

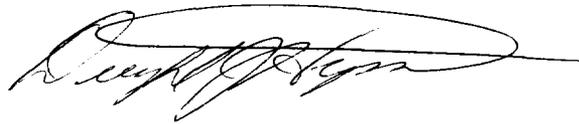
Fetal Alcohol Syndrome: A Case Example

An Honors Thesis (Honrs 499)

by

Shannah J. Mckee

Thesis Advisor
Dwight Hymans, MSW

A handwritten signature in black ink, appearing to read "Dwight Hymans", with a long horizontal flourish extending to the right.

Ball State University

Muncie, Indiana

April 1999

Graduation Date May 8, 1999

SPC
100
24
1989
1137

Purpose of Thesis

The purpose of this case narrative is to educate people on the trials and tribulations of not only a family dealing with a child afflicted with Fetal Alcohol Syndrome, but also the surrounding issues of single motherhood, the welfare system cycle, and the lack of education and medical knowledge base for Fetal Alcohol Syndrome. It is important that professional's who may encounter FAS understand that there are usually many other multifaceted problems that the family is dealing with. This thesis also points out needs that various people in the education, medical, and social welfare fields should look into when confronted with a possible FAS diagnosis. The ultimate goal of this thesis is to provide an example and a knowledge base for professionals, so that future FAS children and families are given the help and support that they need to survive and prosper happily and healthily.

ACKNOWLEDGEMENTS

I would like to give my thanks to the alumni, faculty, and Honors College staff who have helped me with the preparation of this thesis by answering a plethora of questions, providing examples, and being flexible with the HONRS 499 process. I would also like to thank the Social Work Department faculty and staff for being supportive of this project and for helping me gather the resources needed for completing the project. I would also like to extend my deepest thanks and gratitude to Professor Dwight Hymans of the Social Work Department. He has been not only my HONRS 499 advisor, but he has been my mentor, my supporter, and my friend for the past three years. I appreciate all that he has done for me. Prof. Hymans truly went above and beyond the call of duty for me. I could not have done this thesis without his help and support.

The following is a fictional example of what a single mother who has a child with Fetal Alcohol Syndrome might go through. It is based on factual elements of FAS, gathered from various websites and literature, that address such issues as physical and behavioral symptoms of FAS and how the social welfare system and the educational system handle children with FAS.

1-15-98

Dear Diary,

Today I found out that I am pregnant. I cannot believe it! I am only eighteen. I shouldn't be having a baby! I should be going off to college and meeting new friends. I don't even know if I can take care of myself, let alone a baby! Michael, my boyfriend, told me it would be okay if we didn't use a condom. He said that he would pull out in time! I don't know how he is going to handle this. I wonder if he will leave me? Then what would I do? Then there are my parents. Dad probably won't care, but then again he really isn't around enough to care. He stopped coming around a lot after he and Mom got divorced. Mom, on the other hand, is a different story. I just know she will freak out. She didn't even know that I was having sex! She told me once that she would kick me out of the house if she ever found out that I was sleeping around. I can't imagine what she is going to do when she finds out that I am pregnant! I don't know how I am going to tell everyone. On top of the problems with my parents and Michael, I am also afraid of what will happen to the baby. The doctor says that I am already three months pregnant! I guess I should have gone to the doctor earlier, but I didn't want to face what I knew to be true—that I was indeed pregnant. The problem was that even though I skipped my periods, I

still went out and partied as if nothing was wrong. I did not want anyone to suspect that something was wrong with me. The doctor says that I should stop drinking. I am not sure how it could harm the baby because the doctor didn't really tell me that much of the danger. Regardless, I did not tell him that I had been drinking since I suspected that I was pregnant. But I didn't drink very much, and I never got drunk. So, the baby should be all right, right? I just can't believe this happened to me. I know that I had sex, but I always go to church, and I am a very nice person. God, what did I do to deserve this?

1-25-98

Dear Diary,

I told Michael today. I feel completely devastated! He actually told me that the baby is not his! That is not even possible since I have only been with him. But he didn't listen to me. He said that I was a whore, and that he didn't want to have anything to do with me. He told me not to go over to his house or to call him. As upset as I am, I guess I almost expected him to act this way. Everyone said that he was just using me. I guess hindsight is always twenty-twenty, though. I feel more sorry for the baby. I hate the fact that our child will not have a father. But I guess there's nothing I can do about it now. What's done is done. I am going to have this baby- abortion is definitely not an option!

I also told Mom today. It went about as well as the conversation that I had with Michael. She blew up! She called me an easy, irresponsible brat. I know that she is completely disappointed in me. I wonder if I will ever be able to make her proud of me. If I do, it won't be for a very long time because she kicked me out of the house. She said that she was going to make sure that I become independent and responsible. So, here I am

pregnant and homeless. My friend, Debbie, told me that I could move in with her for awhile until I find a place of my own. The hard part is money. I have my job at the mall, but it doesn't pay enough to pay all the bills that I am going to have. I was also hoping to go to college next fall. I don't see that happening now. I just don't know what I am going to do! I have never felt more isolated or alone.

3-28-98

Dear Diary,

I went back to the doctor today. I am still worried about the fact that I drank early in the pregnancy, but he says that the baby should be fine. I just don't know what I would do if I hurt it in any way! But on the brighter side, things seem to be going all right with the baby. Things with me are all right, I guess. I found a pretty cheap apartment across town with the help of a social worker that I have been seeing. She has been pretty helpful, and because I don't make much money, I get to see her for a minimal fee. I am also receiving help from WIC (Women, Infant, and Children) program. They give me food vouchers so I don't have to pay for it out of the slim paychecks that I do get. They also help pay for some of the necessities that I will have to have once the baby is born (formula, diapers, baby wipes, etc.). They have been a huge help! Unfortunately, they said that I have to establish paternity through Michael. But of course he wouldn't admit to paternity. So, they got a court order for me. That didn't work either because suddenly, Michael left town. No one seems to know where he is. I haven't talked to him. But before he left, he was still insisting that the baby is not his. I have decided that I am just going to let it go. I can't change his mind, and I don't really have time to try. WIC said that the police or somebody was going to send some investigators after him. I don't think that will

help though. I talk to Mom every once and awhile. I know she still loves me, but she still won't support me. But at least she and I still talk. Other than that there really isn't anything else new.

9-20-98

Dear Diary,

Sorry that I haven't written in awhile. Things have been pretty hectic the past couple of months. Well, the baby was born September 7 at two o'clock in the afternoon. It was a girl, and I named her Carrie. She had a low birth weight, only four and a half pounds. She also had some other features that weren't quite right. She has a small head and small, beady eyes. Her upper lip is also underdeveloped. I asked the doctor if it had anything to do with the fact that I drank the first three months of the pregnancy, but he said that he didn't think so. Other than that, Carrie and I are doing pretty well. I still get help from WIC, my friend Debbie helps with her, and I am also getting unemployment since I am not working. It's a struggle, but we are surviving.

(four years later)

11-12-2002

Dear Diary,

Things have been difficult lately. First of all, I have been trying to get myself off of welfare, but there are some complications. I don't have a college degree, so I can't seem to find a job that pays enough to pay for rent, food, the car, and especially day care for Carrie. It just seems like an endless cycle. I mean first I find a job to get off welfare. But then I can't afford to pay for Carrie's child care, so I quit the job. Then I end up where I started, back on welfare! I just don't know how to balance all the expenses

without the welfare check! Once the agency told me to enroll Carrie in a day care that was partly paid for by the state, if you didn't have enough money. So, I tried it. Within four weeks, Carrie had to be removed because of her behavior. That leads me to the next problem which is Carrie. She is having quite a few behavioral and developmental problems. Although she is only four years old, she is already displaying signs of poor sensory awareness. For example, yesterday she accidentally touched my hot curling iron. But instead of crying from the burn, she just sort of stared out as it blistered up. She also has a really bad attention span. I realize that she is very young, but most of the time she can't even listen to me for a whole minute. (That was one of the problems at the day care. She wouldn't pay attention to her teacher at all.) She also doesn't seem to understand when people talk to her, even though she has a very good vocabulary. (This was her other problem at the day care. The teacher would tell her to do something and she would just stare at them like she had no clue what they were asking her to do.) Carrie is also showing what the social worker classes as behavioral problems. At times she acts really hyper and out of control. The social worker calls this hyper-activity. She will run around and around and won't stop until she feels ready to. Sometimes I just don't know what to do with her!

The social worker that we see says that she doesn't know what to do with Carrie. She says that she probably is just hyperactive. But I think that it's more than that. Unfortunately, the pediatrician also thinks that there is nothing really wrong with Carrie. He says that I just need to learn how to control her. Can you believe that?! I cannot believe the nerve of that doctor! At least I know one thing...I am definitely getting Carrie a new doctor!

Well, as you can see diary, I seem to be at my wits end. I just hope I find someone who can help me with Carrie.

9-30-2003

Dear Diary,

Well, Carrie started kindergarten about a month ago. Problems have arisen already. Her teacher is convinced that she is slightly mentally retarded based on Carrie's behavioral problems. For example, there are times when Carrie will act out impulsively. She may suddenly start crying or yelling. One time she even got up out of her chair and walked out of the classroom without saying a word. Carrie also seems to have problems with self-centeredness. A lot of the time she acts as though the world should revolve around her. She will throw a temper tantrum if she thinks she isn't getting enough attention. I have seen this problem quite often when Debbie baby-sits her. Debbie has a child of her own, and I think that Carrie finds that some sort of threat. So, she might act out to get the attention back to her. Carrie's teacher also says that she thinks that Carrie has ADD, Attention Deficit Disorder. I'm not sure. I know that she has problems, but whenever I talk to her about her behavior there is this genuine innocence or detached attitude that surfaces in her. It just doesn't make sense to me. I just know that there is more to this, and that she is just not "retarded." The only problem is that I can't seem to find someone who agrees with me! On top of everything else, her teacher is threatening to place Carrie into a special education class. I will not have that!

10-14-2003

Dear Diary,

Well, I have some good news to report. Carrie has calmed down a little bit at school. Her teacher and I both think that her improvement might be due to the fact that she is now more used to school and the routines that she does everyday. She still has a problem with paying attention and wanting to be the center of attention, but at least there is progress! I am definitely not going to complain about that. Furthermore, I got a new job!! I am working as a secretary for an executive at the Ford plant. It pays a lot more than welfare, and because of the hours, Carrie will only be at day care for two hours after school, which I can afford! Money is still somewhat tight, but this is a huge step for us in the right direction.

Unfortunately, there is also some bad news. I talked to the investigators who are trying to locate Michael so that he would pay the child support that he owes her, and they told me that they have exhausted their leads. They still haven't found him, and now they have no idea where to look. I think that they were trying to tell me, in a gentle way, that they were giving up on finding him. I guess I'm not too disappointed because I always knew that they wouldn't find him. I just feel bad for Carrie. She deserves that money. At least WIC won't be hounding me about it anymore. In other bad news, Carrie's teacher has told me that unless Carrie's behavior and grades drastically improve by the end of the semester, she is going to recommend that Carrie be removed from the class. I have talked to the principal, and she is of the same mind as Carrie's teacher. I just have to find someone who can help with this. I refuse to have Carrie removed from her class. She deserves a normal education like all the rest of the kids in her class.

11-6-2003

Dear Diary,

I took Carrie for a checkup today at a new doctor's office (Debbie suggested this guy. He's her kids' doctor). Physically Carrie is fine. I then talked with him about the behavioral problems that she has been having. After that discussion, he left the room. At this point, I wasn't too sure what to expect. When he returned, he told me that based on the behavior that Carrie had been exhibiting and on some of her facial features, he thinks that Carrie is afflicted with Fetal Alcohol Syndrome, more commonly referred to as FAS. I then told him about how the first three months that I was pregnant I didn't see a doctor, and I occasionally drank a couple of drinks. I told him how I never got drunk, but he said that just one drink could have done the damage to Carrie. My first gut reaction was guilt. I did this to her. If I hadn't been so irresponsible, she would be okay. I don't know how I will ever forgive myself. At the same time that I was feeling guilty, I also felt relieved. I know that sounds strange, but I was happy that I now knew the cause of her behavior. What I did ask though was why the other doctor's did not diagnose Carrie with FAS earlier. He informed me that many doctors don't know enough about FAS to diagnose it. He said that FAS isn't something that is considered a "real" disease. I suddenly got very angry. My little girl goes untreated, just because arrogant doctor's didn't know any better! After I cooled down, he and I got back to the important discussion about what we can do for Carrie.

We then talked about the treatment options for Carrie. He suggested that the best option would be for Carrie to get a psychiatric evaluation and then to receive therapy from someone who knew something about kids with FAS. Finding that therapist would be the hard part.

11-30-2003

Dear Diary,

Today I took Carrie to a psychiatrist for an evaluation. (Lucky for me the insurance that I get through work decided to foot the bill since the appointment was for medical reasons.) He decided to put Carrie on what is called psychotropic medication. This will help her with her attention disorder and other behavioral problems that Carrie displayed. He seems confident that it will work. I sure hope so. He also gave us the name of a therapist (who is a social worker, wouldn't you know) who has dealt with FAS children before. We have an appointment with her tomorrow afternoon. With all that is happening in our lives, I think that it important to note that Carrie seems to be dealing with all that is going on around her quite well. I am not sure if she understands it completely, but she is getting attention, and I know how much she loves that! Things with me are going pretty well. The people I work with are sweet, and it is a steady income. I am still trying to deal with the fact that I hurt my daughter by causing her disease. I don't think that I will ever be able to get rid of the guilt completely, but I am starting to live with it. That's a positive step, right?

10-10-2003

Dear Diary,

Carrie has now seen the social worker two times, and I am pleased with the results. Carrie will also start using what is called "Sensory Diets" at home and at school. This special diet will help normalize her sensory processes. It seems Carrie's nervous system has a problem being either over-aroused or under-aroused. When this happens, Carrie becomes distant, abusive, and acts impulsively. This treatment is supposed to

balance her senses. The therapist is also using AIT, Auditory Integration Training. This emphasizes the use of labels on Carrie's feelings. It is designed to help emotional and social development. Furthermore, the medication that Carrie is taking seems to be helping. Her teacher has commented that Carrie is more alert in class and her impulses have become less frequent. Her teacher and I have also talked about Carrie's future in that class after the semester ends. She has decided to give Carrie a trial period. We sat down and talked about what can be expected of Carrie, and what her needs will be.

All in all, Carrie and I have come a long way in this year. I must admit that although there are still many obstacles to go through, I do believe that I am starting to see the light at the end of the tunnel. Things may not be perfect or completely functional, but I think that Carrie and I have enough working in our favor to make it!

Discussion

The previous case was not a true story, but a collaboration of possible problems that would more than likely affect families who are dealing with kids that have Fetal Alcohol Syndrome. The number of children that have been diagnosed with Fetal Alcohol Syndrome has risen quite significantly since 1968 when the syndrome was first described in published medical literature. The statistics today show that there are an estimated three children per 1,000 births in the United States who are born with FAS (NCADI, 1997). However, experts claim that this statistic is misleading because most children with FAS usually go undiagnosed, as in the case example above. One of the many reasons FAS goes undiagnosed is because it is not present in the majority of the medical school curricula (NOFAS, 1998). Last year, the University of New Mexico became the first school to formulate a mandatory course dealing with FAS for second year medical students (NOFAS, 1998).

Children with Fetal Alcohol Syndrome are born throughout the country. Thus far, there has not yet been one section of the U.S. found to be more prone to giving birth to children with FAS. FAS children are born into families of all socioeconomic statuses. Whether rich or poor, FAS does not discriminate. But because of unavailable resources,

poorer families, as in the case example, may have more trouble dealing with their FAS children. The ages of the females who give birth to babies with FAS have been described as women within childbearing age. However, younger women may be more at risk because of their lack of knowledge about the effects of alcohol on their babies. Furthermore, women who have had one child with FAS are about 25% more likely than other women to have another child with FAS (Ruton, 1998).

With regard to race, there are no clear statistics that indicate that women of a certain race are more likely to have FAS children than any other race. However, there are some differences between races indicating that some women are more susceptible to giving birth to child inflicted with FAS. For example, in comparison to Caucasians, the Chinese, Native American, and Japanese have a higher rate of alcohol metabolism. Therefore, their fetus would be more susceptible to FAS. Also, some racial groups, such as Orientals of Mongolian heritage and Native American, have a higher sensitivity to alcohol related symptoms. Hence, their baby is more at risk for FAS (Ruton, 1998). Furthermore, the National Center for Health Statistics conducted a study that found those doctor's appear 30% less likely to tell African American women to quit drinking during their pregnancy than to tell Caucasian women (NOFAS,1998). This could have been what happened to the mother in the case example. Obviously, this could result in more FAS children to be born to African American women. Another fact found in the study done by the National Center for Health Statistics was that of those women asked about their drinking and were found to have a drinking problem. Only 3% nationally were referred to treatment (NOFAS,1998).

There has also been no apparent research found that examined the education level of women who give birth to babies with Fetal Alcohol Syndrome. However, there are some issues that could make a woman more at risk for having a baby with FAS if she did get pregnant. These issues include women who have experienced any type of verbal, sexual, or physical abuses, or have come from families where drugs were abused. They also could have had problems, as the mother in the case example, where the woman had just gone through a traumatic life event, such as an unexpected pregnancy (Hepworth, Rooney, and Larsen, 1997). These women are considered to be more at risk.

There were also assessment and diagnostic issues that surround FAS. These issues consist of multidimensional problems that these innocent children will have to deal with for the rest of their lives. The damage done to them can never be completely remedied. One of the dimensions of FAS is the biophysical problems that the child and the child's family must learn to endure. Some of the physical problems include prenatal and postnatal growth retardation, damage to the central nervous system, and dysmorphology, which includes abnormalities in the size and shape of the child's head and/or face. For example, Carrie, the example FAS child, had small, beady eyes and underdeveloped lips. One of the many physiological issues that arise with kids with FAS is the fact that most are found to be mentally retarded. In fact, FAS is the leading known cause of mental retardation (NOFAS, 1998). This mental retardation would also include learning and developmental disabilities (NCDAI, 1997). Some of these disabilities include poor memory, differences in sensory awareness, reduced attention span, poor problem solving strategies, and higher language production than comprehension

(NOFAS, 1998). Many of these problems were exemplified in Carrie's case. Although the level of retardation and disabilities varies with each child, it is obvious that these kids, like Carrie, are left at a serious disadvantage compared to children who do not have FAS.

As in Carrie's case, children with Fetal Alcohol Syndrome also have a variety of behavioral symptoms and problems that manifest themselves once the child begins the process of socialization. Some of these problems include unresponsiveness to verbal cautions and instructions, acting impulsively (both physically and sexually), violent mood swings, hyperactive in a non-goal oriented focused activity, skilled at shifting blame, and the inability to accept responsibility (Findley, 1998). As a result of many of these problems, many children with FAS find themselves being shifted from their family of origin to various foster care homes. One of the most frustrating problems for these kids is that after they have behaved poorly, they usually feel a genuine innocence or detached attitude from how they had acted (Findley, 1998). Carrie's mother ran into this problem when Carrie acted out at school. It makes it harder to discipline a child when they really did not know that what they were doing was wrong. These kids simply do not know how to change their behavior. Unfortunately, most parents do not know how to deal with their behavior either. Consequently, out of frustration, some parents give up their kids to social service agencies.

On a more positive side, there are certain disciplines that parents who have children with FAS can use. One of them is to change rewards for good behavior. This is done to keep the interest of the child alive. Parents should also avoid threats and allow the child to debate over already established rules. Other forms of discipline include setting and following limits closely, redirecting behavior, reviewing consequences of behavior,

avoiding over stimulating situations, and noticing and complementing the child when they are doing well (NOFAS, 1998).

There are a few national agencies who have lead the way in developing programs and research for children who have Fetal Alcohol Syndrome. One of these such agencies is the Fetal Alcohol Syndrome Family Resource Institute. They are a nonprofit corporation whose mission is to identify, understand, and care for individuals disabled by FAS, and to prevent future generations from having this disability (Findely, 1998). This national agency has different branches throughout the United States with their headquarters in Lynwood, Washington. They provide support and literature for those who are struggling with FAS. They also have parenting classes for parents with FAS children. These parenting classes have been found to be extremely beneficial because kids with FAS act differently than unaffected kids. Therefore, they would need different styles of parenting. They also provide many workshops that are available to those interested. Some of these workshops include: "FAS 101: A Practical Medical Overview"; this is geared toward doctors who may have to diagnose FAS; "Strategies That Work for FAS"; "FAS: A Kaleidoscope of Grief and Hope for Mental Health Professionals"; "Terrific Tips for Teachers"; and "Advocating: Successful Accessing Services." All of these workshops would be very beneficial for those who are effected with FAS in any way. The problem with this agency is that they are not very accessible to most people because they are not located in every city.

Another agency that is available for families who are dealing with FAS is the National Organization On Fetal Alcohol Syndrome (NOFAS). This is also a nonprofit organization. On a macro level, they engage in much of the new research that is being

conducted on FAS. They also work to promote education and awareness about FAS in the hopes of preventing future cases (NOFAS, 1998). On a micro level, they provide affective strategies for those clinicians working with children that have FAS (NOFAS, 1998). One of the setbacks of this agency is that they do not provide local support. They also do not advertise or promote themselves which make their organization and their programs less visible to the public; therefore, those that need their services may not be aware that they are available.

The latter agencies that were mentioned above are taking steps in the right direction to combat Fetal Alcohol Syndrome. They are providing the cornerstones to the foundation of prevention and education for FAS. There are still many obstacles that victims of FAS and their families must still fight to overcome, as was exemplified in the case example. The medical field still does not diagnose FAS nor do they know enough about FAS to consider it for a diagnosis when they should, the social service and educational systems also do not know enough about FAS to recognize the behavioral symptoms nor do they have an ample amount of knowledge about FAS to know how to go about treating its victims, and finally we, as a society, need to do a much better job at educating women, especially pregnant women, about the effects even one drink of alcohol can have on their future children. We can accomplish these goals by conducting more research, publishing more information, and writing and sponsoring more programs that are focused on FAS and the problems that come with it. Therefore, the priority must be set that in order to better meet the needs of future generations, it is essential that more information be available to professionals working with children and future adults afflicted

with alcohol during gestation. For if we do not know how to protect our children while they are enveloped in the womb, how can we begin to protect them and their innocence once they are born?

Bibliography:

1. Findely, Doug. "Behavioral Symptoms of Adolescents with FAS Through the Eyes of Parents." <http://www.accessone.com/>.
2. <http://www.health.org/>. "FAS Executive Summary."
3. <http://www.health.org/pubs/factst/fetal.htm>. "NCADI Fact Sheet On FAS."
4. Hepworth, Dean II., Ronald II. Rooney, and Jo Ann Larsen. Direct Social Work Practice. Brooks/Cole Publishing. Pacific Grove, CA. 1997.
5. <http://www.nofas.org/strategy.htm>.
6. Ruton, Anuppa C. <http://192.41.59.23/digitali/hst/fetal.html>.