connected. You teach this by being nice to them and by making them feel that you are really are on their side.

Families that are doing the best with older kids and adults with FASD are ones who have planned ahead and who are assisting their child.

They need cradle to grave support.

Goal 4: Get your child Diagnosed as soon as Possible

The earlier the diagnosis the better. 95% of kids are misdiagnosed as having ADHD. Some parents do not want their kids to be labeled. It is better to be labeled as having Fetal Alcohol, which, may help them to get services, then to be labeled as a troublemaker, dropout, sex offender, criminal, or dead. Find services and advocate for them. This will not only help them but it will make you life better also.

Goal 5: Change their socially unacceptable behaviors

It's not fair to a child or a parent to not try to change a child's bad behaviors. Some behaviors you will not be able to do anything about, but you should at least try. Often you cannot change their behaviors but you can change their environment. You can change the way they look at something or you can eliminate the temptation.

Your job is not to "get them" when they blow it, it is to "train them." Strive to feel good about your parenting.

Wear them out, and keep them active. Kids who are tired are often nicer

Goal 6: Teach them about FASD

This is to help them understand about their behaviors, confusion, and their need for help. Teach them about friends, proper sexuality, and the percentages. (Use these notes to teach from.)

Teach them about "Friends." "Friends" are people who help you to do well, and do the right thing. "Friends" help you meet your goals in life. "Friends" are not people who get you to use alcohol or drugs, get you to steal, be wild, lie, sneak, be crude, hurt people or things, or get you into trouble with the law.

Sexuality can be a very big problem. 60% get into legal trouble over sexual issues. (impulsiveness =lack of self control. At the age of 13 they are often developmentally only 5). Teach them sex is for married couples only and in order to get married they have to be eligible. They must have a job and be able to keep it; they need a place to live, a life plan in place. Tell them sex is a wonderful thing for married couples. Tell them sex may feel good if they are not married but it can cause a lot of confusion and trouble. (if your kid does create a baby and they want you to raise it, consider carefully whether you should or not.)

Teach them the percentages: 90% have mental health issues, 81% need assisted living, 79% can't keep a job, 70% are victims of violence, 60% get in trouble with the law over sexual issues, 60% have disrupted school experiences, and 60% are either dead or in prison by the age of 30. You do not teach them these percentages to discourage them, but to teach them how important it is that they avoid these problems and how important it is for them to let you or someone help them.

They often need someone to help make decisions for them, keep them on task, and help them have self-control. That person is sometimes referred to as an "External Brain." We all have them; a boss, husband or wife, God, policeman, or friends.

We also try to teach them to be their own external brain by using lists, structure, or "Home Base."

"Home Base" is a table or place where the child must be at whenever they are not doing something else. At the table, they can ask permission to do something else like: talk in low voices, play games, read, do crafts, or do school assignments. The purpose of this is to teach them to "stop and think" about what they want to do, be calm, and get focused.

Goal 7: Be involved in their Education

All too often school is where they really start getting into serious trouble.

Public School – One national speaker said that if you were going to design the worst place for these kids it would be public school. However, there are some schools doing a great job helping kids with

FASD. They are usually schools that have received special training, and which have embraced FASD. They are schools in which the parents are part of the “Team.” Educate your school about FASD.

Concrete Vs. Abstract – Most of our children are very concrete, and it causes them problems and frustrations in both academics and behaviors.

Sometimes when I ask some of my children a question, I want to say, “Why won’t you answer me?” Some of them have a problem retrieving information. Many times a delayed response from them is not defiance, but it’s that they are still trying to figure out the question. (sort of like a stroke victim with brain damage.) Imagine what this must be like for both them and their teacher.

A professional explained to me once that one reason many children get into trouble at school is because they cannot do the academics. He said “According to kid thinking it is “kind of cool “to be a troublemaker, but it is not ok to be stupid.” So, if your child gets into trouble, ask him/her if they don’t understand the work.

School needs to be as non-frustrating as possible.

Many kids with FASD find it very hard to understand time and money. They may be able to do it on paper, but not transfer the concept into life.

Give them the opportunity to go as far as they can. Gently push them. Be there for them when they can’t go any further, back off the pushing, and then revisit it again later. They are continually growing, maturing, and developing, but often much slower than their peers.

Even if a student has the intelligence to go to college they may not be able to because socially they may not have the ability. So they need to either do something else or they need assistance.

The first time I went to our Special-Ed department I asked, “How long do I try to teach the difference between nouns & pronouns?” His reply was, “Teach life skills, life skills, life skills.”

Our home schooling is going the best it ever has. The following is the schedule we are currently using.

Before breakfast: room clean up, be available to help with household chores, meals or childcare.

8:30- 9: eating, explain the plan for the day, teaching, and devotions.

9 - 10: house clean up, chores, projects, and make bread (Life Skills).

10 -12: crafts, PE, music, special projects. (Crafts: pottery, hand and machine sewing, crocheting, beading, cloth weaving, basketry, leather work).

12 - 1:30: lunch, dishes, maybe free time.

1:30 - 3:30: academics, sometimes group school but usually self directed studies. (Learning the life skill of two hours of focused no nonsense work.) During this time they can be taken by an adult for special instruction or for a project.

3:30 - before dinner: free time but must ask permission for what they want to do. (Not, “May I go outside,” must be specific.) Some may help do other things at this point, such as helping cook dinner.

Goal 8: Inspire them to do good

They can live a good life. Many can even marry and have children, but most will need assistance. Teach them it’s ok to have FASD; however, their life will be different. We all need help in some areas. Tell them they can live a good life; most people with FASD can marry and have children.

They can give hope to others, show the world they can make it, and they can be a good team player, and be a good community member.

Teach them the price is too high for them not to do well.

Negativity, point it out, fight it. If you ask them what frustrates them, you will often hear; “I’m bad, I’m stupid, I’m a retard, I lie, I can’t do good, or I steal.” Building their self esteem needs to be one of your goals. Realize they often feel lonely, sad, confused, and they have a higher suicide rate.

Set an example, model for them corrects behavior, and tell them the right answer. We often assume they know the right answers when often times they don’t.

Goal 9: Help them to write up their life plan

Use it as a training tool, a behavior modifier, and inspire them, to give them hope. Work on a “Life Plan” together. If possible, you need to start this process when they are around 14. They need to be involved in it. The “Life Plan” needs to be a plan of what they want in life: where they will live, what they will do for a living, if they will marry, who their friends will be, and how they will keep out of trouble. It becomes their goals. You need to talk about it regularly; you need to update it as they change, and as their skills and desires change. You can look back at it when they are having trouble or when they are getting into trouble. The “Life Plan” becomes part of their external brain.

Regardless of what type of home they were brought up in, if they leave home between the ages of 18-21, they will probably fail. If they can either stay home or in an assisted living situation until they are 30-35, then they have a much better chance of making it. It is not because they are bad people or that they fail, it’s because they will make really poor choices. They often will not learn from their mistakes, and they will make friends with people who will get them into trouble.

Would you let an 11 year old live on their own? At age 18, many have only developed life skills of an 11 year old, and have socially developed to that of a 7 year old.

Individuals with FASD have normal desires: to live on their own, get married, have sex, have children, go on vacation, go shopping, go to restaurants, go to sporting events, and to be normal. Get with other parents and caregivers and create an “FASD Assisted Living Center.” Make it a place where they can have a good “quality of life.”

My wife and I have joined with other concerned adults and have created “HaysKids”. HaysKids will be a FASD assisted living center which will act as a protective umbrella for young adults on into their old age. We will teach life skills and do jobs training; we will also create jobs at the center. “HaysKids” will be staffed by understanding people trained in FASD. Quality of Life will be a constant concern for both the residents and staff.

We are involved with FASD education for persons with FASD, for parents and family, support staff, professionals, and for the general public. We are also available to help others start FASD assisted living centers.

Goal 10: Quality of life, both theirs and yours

Not only now but also into their future.

Don’t buy into lies; as parents we are often told their bad behaviors are just “normal kid stuff.” The difference is the frequency upon which the behaviors occur, the intensity of them, the fact that they often do not learn from their mistakes, and that normal parenting techniques don’t stop the behavior.

You may be misunderstood by professionals. Some professionals really do not understand FASD; look at the parents as the source of the problem, and they think the child is fine.

Deal with your feelings of failure as a parent.

Be emotionally involved with your kids, not their undesirable behaviors.

Don't remove the services if the child is doing better. They are doing better because of the services.

Goal 11: Take care of yourself

Find respite, become part of a support group. Be calm; learn about FASD and parenting techniques that work with children with FASD. Have hope, for without it life can definitely be overwhelming.

Beware! The divorce rate is higher among adoptive parents, so take special care of each other.

As caregivers we are human too – when we fall apart and blow it, we need to ask forgiveness.

Your ex-friends vs. new friends: Often if you adopt or foster a child with FASD, many of your old friends fade away. But that's ok, your new friends will be much better ones, and they will be patient and want to understand.

Tell your child with FASD that they must “forgive” their biological mother. (You have to forgive her also.)

Goal 12: Realize they have organic brain damage

They need your help; you are doing a very hard and important job parenting them.

Think about what they have lived through, (FASD + Reactionary Attachment Disorder + Other Diagnosis = Who They Are) have compassion.

Go hug your child!

The following is a Vision for “HaysKids” a FASD Assisted Living Center. It's given for the purpose of inspiring others to start their own assisted living centers.