

“Colorless in a Rainbow:” An African American Female with Albinism in the Hawaii Public School System

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Abstract: Culture, ethnicity and ability: these are just three attributes that encompass the life of a female African-American student living with albinism and attending a local Hawaii public school. From February 2003 – April 2004, through personal and family interviews, a personal journal and autobiography, field notes, observations at home, school and in extracurricular activities, the personal perceptions and experiences of what it is like living with albinism and being African-American surfaced for this student. This article addresses identity issues regarding race, gender and ability, and discusses two theories: Critical race theory (CRT) and disability theory to answer the questions, who and what defines this female’s identity?

Utilizing the lens of critical race theory and disability theorists, the following case study will examine issues related to being an African-American female student with albinism in Hawaii. The complexities of issues that make up Taylour’s life include: 1. The societal definition of her race and the implications of stereotypes and name-calling that reflect these views; 2. The issue of how society defines her disability, which often excludes blindness, but focuses on albinism and finally; 3. Self-identity and personal reflection and how Taylour relates to being African-American and having albinism.

Key Words: Critical Race Theory, African-American, Albinism

“Just as our skin provides us with a means to negotiate our interactions with the world – both in how we perceive our surroundings and in how those around us perceive us – our language plays an equally pivotal role in determining who we are.”
(Lisa Delpit)

Taylour

Taylour’s skin is as white as snow and her eyes are light gray. However, her other physical features are African-American. She has albinism, a deficiency of pigmentation in the skin, hair, and eyes affecting one in 20,000 individuals in the world. Taylour is the youngest of three children in her family, and the only girl. At home she is surrounded by culture - the walls are covered with African, Hawaiian and Japanese masks and African-American and Japanese furniture; paintings and sculptures fill each room.

Taylour’s family has long been associated with the military. Her father is a Gunner Sergeant in the United States Marine Corp, and has served for twenty years. Her mother is a Chief Petty Officer in the United States Navy Reserve; she served active duty for twenty-two years. Both of her brothers attend military academies. Her oldest brother is at King’s Point Military Academy and the other is at West Point Military Academy, both on the mainland. The family has lived in several US states and in Okinawa. Taylour spends a lot of time with her parents going out to dinner, sewing and going to the movies. She says her mother is her best friend because she can talk to her about any and everything.

Taylour loves to sew and the family business, “Taylour Made Embroidery” is named after her. She is very creative with her hands. The first time I went to her home, she showed me quilts, pillows and a jean skirt she had sewn out of two pairs of old jeans. For the past two years she has been taking Karate and in April 2003 she earned her green belt. Over the past ten months she was awarded two additional stripes. When she grows up, she wants to be a Navy attorney because she feels that people are mistreated in the world for being different with regard to their culture and ethnicities, and she

knows she will come in contact with many cultures if she stays connected to the military. The following is a composite narrative of Taylour's experiences from birth to present. The words are taken from her personal journal, a written autobiography, personal interviews, and interviews with her family and teacher conducted over the past 16 months. The words of Taylour's parents are also interwoven throughout the narrative. The University of Hawaii Human Subjects Board, and the permission of the student and parents granted permission for this case study. Actual names are used because the family wanted their true identities and voices heard.

Taylour:

"I was asked to describe myself as an African-American female living in Hawaii. I thought about it for a long time and I had to ask Mrs. Hairston to rephrase the question to: What is it like to be an African-American female with albinism living in Hawaii. I added the albinism because even though my family and friends don't talk about it everyday, I see it every time I look in the mirror. When I think of who I am, I often don't mention the albinism though. I'm not ignoring it. I've just gotten used to it so when people call me names because of it, that's when it bothers me. So, what is it like here in Hawaii? I'm colorless in a rainbow. There are so many people and cultures here, so many tans, shades and colors, and then there is me. My color is inside and I am filled with African-American culture, but I am white on the outside. I hate the sun because it burns my skin and eyes. Although I could say that I'm white because of my skin, it is still a color that no one else relates to me when they call me names like ghost and banshee. These things are invisible, so, I say I am colorless in a rainbow!

My life story starts as far back as I can remember clearly, at the age of five. First, I'll start with my family and the way I feel more than half the time about things that deal with my family. I am the youngest of three kids. My mother's name is Jill and she is 41 years old. My father's name is Antonio and he is 38 years old. I have two older brothers, Allen, 23, and Jermaine, 21.

The relationship I have with my parents is getting stronger each passing day. I know they do what they do for a reason (to prepare me for life), but I'm scared to grow up and the changes that are happening to me are happening so fast. I want so much out of life - to go to the prom, get a driver's license, and go to college and become a lawyer. Sometimes I feel like I just can't do it, but my mom and dad keep me focused. Life for me has been better than this past year, but I have tried to stay far away from complaining so that I can build a good strong system of discipline. I have been feeling sort of sad thinking about my life. Sometimes I just don't fit in. All people, including black people, often say I'm not black because I have white skin. They reject me. One thing for sure is that my family will never reject me. When I need them and when the world gets overwhelming, they will always be there and I am thankful for that. That's how I feel about my family and myself.

I often get stares on the street from strangers. It's different in Hawaii. The people talk about me right there in earshot, and they can't even wait until I've passed. I face the biggest problems of people treating me different and talking about me in school. When I moved to Hawaii the second time, (we have lived here twice), the most unexpected turn in my life happened (my parents tell me that it was worse the first time we lived here, but I can't remember). I was in the 5th grade, and the first day of school was awful. Never in my life, including all the other schools I had attended, did so many classmates talk about me like they did in Hawaii. That much I can remember. I was called so many names and it was because they didn't know me. My parents remember every incident that happened to me. They remember all the tears that I cried. I try to forget them as much as I can.

Now I am in the 8th grade and I'm almost a freshman. I asked my parents if we could move from Hawaii and go to New Baltimore, Michigan. I want to go to school there, or at least be there my senior year so that I can graduate from a good school like my brothers did. It is a very clean place and everyone is nice and knows everyone else. It's beautiful and to think about graduating there is wonderful. Although this year has gotten better for me, I am so ready to leave Hawaii.

I know I'll do fine when I get older as long as I study and work hard. The only person keeping me from my work is myself. The only reason why anyone is afraid of me is because they never take the time to get to know me. I may be different on the outside, but on the inside I am a person who wants to do the same things that every teenager wants to do. If black people with dark skin think it's hard in America, it's twice as hard for a black person with white skin because it just is."

Mrs. Smith:

"Taylour was born on September 10, 1990 and I kind of knew I was having a girl, even though I didn't have any tests, ultrasounds or anything to find out what I was having. When she was born, I looked at her and her hair was beak red and her face was so bright. I asked the doctor right away, does my baby have albinism? At the time I asked if my baby was an albino. I didn't know that saying 'albino' was politically incorrect. The doctor said no and that she was just fine. So they only gave her to me briefly because they had a six-hour waiting time before the mother could see the baby again. All the time that they were cleaning her up, my husband Antonio was over her taking pictures. I kept telling them that I needed to see my baby again and that my baby was albino.

During my waiting period, I was supposed to relax, but I couldn't because I kept wondering if my baby was going to be blind, and why wouldn't anyone listen to me? Finally it was about the fifth hour and I asked the nurse to check on the baby and she said that she was all cleaned up. I said that I saw my baby and she has albinism. The nurse kept saying no, no she's fine. So, they brought her to me, and I asked to see a physician, the one that was on duty. The nurse wanted to know why? I said because I am concerned about her vision, can she see? The nurse then looked at me, she looked at Taylour, then looked at me and then looked at Antonio, and then she said, 'all black babies come out light.' I responded that they may come out light, but they don't come out with blond hair. This made me think that maybe she thought something else was going on in my marriage. So, she took Taylour back. A few minutes later, the doctor came in and said, 'I hear you have a concern.' I asked him if he had seen Taylour. He said no. I told him that my baby has albinism and I asked him if she could see? I was so frustrated by then. So, he went out of the room and when he came back he had Taylour and he said, 'Yes, I do think she's albino and I'm going to be back with you in few moments.' Then the same nurse who had been with me all day became so apologetic to me, and she said that she had never seen an albino baby before. She explained that this was the first child born with albinism at this hospital."

During the next two years, the family educated themselves and joined the National Organization for Albinism and Hypopigmentation, which is a support organization for people with albinism. During Taylour's infant and toddler years, her parents dealt with the stares and questions from people they came in contact with about their daughter's albinism. It wasn't until Taylour turned three that her parents began to see how she understood her albinism:

"On Taylour's third birthday, I asked her what she wanted as a gift. She said a baby doll. I was so excited because I had been waiting for this moment. I could remember when I was little and I collected baby dolls. They were all African-American and I kept them clean and organized in my room. So, as we were walking through the aisles of dolls in the toy store, I immediately stopped in front of the black baby dolls. I began to point to this one and that one, and when I looked around, Taylour's focus was on the white baby dolls. I can remember asking her, 'Taylour don't you want to get a black baby doll?' She replied, 'I want this one, (she was pointing to a white Barbie with blond hair), it looks more like me.' I realized that she wasn't choosing the doll because it was white; race had nothing to do with it. She chose the doll because it resembled a person with albinism. At that point, I realized that my child related more with having albinism than I thought. You have to understand that although Taylour has albinism, we still focused on our culture and ethnicity at home and never thought about the white skin as a factor."

Over the next three years, the Smith family moved both within the US and outside the country as a result of military relocations. Taylour began kindergarten in a local Hawaii public school. She attended the same school in Hawaii through second grade:

“Taylour had become so defensive and built a wall around herself because of the hateful words that students at school have said to her. Not one day passed during kindergarten through second grade that my daughter did not come home crying or upset because of the other children teasing her. All the kids made fun of her, white and local students called her names like, albino nigger, white nigger, snowball, black ghost, banshee and powder puff, and black students told her that she is not black. If people could just look past the albinism, they would see the strong willed, sweet, pretty and courageous daughter that we have raised. During her second grade year, we had a conference with the principal and teachers at the school. I have to say that the teachers and principal were very supportive and protective of Taylour, so when problems did arise, they immediately handled them. But, this particular year, we (me, my [wife?], the teachers and principal) all decided to get a professional speaker to come in and talk to the student body about albinism. We all agreed that maybe if the students were educated about albinism and could ask questions, they would be less hateful toward Taylour. Unfortunately, this plan backfired; it made it even worse for Taylour. The teasing increased. Kids can be so cruel.”

During the next three years, the Smith family went to California for two years and spent one year in Okinawa. During her time in Okinawa, Taylour attended a Department of Defense (DOD) school. In Okinawa, Taylour had a different experience. Taylour explains in the following excerpt:

“I liked living in Okinawa. I know that I am different because I have albinism, but for some reason the people didn’t stare as much there. In school, the kids made jokes and still called me names, but it wasn’t as bad as when I was in Hawaii the first time. In Hawaii, people pass me on the street and talk about me right there. I can hear every word and every comment. In Okinawa, if they were talking, they spoke Japanese, or they just waited until I was out of their hearing range. I guess it was good that I didn’t understand Japanese; that way I didn’t know if they were talking about me or not. School was fun. We learned about all the cultures in the world; we celebrated Black History Month, along with other cultural holidays, and I felt safe. Maybe it was because it was a DOD school (Department of Defense) and all the students were military dependents. I remember the day my parents told me that we were moving back to Hawaii. I was a little anxious. I mean it was exciting because I loved the weather, even though the sun is terrible on my skin because I burned so easily and it hurt my eyes. But, the last time I was in Hawaii, school was not a good place to be. I was not looking forward to returning to school, being the brunt of the black ghost jokes, and crying everyday in my mom’s arms when I got home from school. But what could I do? We are military and we go where the U.S. Marine Corp says we go. I had no choice, so I planned to make the best of my return.”

On July 5, 2000, the Smith family returned to Oahu, Hawaii. Taylour began the fifth grade at a local school because the enrollment on the military base school was too high.

Mr. Smith:

“These past three years have been the hardest years of my daughter’s life. From our end and the school’s end, we have established what Taylour needs with regard to her eyesight. She has been declared legally blind, so in school she uses a special device to help her read. She likes this because it looks cool and the kids like it too. Anyway, when we arrived back in Hawaii, we immediately went in and advised the teachers and administrators about Taylour’s needs. Once again they were supportive and she received the necessary services. But, we cannot stop the mistreatment that comes from the other kids. This is where a lot of the social problems come in. From fifth to sixth grade, Taylour got into trouble at school for defending herself. She has an attitude, but the attitude is a defense mechanism. Elementary school was hard, but the past two years of middle school have been

a little better. In seventh grade she did get into a fight with a boy for calling her an albino nigger. The boy was suspended for two days, and she had two days of detention. This really upset her, but she managed to get through it. She came home about two weeks ago and told us that a rumor started at school by some local kids that she was from another planet. They called her an alien freak, and told her she was different, so she had to be from another planet. This devastated Taylour for a few days, but she jumped right back on the horse and held her head high. On a positive note, she did say that she has made friends who like her, take up for her and accept her. This summer (2003), Taylour made more friends on the military base and these relationships carried over to school. She's not crying all the time anymore. I know that she is growing up and the kids have been around her now for almost three years, so they are getting used to her, but most important she is being accepted for who she is and that makes us all happy."

This go-around in Hawaii, Taylour has developed some good peer relationships. Taylour has one "true" friend, as she puts it. She is an African-American and she lives on base. She and Taylour see each other in and out of school. Her other friends are also African-American military students who she rides the bus with and/or has classes with at school. Taylour says that she gets along very well with some of the African-American males from base too, most of them are in the 7th grade and younger than her. She says that they laugh and joke about everything, and they even take up for her when some of the local boys make fun of her. She has two other friends who are Mexican females. They live on base too. She goes to their house after school and on the weekends and sometimes they go to the movies together. Outside of base kids, Taylour does not have any peer relationships with the local students at school. She speaks to them in class, they talk in the hallways, however she does not consider any of them close acquaintances. As Taylour transitions into the 8th grade, her current friendships grow stronger and Taylour's acceptance and self-esteem levels begin to increase. The remaining narrative is from August 2003 – April 2004, Taylour's 8th grade year at a local intermediate school in Hawaii.

August and September 2003:

"The year has been going well. It's so good to be back in school and see my friends. A lot of them moved during the summer. I hate when my friends move away because that means I have to wait for new friends to get used to me. This is the worst part of being in the military! My teachers are okay, so far. I've been in school three weeks and I am already the victim of a rumor. It never fails. Someone starts saying I'm a "black ghost" or "banshee" because I look different. Yesterday (September 10, and my birthday) at school, my friend got into a fight with a local boy on the basketball court because he was making fun of me. He called me a freak and an albino nigger. When he was down, I ran over and kicked him in the stomach! It felt so good. I got in trouble and had to have a parent/teacher conference, but it was great to have someone else take up for me and it was great to kick him. He did apologize later. The kick had to hurt because I just earned my green belt in Karate. My sensei would really be upset with me if he knew I did it, but hey self-defense is self-defense – words hurt just as bad as punches sometimes. Anyway, we both got in trouble. First nothing happened, then, I went home and told my parents. They were upset about the incident and not too mad at me. They went to the school and had a conference with the principal. She gave the local boy, my friend, and me detention. Although the other boy started it, my friend and I got in trouble for hitting and kicking him.

After this incident, everything seemed to cool down at school. If rumors were still spreading, I wasn't hearing them. People think I'm mean because I defend myself and speak my mind, but I can't change who I am."

October, November, December 2003:

"In October, my mom came to school to teach embroidery to my Home Economics class. All of my classmates said that she was so beautiful. Some of them asked me if I was adopted because I looked nothing like her. I pretty much said, 'duh I have albinism!' Other students said that she was a

beautiful black woman. When I told my mom this, she laughed. That night we sat down in front of the mirror and looked at the things we had in common. The only difference we both saw was the color of our skin. My mom is such a great mom, hard at times, but great!

November was a sad month because my mom was gone most of the month to conferences and reserve duty leave. I am glad my dad is home now and he doesn't have to deploy this time around, but my mom leaves a lot. I want to tell you what it feels like when your parents go away. It is really hard. Sometimes I can't concentrate on my homework and when I come home from school and she's not here, I get sad sometimes. My dad is so cool though. Usually it's my mom who is at home with me, so now my dad is here. At school when I don't have my homework, the teachers get mad and call home. They just don't understand that I miss my mom. I know I have to keep on track, but I'm just saying, it's hard!

December is coming and that means Christmas break and my brothers are coming to visit. I cleaned for two weeks straight and cooked for a week straight to get ready for their arrival. I was so excited about seeing my brothers, but when they were here, one blew me off and the other was never at home. On January 3, 2004, I broke down in tears because Jermaine was ignoring me and Allen made so many plans outside the house, I hardly saw him. I guess I'm too young to hang out with them, and it hurts really bad!"

January and February 2004:

"January 10 had to be the coolest day of my life. Today Mrs. Hairston took Symone and me to Valerie's house. We got to eat and talk about life as African-American females in Hawaii. I feel that today was a good day. I am happy that I am participating in Mrs. Hairston's study; it gives me a chance to tell my story about how I feel. Sometimes I feel that people don't really care about my feelings. Anyway, today was great. Mrs. Hairston picked me and Symone up, and we drove to the other side of the island to meet Valerie. Symone and I are pretty good friends; she really speaks her mind. Valerie was so cool and she cracked me up. As I listened to them talk, all I could do was nod my head, especially when we were talking about how the local kids wear the same clothes as us, walk and talk like us, but they are still racist. It does seem like me and Symone see racist acts at least once a week at school while Valerie doesn't. Regardless, I know that what we all said today was true and I don't think, no, I know I'm special and that I'm wonderful. I don't need anyone to tell me that much – I wish we could have had a sleep over!

February has been the worst two months of my life. At home, I'm in trouble for everything - at school, I just wish that people would leave me alone and give me my space. Sometimes I just want to go up to them and scream in their faces, 'Leave me alone, just let me breath[e]!' If I do or say one thing wrong to anyone, there will be fireworks; I'm just trying to stay to myself!

At school, sometimes it would be nice to learn about other cultures. When we talk about history, it is usually Hawaii, but I love my history class and the teacher is my favorite teacher. She is cool and she lets me bring in African-American information and artifacts. For Black History Month, I brought in information on famous African-Americans, but whenever I bring in anything at anytime, she lets me share it. The other students are really interested in the things I bring in. At the beginning of February to acknowledge my history, I brought in an African-American Trivial Pursuit board game. No one knew the answers, not even the black kids, so we all ended up reading the cards instead. It was cool because we were learning about so many African-American contributions to American history. Finally we were talking about my culture. I need these connections in my life; cultural heritage is important to my family, and me and it is great to share with other people."

March 2004:

"This month (March) I have been doing some soul searching. I need a spiritual connection, so Lent is coming and I am giving up meat and chocolate- OUCH! I have been going to church on

base. I am really enjoying church. It is a time for me to sit, listen and reflect on who I am and what I really want out of life. My parents have always taught me to treat people with respect. When we were on the mainland we used to go to church a lot, but now with the family business it is hard for my parents to go every Sunday. I think I'm going to keep going. At church I feel safe and connected to God."

April 2004:

"A lot of people say that I am mean. I guess I come off that way sometimes because I speak my mind. My parents have always taught me to speak my mind, so I do, but when I overdo it, I get in trouble. My mom keeps telling me to choose my battles wisely, but sometimes it's hard. I am trying to control my actions. I've been going to church and I really want to be baptized. I memorized the Lord's Prayer and I feel pretty good about myself.

When I am in church or with people from church I feel safe. During this time, I don't have to defend myself or worry about people calling me names. This is one reason why I love going to church. When I learned the Lord's Prayer, it reminded me that God is with me at all times and no matter how evil people can be, he will protect me. My favorite part of the prayer is – 'and lead us not into temptation but deliver us from evil, for thine is the kingdom and the power and the glory forever.' That is real. No meanness, no hurtfulness, just peace for me to be who I am – Taylour!"

From a local and teacher perspective, Taylour's "favorite teacher," offers her perspectives about African-American military children, the local culture and Taylour's experiences in school.

A Teacher's Perspective:

"I am a local. I was born in Hawaii, attended the public school system here, graduated from a local college, and now I am a teacher of nine-years in the Hawaii school system. When I was growing up I rarely came in contact with any African-Americans or military people. If I did, I don't remember anything about them. In school everyone was local, so all of my friends were local. If I were to define racism, it would be a little different from the mindset of those that come from the mainland. Racism is putting someone down based on their race, but in Hawaii often it is taken lightly through joking and laughing at stereotypes. I don't think its right, especially now as a teacher and I see how it effects the students. However, in school, I stay to myself, so I have not really witnessed any issues of racism firsthand; I only get the rumors and tales from my students.

As Taylor's teacher I see her as a child who handles herself very well. She is very respectful and I know that this has been instilled in her through her parents. They are both very involved and good people. Socially, Taylour has a lot of friends, but when there is a problem she doesn't back down. She speaks her mind and stands up for what she believes in and she doesn't hide her ethnicity. I mean she wears her hair in braids, she is always bringing in information to share about different African-Americans and she is very proud of who she is. In my class, the albinism is not an issue, but I know that she has had some incidents in school where kids called her names and were very cruel to her. She doesn't really talk about it with me.

One thing that I don't understand is the military transitions. Why do they move these poor families at a moment's notice? I mean the kids are coming in the middle of the year, during a quarter term, at the end of a quarter term and some even come with a week or two left in school at the end of the year. As a teacher it is very hard to catch these students up or even get them prepared to test. To me it just seems like the military should take this into consideration when they move the families. Why not shoot for the beginning of a school year or in January after Christmas break?

I think the students handle the transition better than I do, I guess because they are used to it. At least most of them handle coming into a new school. They usually have one or two other students who are just arriving. The parents are pretty involved. I have noticed that the military students and

especially the African-American kids have a hard time with it. They seem to have more social problems. It is hard for African-American military children because they are only here for a short time and really don't get a chance to learn and experience the different cultures and us locals really don't know that much about their culture either. I think they come with a lot of negative preconceptions of Hawaii and this often hurts them socially because it is almost like they are looking for something to happen. They bring their mainland ideas about racism. Every thing isn't always about race, but sometimes I think they may feel that it is.

Overall, I think Taylour is happy. I don't think she wants to live in Hawaii forever, but she seems to be dealing with it pretty well. If I had known her before she came and could have given her some advice, I probably would have told her several things. First, stand back and observe and don't take everything so personal. Second, try not to be so outspoken because a lot of locals are not used to it, and third be proud of who you are regardless of the stereotyping. The stereotyping is often in fun; it does hurt, but try to remember that most of the people who are using the stereotypes don't know the history behind them."

Taylour's Final Reflections:

"In Hawaii, it is really hard to be African-American and a military dependent. The local and Hawaiian kids don't like us (military kids) because they blame us for taking their land. I know what racism is; because the kids here judge me before they even know me. I used to think that it was just because of the albinism, but I know it's because I'm African-American and military too. I have some really cool friends this year; they are all black and I think its because we have more in common and we band together whenever there is a racial incident at school. I have been called so many names in my life. The one's that hurt the most, and the ones that I remember the most are white nigger, albino nigger and black ghost. The local and white kids that called me these names realized that I'm African-American and that I don't just have albinism. What they don't realize is that I have been declared legally blind. Do they even care? I have to wear contact lenses and use eyeglasses and special magnifying scope, and when I read a book it takes a long time. This summer I read the Harry Potter books, and it took a long time because my eyes hurt if I try to read too much at one time. But, I don't think that I have a disability because I can see and I know that having albinism doesn't make me disabled, I'm just different.

I am your typical teenager; I have my ups and downs. The end of the school year is coming so quick and a lot of my friends are leaving. It's so sad! My parents told me that we would be leaving soon too, possibly this summer. I am excited about moving because that means I can go to a good school on the mainland. When I say a good school I mean, no dirt flying all over the place, air conditioner, classes about black people and our history, and a school building that you don't have to walk outside of to get to your next class. We are going to buy a house too! I can't wait. I hate living on base; the house is too small and I miss living in a big, unattached house.

Doing this study with Mrs. Hairston has taught me some things that I never really thought about before. I do realize that you have to be willing to forgive other people especially when they don't have a clue about who you really are. I'm getting baptized in three weeks (May 1, 2004) and as a Christian, I have to be able to forgive and change my ways too. My mom and dad are very happy and very proud of me because I made this decision on my own. I also realized that I know that I have the ability to do whatever I want and I will do whatever I want until I die. I am an African-American, and being an African-American and living in Hawaii means having to adjust to the culture and the way they do things here, but also remember my own culture. I am African-American, its my specific culture, I don't care what others feel, I'm African-American, military dependent, female, person with albinism, and I will soon be a Christian. Although 60 percent of the time it is tough, I'm happy with who I am."

Theoretical Analysis

Since the early eighteenth century showmen have exhibited African-Americans with albinism and vitiligo in circus sideshows, taverns, and dime museums. The mystery of the African-American with skin as white as snow challenges the color line and clearly implies that an African-American can be white. Martin (1962) explains, "The term 'white Negro' has served to describe an individual born with albinism as well as those who have vitiligo, a disorder that robs the skin of its pigment in ever-growing patches." Today in America people are judged by their race and ability. An African-American who has albinism faces many challenges and issues with regard to self-identity and cultural assimilation. The experiences of a person with albinism in Hawaii are unique and complex, especially for Taylour who is an African-American military student attending a local public school. The experiences she faced in her life, though similar to other African-American females in Hawaii public schools, are different because she is an African-American in a white body and she has a visual impairment.

Race and disability theories offer evidence for factors in which society judges and defines people based on these attributes. Along with other contemporary theorists, it has been concluded that what constitutes a disability, as what constitutes a racial category, is socially constructed (Asch, 2002). Asch goes on to explain that, critical race and feminist theories contend that the viewpoint of the discriminated-against, oppressed individual or group must be better understood by the larger society. Race and gender discrimination have become a normal part of societal views, and in order to reprimand society, the law should look not to the wrongs of perpetrators but to helping those who have been victims of discrimination. In addition, disability theorist Harlan Hahn (1988) characterizes, "Disability as eliciting existential and aesthetic anxiety in others. Notable in the history of governmental discrimination and segregation documented in the Garret Case is that people with only certain conditions received some of the most isolating and demeaning treatment."

Societal Definitions of Race and Ability

Who Defines Race

During the first five hours of Taylour's life, issues of race and ability began to shape her identity. From the nurse who stereotyped all black babies as coming out light to her mother's concern about if her daughter was blind. The questions raised here are how does race define Taylour if she is with white skin in an African-American body and how has albinism become the disability, when in fact the impairment is her eyesight?

The first sign of society defining Taylour came through racial epithets and stereotypes. Parts of the names that students called Taylour referred to the color of her skin (white, albino, powder), other parts of the names referred to her race (nigger, black). Stereotypes and name-calling are defining Taylour's race. Racial slurs and stereotyping others are amongst the two most common forms of racism. Stereotypes come in many forms, from verbal implications about ones culture and character, to negative depictions of them in literature and pictures. Racial slurs are direct words aimed to wound and humiliate a person based on their ethnicity.

Critical Race Theory scholars focus directly on the psychological harm of racial issues toward children of color. One of the most painful racial slurs for African-Americans is the word "nigger." Delgado (1982) explains that race-based stigmatization is one of the most fruitful causes of human misery and that poverty can be eliminated, but a person's race cannot. He goes on to say that stereotyping and racial slurs can injure a person's dignity and self-regard because the listener who "internalizes" the message can suffer both mental and emotional distress, and often due to retaliation, physical harm to their target. In addition, he states that, "Subtle racial stereotypes transmitted through films, television, videotapes, and other popular media can leave deep emotional and psychological scars on children of the targeted ethnic group, and on others as well" (129). Both

writers agree that racial slurs and stereotypes may cause long-term emotional pain. In addition to pain, Delgado expresses that children come to question their competence, intelligence and worth. Waugh (1999) adds that teasing and name-calling a child with albinism is very dehumanizing and, “Almost all children will encounter this during the school years, and they need to develop positive coping strategies.” She goes on to say that parents and the school should increase education about albinism to help with the problem.

Although Taylour was called an albino and white nigger, the African-American stereotype of the word attached itself to her identity. The students looked passed her white skin, and found her ethnicity. In addition, during the second grade when her parents brought in a person to discuss and educate the students about albinism, it actually made Taylour’s situation worse. Stereotypes overpowered education with regard to albinism in this particular case.

Who Defines Disability?

Racial epithets were not the only derogatory actions Taylor faced; she was also told that she was from another planet and singled out as being a freak. This implies that she is not normal. Waugh (1999) explains:

“Albinism carries with it myths in cultures throughout the world. These run the spectrum from the notion that those with albinism have magical powers to the belief that they are retarded... The media including literature and film, have contributed to stereotypes of albinism. The character with albinism is often portrayed as villainous, deviant, supernatural or sadistic. Also some news reports and encyclopedia articles have included false or incomplete information about albinism. It is difficult for the public to know what is true and untrue about albinism” (2).

During the 1800s African-Americans with albinism were considered as disabled freaks. Martin (1962) explains that, “It is important to note that at this point in time the bodies of African-American men and women... qualified as disabled under this rubric (the disabled body is not self-reliant) since they were deemed incompetent to perform the rites of citizenship” (3). The Americans with Disabilities Act (ADA) defines a disability as an impairment that limits one or more of the major life activities of an individual. However, disability theories, which consist of many definitions and paradigms, do have one commonality. Pfeiffer (2001) explains, “Many people with disabilities live lives not acting as if they are disabled. It is only when they encounter acts of discrimination based upon artificial barriers that they feel disabled... They are not being treated fairly and not being treated as other, non-disabled people” (41). Neither the general public nor those with albinism agree about whether to identify albinism as a disability. This ambiguity creates a problem in the language used to talk about albinism. The disability is the eyesight impairment, not the lack of pigmentation in the skin, however the appearance of a person with albinism draws more attention and less attention is focused on the concept of legal blindness. Martin (1962) concludes:

“Current critical discussion of the extraordinary body identifies vitiligo and albinism as a disability... these skin conditions cause little or no physical debilitation, yet the stigma assessed to them is the same as those that more greatly hinder negotiation with the world. Our language acknowledges this. We call albinism a disease, a disorder, we consider a person to ‘suffer’ from vitiligo” (187).

Disability theorist, Thomson (1996), in her book, *Extraordinary Bodies: Figuring Disability in American Culture and Literature*, discusses a critical rubric that defines “normalcy” in American society. Thomson explains, “Disability is not bodily insufficiency, but instead arises from the interaction of physical differences with an environment... Disability is unorthodox made flesh” (187). In Taylour’s experience, society decided that albinism was the disability, and relied on

stereotypes and myths to justify their actions toward her.

Self Identity: Taylour Defines Who She Is

For over thirteen years of Taylour's life, her identification with being African-American and with having albinism has intersected. When Taylour was three she chose a white Barbie Doll because it had similar features to her, however, now at the age of 13, the majority of her friends are African-American military dependents. She says. "We have more in common and band together whenever there is a racial incident at school."

Throughout her adolescent years, some African-American students have rejected Taylour stating that because she did not have black skin, she was not a black person. Taylour explained that in 7th grade a group of African-American girls refused to talk to her because they had decided that Taylour was trying to "act black," by wearing her hair in braids, listening to hip-hop music and having other African-American friends. She could not convince this group of girls that she was black because her skin color was white. She asked the girls, "If I'm not black, then do you think I'm white?" One of the girls replied, "We don't know what you are, you're just different." Another time a group of local kids were teasing Taylour and calling her black ghost. They told her she wasn't white or black. Taylour said these two incidents were the most hurtful times in her life. She explained that she did not feel like a person. For a brief moment, Taylour questioned who she was and if she fit in anywhere.

Unfortunately, the lack of education about albinism led to discrimination and placed her into the category of disability based on societal perceptions, myths and stereotypes. Neither the general public nor those with albinism agree about whether to identify albinism as a disability. This ambiguity creates a problem in the language used to talk about albinism. In Taylour's case, race (African-American) and disability (albinism) intersected in ways that dehumanized her, and constructed her as a racial and social outcast.

Final Thoughts

The mystery of the African-American with skin as white as snow challenges the color line and clearly implies that an African-American can be white, if affected by albinism. Critical race theory, feminist, and disability theories discuss the ways in which society objectifies people based on their race, gender and ability. For Taylour, this occurred primarily through being the recipient of racial epithets and stereotypes. The names she was called referred to the color of her skin (white, albino, powder), and to her race (nigger, black). In addition to the racial epithets, Taylour was also told that she was "from another planet," and called a ghost, a banshee, and a freak, implying that she was other than normal or human. Peter Putman (1963) wrote:

"Blindness is a confining handicap, but it would not confine the boy to the life in the Negro ghettos that are the shame of our cities, North and South. If he had a Seeing Eye dog, he would be excluded for his dog, not for his skin. In blindness, he would know moments of humiliating helplessness, but not so bitter as the practice of Jim Crow, the loss of civil rights, or the experience of police brutality Baldwin describes, not in the South, but in New York City. Yet, blindness is a genuine handicap. Blackness is not. The blind man has lost an important sense. The Negro has all his faculties. The handicap of blindness is intrinsic. The handicap of blackness comes from the outside, imposed by force of the threat of force. The handicap of the American Negro has been the American white."

In other words, race and ability are two components used by society to judge and dehumanize individuals, but strong individual will and determination can only determine how they will be

defined and how they will maintain control over their lives and personal choices. Being blind and Black in America opens doors for discrimination, racial conflicts, stereotypes and racial epithets.

This case study and the many issues it raises can be addressed and resolved through disability awareness and multicultural education. Such awareness is essential for children, teachers, parents, and administrators in America's schools. I conclude with a poem I wrote the day I met Taylour. These words are my first impressions of Taylour and my personal perceptions of who defines me.

Who defines me?

My race, my gender, my ability, my ethnicity?

African, Negro, Colored, Black, Afro-American, African-American, Nanny, Gal, Female, Woman.

Who determines who I am?

The state I live in, demographics, economics, the government, the law, the census bureau, the man, my boss, my teachers, my colleagues, my family, my friends?

Who labels me?

Liberal, radical, extremist, loud, out-spoken, aggressive, strong-willed, determined, proud, ready to fight for what's right, ready to lead a revolution, scared, scorned, angry.

I am defined by the color of my skin, the texture of my hair, the tone in my voice. I am defined by my femininity and grace, my sexual preference and the way I walk into a room or invade someone's space.

I am defined by my history and past. Stereotypes that were created based on hate and ignorance but linger and linger and linger - day after day - as the years pass.

I am defined by my financial status, the job I hold, my education and where I live, what type of car I drive, how I eat, who my husband is, his rank in the military, where my children go to school, the degrees I hold and my grade point average.

Who defines me?

What do you see?

If you didn't know who I was, how would you define me?

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