

dignity:

**creative expressions from
the inspiration project**



Spring 2011: Volume 1

about:

The Inspiration Project is a volunteer collaboration between the University of Rochester and CP Rochester, a nonprofit organization that supports individuals with physical and developmental disabilities. During the spring of 2011, six writing students from the University of Rochester met weekly with six writers from CP Rochester. Through extensive one-on-one conversations, the UR students and CP Rochester adults have produced the creative works assembled here.

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preface:

I really wanted to start this program, because I wanted to show college students that individuals from CP Rochester are good writers who have interesting stories to tell. I thought it was important for students to learn about different disabilities, and I wanted the individuals to learn to work with college students and combine their Inspirations. I wanted these individuals to have an experience like they really were in college, by coming together with student writers. I wanted to show the students that we are just like them and have a voice that we want to be heard. I hope that this project teaches the students how to work with people who are different from them, and to realize that we are all really the same, even though we may have different abilities and goals in life. When you read these stories, I want you to hear what we have to say, and be inspired for yourself.

Latrice Person

April, 2011



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From the Age of Seventeen

By **Thelma Barnes**

In Collaboration with Zarah Quinn

I left North Carolina at seventeen. I had an aunt living here in Rochester. She mailed me a ticket to come here. My sisters came here every summer, and I didn't get to come. I wanted to come too. I couldn't come. I was having seizures. So my aunt she mailed me the ticket to come. I was so surprised and happy. I was living with my mother and my grandmother. She didn't know I was coming. I just ran away. What I did was when I got here: I called my mom and told her where I was so she wouldn't come looking for me. And I told her why too. I was seventeen years old.

My aunt told me I would live with her. When I got here, my aunt met me at the bus station. I went straight to her house. She had a house of her own. It was a big house. It was really pretty good living with her. I started making friends and looking for a job, taking care of old people, grandmas and stuff like that. Going to their house and taking care of them. I did that kind of work. I went to school for that kind of work. In high school I was trained to be an aide. I was going to school and working as an aide. The more I learned how to be an aide, the more I learned how to help people. I helped keep their house clean for them. My grandmother taught me how to house-clean, cook, all that kind of work.

Taking care of my cousins, taking care of kids. I worked as an aide until I started having more seizures. When they got worse I had to stop. When I first started having them I was twelve. The older I got, the better they got. And then after I got pregnant, they stopped for good. And then they started coming back little by little. My daughter's thirty years old. A lot of people ask me if my daughter has seizures. And I just tell 'em no. Now every now and then I have one. It runs through my family. I had a great uncle that used to have them. I was twelve years old when I got them. My classmates picked on me and laughed at me. I tried to walk away and pay no attention, try not to let it bother me. That's why I left home. I got out of school and came here. My sisters felt ashamed of me. They felt like they didn't want to own me or something. I was told that by having seizures I couldn't get pregnant. And when I got pregnant, my family was surprised, and so were the friends I made in Rochester.

I used to go out and drink with friends. There was a time I used to drink beer, alcohol, stuff like that. A lot of times my friends would drink with me. They'd buy beer, wine, alcohol, and we'd sit and drink together. Laugh and talk and enjoy each other. To me, I didn't want to spend my money on it. That's why

I never had drugs. I didn't believe in it. I had a good friend who died from drugs. It was an overdose. When I found out they died with it, I was in the hospital group home. I had some friends that came to see me, and they told me all about it. A lot of friends I had did drink. The other friend I had was an alcoholic. The guy that I was going with and been with, Frank, he didn't drink or do drugs.

I was told that by having seizures I couldn't get pregnant. And when I got pregnant, my family was surprised, and so were the friends I made in Rochester. I met Darryl through a girlfriend. We were just friends. One of my girlfriends told Darryl I was pregnant. She was afraid of him, too. I figured that if I told him, he wouldn't believe me. A lot of guys, when they get you pregnant, they don't want to take care of the kid. I was glad I got pregnant because I was told I couldn't get pregnant. I had a lot of sisters. My sister ahead of me got pregnant at sixteen. I watched myself having sex. I started at the age seventeen. I didn't want to get pregnant too young. I couldn't afford to do it by myself. When I did get pregnant, my aunt helped me while I was pregnant. She helped me do everything. When I had my daughter, my aunt helped me take care of her. She showed me and taught me how

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to do everything. I used to take care of her daughters, and so she helped me take care of mine.

Last time I saw Darryl, I was walking back out of the club. He saw me and ran. He knew I was pregnant. He knew my aunt, she was the kind of person who would fight men, you know? A couple times she ran men out of the house. If they were ogling me, if they tried to beat me, she chased them out of the house. That's just the way she was. She'd fight a man in a minute. He knew her too good, too. Anytime I'd be with a guy, I'd introduce

her to him. When I got pregnant, he didn't come back to my house. He figured that he wouldn't come back around no more. He knew my aunt would hurt him.

When I met Frank, I was living with my aunt. I met him through my aunt. When I met Frank, I was pregnant at the time. He was a real nice young guy. He was just a year older than me. We cared for one another a lot. He took me out a lot, he'd get me anything I wanted, anything I needed. If I asked him for anything, he'd give it to me. He cared for my daughter, treated her

like a father. He made me love him. What he did, the way he treated people, he made you love him. That was the kind of person he was. He never hit me or nothing. All I could do was love him.

When I was about twenty-eight, I got shot in the back of my head. A guy who asked me . . . a lot of guys that I meet and be meeting, they be around. There was a guy who knew I had a boyfriend. Sam knew Frank. He knew that Frank and I cared for one another. He didn't want Frank to be with me. He was just a guy who wanted to have sex with me.

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It was when I got with Frank that he started acting up. He liked me, but he didn't love me. He cared, but he didn't, you know? He just didn't want Frank to have me. He didn't want me, but he didn't want nobody to have me. He just wanted one thing: sex. He figured that he could come and see me when he wanted, and then just walk away. He asked me to have sex with him because I was nice to him. I said if I got pregnant I wouldn't know who the father was. He said, "if I can't have you, nobody will." I thought it was funny. I thought he was joking. Then I turned to walk away and he shot me in the back of my head. I woke up in the hospital and . . .

Forgot a lot of things when I got shot. It was a couple years later when I realized what happened to me. They had to shave all my hair off to get the bullet out. They told me if they didn't do it, I would die from the shot. I couldn't walk or talk. Neither one. Out of my head, didn't know nothing for a while. It took a lot to bring it back to myself. I lost a lot, you know? I was in the hospital ten years. Then I realized what it was. When my family at the time told me what happened to me, then I realized why I was in the hospital.

I was nice to everyone. That was the kind of person I was. I was kind to people, I had a nice friendship with people. And my grandmother always said, "Treat people the way you want to be treated." And I should have been careful the way I treat people. I was too nice. They tried to ask me to do things that I didn't want to do. Take advantage

of me. They tried to have sex with me, and I said no, and they would try and beat me. The neighbors would hear arguing and call my aunt. Someone would call my aunt, and she would come and chase 'em out.

Down south, where we lived there were a lot of white people. I didn't go by color. I didn't like that, you know? And then when I came here, I met a lot of people, black and white. I met all kinds of people. So if you nice to me, I nice to you. Mostly my own color took advantage of that. And I didn't like that. And I still don't like it, you know?

First he ran away and nobody knew anything. And then, he shot a girl in the mouth and killed her. And a friend came to the hospital and told me about it. And her boyfriend killed him. The same guy who shot me. You know, God don't love ugly. He dead, I'm still living. My grandmother would tell me, God don't love ugly. You can't run and get away.

So my memories started to come back after a while. But I walked for a while in the hospital. I knew how to walk with a walker. My left leg was paralyzed from the shot. It gives in on me. I'm in a wheelchair for good. They wouldn't want me to walk and fall down.

They moved me from the hospital to the group home. They didn't want me to get an apartment on my own. I couldn't get up and walk around the room or nothing. I couldn't do things on my own. If I needed help I could call somebody. I need somebody around me, somebody I can call on if I need help. I've been in

the group home ever since. When you're in good hands and you're safe, no problem. And then when you need help, you got no choice, you know? The reason they let me go in the group home is because they didn't want me in an apartment on my own. They wanted me to be safe. I felt safe, too.

A friend of mine came to the group home and told me about Frank. I asked my friend about him, they knew I wanted to know about him. When I was in the hospital, he'd come and see me, before he died. The last time I saw him I was in the group home. He died when I was there. And my aunt kept it from me. She wouldn't tell me that he died. She knew he cared for me a lot. A while back a girl set his house on fire, tried to kill him. Happened before he met me. He got burned real bad, messed up his liver. He died from it when I was in the group home.

My aunt tried to hide it from me because she knew how I felt about him. She figured I would get upset. But it made me more upset. When my parents died, after I got shot, my other aunt knew but didn't tell me. They kept it from me that my mother died.

I really don't feel too bad. I know I couldn't do nothing about it. I couldn't bring it back. I put a lot of things in God's hands. I ask God, "What can I do?" I can't call 'em or nothing. Just gotta live on, you know? I had a lot of prayer that helped me and touched me. He took care of me. Anybody that come to me, that I haven't seen in a long time. Come to me, speak to me, say

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they know me. I just give 'em a big smile, you know? Sorry that I forgot about 'em, but happy to see 'em. A lot of my family since I've been in this condition, they have been close to me, you know? If they living, and are close to me, they're far away from me. My daughter is the only one living that's close to me now. So I just be happy the way I am. I live the life I could. Can't walk like I want to, but I just do what I can – and be happy.

After I found out my aunt died, I really had no choice. My daughter wouldn't help. You know how they get when they're young. They get out there on their own. They ain't got time for you. Then they get married, then I can't depend on them, you know. They get older, and then they realize, I should have helped my mother, and then it's too late. You know. "I wish I had did this and I wish I had did that, but it's too late then." With my daughter, I know she has a job, and two kids, that's why I don't depend on her too much. Before she got married, she could have kept in touch more. And I feel bad about it, you know. Then the kids, and I said well, what can I do? I can live my life, I can't change it. My grandmother would tell me, if you do wrong, you pay for it. I thank God right now I'm still living. Like my mother, after a while of my being here, I couldn't keep in touch with her like I wanted to because my aunt wouldn't let me. Because my aunt was her sister and my aunt was close to her. And what she did was, if my mother was sick or something, she wouldn't tell me. So I couldn't call my mother like I

wanted to. And if I called her, she was never home. So when she died, they wouldn't tell me. And my father too. They both died while I been here. When I found out, they were dead and buried.

Father died when I was in the hospital, and Mother when I was in the group home. They were both living down south in N.C. And they didn't want to come get me and take me down there. They figured I would want to go to the funeral. I haven't seen them for a while. Yeah, I did miss them. A couple of times I called home, and they would say she wasn't home, but she was dead. That's the way they did me, my whole family. That's a big excuse for me not to know. That was a big problem that I had. That's another reason I didn't want to go back down South. Only friend I've got is my daughter, and grandkids, and cousins.

I like going to church when I can, shopping when I can, being around people as much as I can. I enjoy meeting people, making friends. I love to cook anything. I'd love to take care of kids if I could. I used to love to do that. I can't take care of them no more like I used to, you know, being in a wheelchair and stuff like that. I used to get my hair done all the time when I was young, anyway I wanted. I miss that. It's a lot harder now.

I used to go to church. When I was young, I used to go on my own. I always believed in God, I prayed to God. My grandma used to take me when I was a little girl. Before I got hurt I used to go to church alone. I take church wherever I go. Keep

praying to God.

I like to be clean. If you're gonna wash somebody, you want to wash yourself good. They getting paid to do it. When the boss not there, they think they can do nothing. But I watchin' them. In my days when I was working and walking, I did a lot, what I wish I could do now. I was a hard worker. I did what I could when I was able. Before I had my aunt and my grandmother, I did all the house cleaning and everything. Took care of the old people, took care of their house. In the old days I used to take care of an old woman. I'd clean the house for her, they loved me. I like people who show how much they care about me. Actions speak louder than words. You can show it by attitude and the way you act. A lot of days I think about it. That's what my grandmother told me. I think back a lot of times about it. How much she taught me, and told me.

My daughter got into drugs. I feel bad about it sometimes. I never had drugs. But I did have friends who did have drugs, but I never had it. 'Cause I know it was bad. I had a friend who died from it; I had an uncle who died from it. That's why I never touched it. She shoulda listened to me. But that's just the way it is. My aunt and my cousin told her she didn't have to listen to me. There's nothing I could say, nothing I could do, 'cause I was in the group home. So I just let her live her life. I pray for her every night and every day. I feel bad about it, but it's the truth. It's my life to live now.

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Yeats: an Interview

By Yeats Chao

In Collaboration with Sandi Cohen

Right now I'm drawing an eagle, with wings on both sides, so it's flying.

I was born on Halloween in 1950 in Taiwan. We moved to China when I was six years old. I came over to the United States at the age of seven. I came from China. I came over here with my mother, Shih. We met my father here. He came over to the United States before us. My father came over looking for a job in engineering – Father Company in Rochester, NY.

I remember seeing RIT and so much snow that people were skiing. I did not like the cold and snow. I didn't like the chills. Skiing looked scary. I never learned.

Math, reading comprehension, spelling, social studies, speech. My favorite was math. I like math a lot. No reason why. I just got into it, wanted to know things and figures and I liked multiplying. Add, subtract, multiply, and divide. Then I got an award for algebra and I said to myself, "That's way too hard." Multiplying letters was confusing.

I had to go to speech and hearing. It was two years and a half.

Sixth grade was as far as I got to. No further than that. I told them I was going to take off from algebra because I couldn't handle it. After I took off from algebra, I went to do some sort of drawing: drawing animals, writing letters to another person . . .

You know, I waited a year and a

half to go to school. I had a hard time speaking English. I learned English until I was nine. It was hard for me to comprehend. I had to say "Excuse me" often. It was pretty hard to make friends, but I got along with other Americans and got used to it.

If I could do anything, it would be drawing pictures, animals. I like dogs, birds. I can do it.

I memorize the animal. I just take a look at an animal and have it done in drawings. I would draw an eagle. Just to see a figure. I do exactly the way I see in my head.

Alice was born in 1953. I'm just three years older than her. My parents had a boy and a girl in the 1960s. Gerald was born somewhere in November in the 1960s. Jeanne is the youngest. She was born in the 1960s. Yeah, so that was two more to take care of. We had a house and the two of us [Alice and I] were busy changing diapers.

The drama was as they grew up, I had to show them the way things ought to be: how to behave, not throwing things like napkins, forks, and knives at the table, mow the lawn. My mom and dad both helped out. I would help my mother, sister, and brother and do chores like mopping the floor and vacuuming the rugs. I tried to help cook, but Alice would help out. The four of us would eat breakfast and go to school. After school, we did chores.

My mother was a housewife. She

bought a sewing machine to make my clothes and repair rips. My mother brought home a lot of food in the back of her car. She was tired, so she gave it to us. Our whole family had dinner together. Every evening we had supper.

I went to my mother and Alice. I picked the oyster out of my shell. My mother went to cook it on the stove. And daddy came home and ate it. We didn't have enough to eat, so we had to buy some more oysters. The shell of an oyster is red. The large shell part of it, where you pick the seafood out. Dark red with some orange coloring.

At night daddy had to teach at RIT. He taught engineering. I stayed wide awake. I would say to myself, "come on, come on, come on, come on, there's some food left on the plates waiting for you."

Alice helped out most of the time. She had to put me to bed. My mother checked on me. My sister, Alice, covered me up and kept an eye on me.

In school I learned to understand English and math, writing. My father took me to a doctor appointment where they put me on medication to treat severe shaking. There were also doctors for toenails, to take them off.

Everyone helped me with stairs. We got a railing so I wouldn't fall down. Alice helped me on and off the school bus. There were no ramps and I was in a wheelchair. In 1986 they changed me to a powerchair and taught me how to use it. Walker: I

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used that later, around the age of eight years old.

I went to a doctor to have my medicine increased or decreased. There was a lot of medication, new meds to be changed to. I remember going to Dr. Smith. I was able to walk, then they wanted to change my medication. That made me unsteady.

I remember riding a bicycle. Remember those four-wheel bicycles? Two wheels in the front, two in the back.

I can't even understand how people do that. I can't even understand football. I don't see how people do it. I would be able to understand baseball, kickball. When I could walk – I was able to walk.

I was the only one who had to be bathed. When daddy came home my mother would get him some cold water to drink, while Alice was upstairs washing my body.

I was allergic to cats. My next-door neighbor's cat came into our house and my mother said "Take it out of the house!" I was so close to the cat, I had tears coming out of my eyes. And I still do have the cat problem. So they gave me eye drops. I don't draw cats.

I did drawing since I was seven. When I'm drawing, I just see the figure on the wall and just draw it with pencil. Then I use watercolors and oil painting. My favorite things to draw are animals such as a whale, fish, shark. Oil painting was a mess. It was hard. I went to do it slowly. I do a lot of cartoons. I enjoyed that. I drew all of the planets in a cartoon. I took different pieces of paper and drew figures in different positions so they moved, like flipbooks.

We had chopsticks, but I had a hard time picking them up because somewhere I started not to use them right. I was the only one who was difficult using the chopsticks.

They cooked Chinese style food.

The house was decorated in Chinese style.

My parents taught Chinese when the kids were small.

When I was seven, I was messed up. That's what the doctors gave me medications for. What I forgot to do is I forgot to read the side effects. It said the medications made you unwalkable – unsteady. That's how I developed into my condition.

Step into it and push with the walker forward. Walk into it, put it down.

I used to go on the school bus and get off the school bus. He gives me the money – I just run to the store and I go back at lunch and I give his change back and he says no, you keep the change.

I moved out of my house to Craig Development when I was thirteen. It's like where they have a staff to take care of you. They bathe you, they buy your clothing, those things. I had money to buy things, drinks like soda, cool-aid, whatever sort of things. I kept on getting more interest. I learned to understand them more. I was there for seven years. I had classes at Craig, the same as public school.

When I was at Craig I slept in bedrooms with other people. I made friends, boys and girls. I got interested in speaking Chinese with other Chinese kids. I moved to Craig because my father and mother had no place to put me. So they took me out

of the family to put me somewhere to get an education.

I remember having it then I stopped shivering and getting out of it. Then I remember stopping having it, the seizures, and I knew what I was having.

In China I remember talking Chinese. Other people could understand me though young ones didn't understand me because I was talking too high for them.

I remember walking on the sidewalk always.

Write letter from right to left in Chinese. That was what the rules were, from right to left.

I write letters to my aunt, uncle, the rest I don't remember. I remember writing small things but I do remember mentioning things to my mother telling her I want some water. I want a drink of water. Alice was sound asleep and I worry about Alice. I didn't want to wake her up and bother her. I snore too loud.

The only time I remember her flying from New Jersey – that's where she lives now. She flies from Jersey to Rochester. We had a great time, speaking things, what I was doing, carrying on conversations, speaking bilingual. Alice doesn't speak Chinese so much and isn't as bilingual. I told her, "You don't speak bilingual, you lose it." Gerald and Jeanne are the same. They tell me, "Yeats, speak English."

I stopped walking, it was 1984.

I couldn't bathe myself. I wasn't able to bathe myself. I could eat breakfast, lunch, and supper. That I could do. Let's see, I was mighty mad when I couldn't walk. So I just started thinking of reading a book, to open a

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book and to read things out of a book which made me draw a picture of animals.

So I just look at the figure. This is how I began drawing animals and do it myself. I enjoyed it plus later it was more, it was full of happiness. When I see, drawing a human's body, [it's] just like you see the inside part. I most likely wanted to know how a human [worked], which I also wanted to look at the inside part of the body. How many bones on the inside of the body, bones that break and bones that were very young, breakable bones that could be shaken like elbow bones and the neck part and the hip of the body, the legs part of the bones, and any other types of bones, the femur.

I was mad and miserable to other people and they had no understanding of me. When I had to explain and talk about it, other people. I tried to express myself, the meaning but I still tried to explain each way. I tried to explain both ways, speaking Chinese and English. And it was kind of hard explaining to Americans.

I was moved to Craig and later on I went to Strong Memorial and my belongings were locked up. I could go to the movies at Strong Memorial Hospital. I would write letters to different people and do drawings, learn more pencil drawing sketches. I would stay up drawing pictures until 10-11:30pm. I slept [in rooms] with males and girls were roommates with girls. Every Thursday during daytime or evening we watched movies. I left there in 1998 and moved back to Craig.

I got [my tattoo] years back. I did ask someone who did tattoos to make a tattoo of a brain I drew on paper. I

drew it because I enjoy pictures. I just wanted it done. I wanted to see if I could do it. I sure would like to tell you why a brain. I wanted to draw a brain just to look at the inside of a head. Take a good look at it and draw it on a piece of paper to see the details of it, the cranium, the different parts of it, the size, general to look at each part of the brain. There are these lines that go around it. Just the same color red, put red as the blood as is a purple color. If you really want to know about it, I would just draw the inside. I looked at a book and took a good look at it, saw all parts: the veins, the bones.

I have my name on my other arm [in Chinese]. I do remember I had it on a piece of paper last name to the first name. Those are the rules.

I was moved someplace I never thought of.

If I could do anything I would wake up at 8:30am. I would check my list of things to do so I don't forget. For breakfast? I would have toast with butter and an orange and milk. I would get ready for showering and dry off, put on clothes – a T-shirt. Some sort of person, next-door neighbor. I would call a friend or a next-door neighbor. I can't remember . . . Nancy, Nancy Taylor. I just asked, "Could you or would you help me out? I was doing nothing but watching television." Alice, my sister, long distance phone call from New York state here to New Jersey would be nice. If I could have someone take me to use my money to buy just some food and carry on some conversation.

When I'm back at the house, watching news on television by myself, I would cook eggs in the kitchen.

I cracked eggs and threw eggshells in the disposal. Separate the yolk. Then you want to add sugar to make it into a cake – adding not too much sugar, it would be too sweet. I would take a shower, take my medicine, and go to bed.

This is my ending part of what I have to say in my life to explain how my life is like in more words of telling you of my experience. This is all for now. This is all.

Now I'm in a group home. 77 Pinnacle Road. With twelve people in the house, which is counting myself. 7:00-11:00 and they change shifts, 3:00-11:30, then to night shift. They have three people with us, but on nights it's only two.

My parents came over first. That was my dad. He found a job in technology at RIT.

When I first came here to the U.S. I didn't know how to speak English. It took me a year and a half to learn. I was only seven years old.

I think we left off when I was telling you the story of my own picture of myself. I forgot to tell you I like to draw myself, just a sketch of the face. Someone has a camera with film in it and I just look at the picture and just sketch the face. There's a picture of myself in the camera so I draw it when it's developed. Like I said before, I just look at the wall and draw it. You have a camera, you have film, you just draw from the film. It's magnificent. They don't see how I do it. "How does he do it?" I've drawn for years. Since I was, what, seven years old? And up 'til now I'm still drawing.

I've always had seizures because my mother and my father said I had it

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when I was a baby.

My mother is down in New Jersey with Alice. My father is deceased.

Gerald lives in Ohio – he works for mechanical, fixes cars, gasoline. He works at a gas station. And he's also busy with other things, other mechanical work at other places. He has to take a break, but he doesn't do it. I try to tell him to stop but he doesn't listen to me. He stays up until 2:00 in the morning. I don't see how he could stand that! 2:00 in the morning. I'd be having seizures if I stayed up until 2:00 in the morning! Jeanne, she's in Washington State.

With Alice, she does things. She works with dentists. And her occupation is dentist. And she is married to Sam and that's my brother in law. Alice and Sam were both married to each other. She flies from New Jersey to Rochester, flying roundtrip. I get a free check-up from Alice and Sam. Alice gives me a roll of floss. Besides giving a roll of floss she shows me some things that interest me, which is the gums where food are caught in between the gums. Most of the time I brush my teeth twice over. I brush them twice. My teeth I brush twice. Sometimes I brush them three times over. Some people at the house say, "Yeats, what are you doing?" and I say, "I'm brushing my teeth three times over. I want my mount to be perfect!"

Sometimes while Sam is cooking food with Alice we both have some conversation.

Today I had therapy. Mondays and Thursdays I have nothing. I don't do anything on Monday and Thursdays because they have me doing things like math or reading comprehension or writing things. I ran out of paper.

Dear Alice,

How are you? How's your weather? How's your day? My weather is kind of cool but is good inside the house. What you been doing lately, Alice? How's your son in NJ? And how is Sam doing? Would you please write to me? Sorry Alice that I forgot to . . .

I was tearing things out of a magazine, a catalog.

I went down to the house, I watched television. I watched the 5:00 news. It's supposed to be 5:00 to 7:00. I didn't eat much for dinner. I ate some fruit, but the rest I didn't eat. I was in a hurry. I had a letter to finish.



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The Home I Never Wanted

By Jane Gefell

In Collaboration with Margaret Soroka

The Flower
This morning as I was getting ready, I was thinking about a flower, from when it's a seed to when it grows.

A flower is delicate.

The rose sometimes is strong and lives for a few weeks.

Other times it will last a short time.

Well, some people are delicate like a flower.

They will blossom in the morning and before the morning is over they wilt.

I want to tell you about the home I have now. It's the home that I never wanted.

But first, let me tell you a little about myself. My name is Jane. I have cerebral palsy. I understand that you probably would like to know more about that.

When I was being born, everything went wrong. My mom and I both nearly died. I had a lack of oxygen and turned blue. As a result I have brain damage which affects my motor abilities. What I mean by that is that my walking is unstable. I use a walker or a wheelchair, though through hope and Jesus' Grace I do sometimes try to walk without anything. I also have a speech problem. What I mean by that is that it is hard for people to understand what I'm saying at times. But I don't give up too easily, I'm a fighter. I do have

problems with my hands. What I mean by that is that it's hard for me to pick up small things, or to button a shirt, or to tie my shoes, or to put my own hair up in a bun or something like that. I do have trouble learning some things like math and spelling and other things. What I mean by that is I have trouble counting money, but I can read a newspaper or book just fine. But sometimes I have to read out loud, and I like to listen to somebody reading to me.

I just want to make one very, very important point. People who have cerebral palsy can do anything that anyone else can. We just might take a bit longer at doing it. What you take for granted, we have to work for a lot more than you. Like writing this page, it was emotionally difficult for me. But writing it was easy because I love to write.

Because of my cerebral palsy I don't have a normal job, and do what other people do. But during the week, I do have things to keep me busy. I have a life. I go to CP Rochester 4 days a week. I've been doing that for 30 years. And on Fridays I go to Open Door Mission. I've been doing that for 14 years. I go to the Al Sigl Center, and they help me to do things. They help me to cope with my cerebral palsy and with my life. Here is what goes on at the Al Sigl Center: We do physical therapy (PT), occupational therapy (OT) –

we do exercises with our hands and arms, speech therapy, and when you get older they work on maintaining whatever abilities you have. I help out at the center. I hand out mail and I help make copies.

I grew up in Webster. My family had eight kids, and I was the youngest. When I was young, I thought I could do anything. I saw myself as handicapped at the time. Not as disabled. In my mind these words are different. I was able to do a lot of things. If you saw me sitting in a chair, or on my bike, you would think I was like anybody else. Yes, my bike was a three wheel bike, but I rode my bike so well. I felt liberated on my bike. And I remember before we had to wear helmets, my hair would blow in the wind. Sometimes I would ride so fast. I was happy at home.

But my life changed overnight when my mom died. That was a really difficult time for me.

Thursday, November 18, 1993

...Thursday night everything was going good. Mom and I did our Bible reading together and then Mom was reading a book by herself and I was listening to a book I think.

I went to bed. A little while later everyone was in bed. Then Mom got up and got sick and threw up many times. I was awake while that was going on... Whenever mom would get sick like that I would get so upset. I am always very protec-

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tive of my Mom. When she would go upstairs I would say a prayer for her. I worried about Mom. Emotions okay.

Friday, November 19, 1993

Friday morning I got up early and got myself ready for my day and went to program and I did what I had to do... That day I didn't feel too good. My emotions were mixed. I was a little sad that day.

Friday night when I came home my mom was still in bed. Inside I was upset. I was watching tv that afternoon and night and some bad thoughts were going through my mind about me and Mom. It came time to eat our supper and Mom didn't get up then. That really got me upset when Mom didn't get up to eat with us but I didn't say anything until I went to the bathroom where I could yell some, but not too loud.

Mom did get up that night for a short time but she was so sick that night. That night I had planned on doing some work in my bedroom. I got ready for bed that night. Then I did some work. I didn't think that it would be too long and I would go out in the living room and be with Mom and Dad. But Mom went back to bed before I was done working. That made me so sad. Deep down inside I knew something was about to happen.

I'm not a good sleeper and I hear what goes on and I would stay up for Mom incase anything went wrong. I always worry about my mom and I always pray for her. I was protective of my mom and I didn't want anything to happen to her. I love my mom very much. That night things

seemed to be okay. Emotions were mixed.

Saturday, November 20, 1993

Saturday was a rotten and awful day.

I got up early to go to the bathroom and I went back to bed because no one was up yet. So I went back to bed, but I didn't fall back asleep. My dad got up a while later and was eating. Then Mom got up to go to the bathroom and she went back in her room. Then mom came back out and dad had to help her. Something was going on. I was still laying in my bed listening to what was going on and praying. Then I got up and opened my bedroom door and I saw my mom was all bent over like a really old lady. Mom could only moan. She didn't talk. When I saw my mom like that I yelled "Jesus, you gotta help my mom now." I was yelling I was so very upset. I also was saying "I gotta help myself. I gotta help myself now."

Then all hell broke loose. Dad called my aunt Dorothy to come, and Dad called 911. EMTs came and everyone else. Everything went wrong. My mom stopped breathing. It was awful rotten to be home, when everything was happening at the hospital. They took Mom to RGH. The morning went on. Helen stayed with me.

Pat came over. Then Ray came over. I said "Why don't we all go?" So Ray, Helen, and I went to the hospital. That was the best thing we did. We went into the room where Mom was and stayed with her. But mom was out of it. Mom was a machine keeping her alive and her mouth was all taped up with a

tube. It was rotten. I told Mom to wake up. I thought mom would be like that for a short time and then Jesus would give my mom back to us all healed up. At that time I was able to, by Jesus' Grace, think about what I needed to do if Mom died. Like, I needed to get an aid to come in to help me. Even though I was so upset I was able to think about these things.

The hospital staff and the chaplin were wonderful. Thank you Jesus for all the wonderful help. My whole family was at the hospital. All but Frank who lives out of town.

After a while the staff came and said they couldn't do any more for Mom. So we had to make up our minds as to what we wanted to do. So we let Mom go.

My mom died as soon as we took the machine off of her. Mom died between 2:38 and 2:40 in the afternoon. It was the most rotten day of my life.

I lived at home after my mother's death for a year. That was no picnic. The home that I grew up in was something else. It was an extremely sad home. Sad stuff went on at that time...

Now, this is where the story about the home I never wanted begins.

One night, I was hanging out in the living room with my Dad. It was only him and I. We were watching tv together just like normal. But then my dad said he had something to tell me. He had received a phone call from the EW group home. They said they had an opening, and they were asking if I wanted it. I cried a little that night.

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Before long I went with my dad and my sisters to see the home I would live in for nine years. It was snowing. I moved there on February 3rd from my home in Webster.

I wonder what my mom thought about this in Heaven. What were my thoughts about life in a group home when I was younger?

When I was younger I did not want to go to a group home. I just thought I could do anything. I thought I could live some place other than a group home – maybe in an apartment with aids that would come in and help you with your needs, or in a house with a few people. That was my dream. I wanted to live freely like my family. I wanted no part of a dumb ugly group home. I was so angry when I thought about having to go to one.

My mom felt the same way that I did. For years, it was so hard for us to talk about them. I had other ideas about where I wanted to live: first I wanted to live in an apartment, then I talked about living in a house with someone. When we visited some high rise towers with a group, my mom asked me to promise to her that I would never move into someplace like that. She was afraid that if there was a fire, I wouldn't be able to use the elevators, and I wouldn't be able to get out of the building. I said, "Mom, I promise you that I will never live in a high-rise tower."

Mom and I would talk about plans for my life. We would think about what I would do when I was older. It was very hard for my mom to think about my older years. And it was rough for me to think about leaving the home where I grew up,

and leaving my mom and dad.

We had a neighbor who lived on the next street over from us who had special needs like me. He moved into a group home. When he was home, he would come by our house and tell about the group home. I was bad. In my head I would call him a "groupy" for living in a group home. I just didn't want anything to do with a darn group home. I was angry inside every time I thought about maybe someday going to one. I was a very very sad young lady. I just wanted to be like the rest of my family- to have a place that I could call my own, just like my brothers, sisters, and cousins had. My mom and dad wanted the same thing for me.

My life changed when my mom died. When my mom died I arranged for an aids service so I could get the help I needed. Well, I found that having the aids service come to my home was not that easy after all. Jesus showed me that it might not be for me to live on my own. The placement in a group home opened up, and yes, I gave up my dream of living independently, and moved into the home I never wanted. Over the years it was for the good. I need more help now. Yes, it was very difficult to give up my dream.

It was snowing and it was cold and when I moved to the group home. I was the only one there. It was a Friday. My sister's helped me unpack in my new room. It was a nice room, with a view of the outside yard, and we brought my furniture from home and all of my things. But when my sisters left, I didn't know what to do. I went out

of my room, to where the staff was, but they were talking about someone who was very, very sick. I didn't know what I should do.

My first night was a taste of what was to come. I was sitting in the living room and watching tv or whatever and up comes this man, or a boy. He was one of the residents at the home. He had behavior problems. Up came this boy, and he hit me. Before I moved, some of the residents had warned me about him. But I thought they were fabricating. That was a taste of what was to come. That first night I probably didn't sleep. I'm usually not a good sleeper anyways.

EW Home, was a very rough start to living away from home. It was so rough for me. First we had that person who had the major behavior problems with hitting and stuff like that. The one that hit me on the first day I arrived. He would hit me often. And not just me, I think he was hitting other residents as well. He would take away someone's walker, and many other things. We were afraid of him. We were hiding in our rooms like battered women. That's what it felt like.

I don't remember how long that went on for. But it was bad. Finally we called the families of the residents for a meeting. I talked to them about what was happening. Before I came to the home there hadn't been a resident who could communicate the way I could. After that person moved out, the group home life did get much better. But there were other people with behavior problems too. So things were never easy.

There was one other big hump I

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had to overcome. There were ladies who still had their mothers. That was so rough on me.

It also just isn't easy living at a group home with all the staff, and knowing what they expect from you with all the dumb written goals and all the notes that all the staff keep on you, because the state says so – it's not fun. People who live in group homes have to have written goals because it's one of the state rules. I wonder if the state workers and their families have written goals that they have to live by like us? I think not. Then why should we have to be scrutinized with our lives when

other people don't have to be? Yes, I know it's for our own safety. That's ok in a way, but it makes me feel bad that people and the state are so untrusting that we need every little thing and every little darn word written down. Because no one is trustworthy of our word.

Yes, everyone has some kind of goals in life. But for most people no one is over their shoulder breathing down their butt every time they make a move. It's sad. It's very difficult living in a group home. I understand why they are like that. The rules come from the time of the Willowbrook State School, when

people with developmental disabilities from the 1930s and 1980s were put in an institution and they were neglected. Thanks to Geraldo Rivera, people learned about what was going on. He was the one who made it come to halt. He shut it down. I remember that. That's why we have those rules now. They came from the Civil Rights of Institutionalized Persons Act of 1980. It was probably where they all came from. I understand why they have all them rules. They are important. I am sure that other homes like nursing home and adult living centers have to do the same stuff as the group homes.



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But still, it's very difficult living in a group home.

I used to live at home with my family. Man I miss that freedom of being able to do things without no one watching over to see if we did everything the right way or not. The normal way of life, it may not be possible, but it'd be freedom. Put it all in God's hands. That's his job to keep us on His path, not the State's.

There were some good things to living in a group home. I knew some of the people before I moved into the EW Home. There was one very, very special peer, a woman. When I first moved in, there was a young lady who wouldn't talk. I think she was autistic. I worked with her and worked with her. I got her talking. And after that she wouldn't shut up. She and I were like two peas in a pod. I loved her so much. We would get in trouble together, like sisters. I loved her. While I lived at the home we would hang out in her room and watch tv together. When she died of cancer, her sister gave me her television set. Getting my friend to speak to me and the rest of her peers was one of the best moments I had at EW.

Also some of the staff were wonderful. When two of the staff acted really goofy over the intercom it would make me laugh. One of them would wear a really funny hat and dance funny. Those were some of the highlights that got me through the tough moments.

This staff member K would make you laugh when you felt sad or something. She was a huge part of our lives, especially my life at that

time

Sometimes we would do things on a whim. Like once we went somewhere to a pumpkin farm for a hay ride or something. I think we got lost and we ended up going for a longer ride and getting a pizza at a dive. We got home late. K was driving and we had lots of fun. We did have a lot of fun in the beginning. This is a happy chapter to write.

We had wonderful birthday parties. We had great Christmas parties. They were awesome! My first Christmas that I spent at a group home, my family came. We had a lot of people there, and a lot of food, and good times. Then over the years the Christmas parties got too big. The group home was too small to hold all the people. So, we would go instead to the place where we have program every day, and we held the Christmas parties in a gym where everyone could come. And K and E would help put everything on. We had a lot of decorations. There would be a Christmas tree, and presents, and a lot of food. And we had Christmas music. My favorite song is What Child Is This. And one year, in the gym, there was a huge tub of balls. My sister and I got in it. We threw balls at each other, and it was fun. K and E organized all of that.

K made our group home a really nice, happy, and loving place. It was a real home. I remember just sitting around in the living room or at the dinner table talking or playing a game just to have fun. I took those moments in and really enjoyed them. Those times reminded me of being at my home with my family

playing games and enjoying each other. Those were the moments that brightened up my life. EW was a warm, for the most part happy home. I did enjoy my time there.

I lived at the EW Home for nine years. But back then, it was easier to get around for me. I could stand up alone and put things away on my own. I used to be able to stand because I had both hips. But then my left hip died. For a long time they didn't know what had happened. Then I had an MRI, and they determined the cause. I had to have surgery to have the left hip removed. After that my friends called me "one hip girl". I was in physical rehab from July 23 to October 2003. I came home on my uncle's birthday. Then I went back to the EW Home. I had to work on getting back to where I was before the hip surgery. But after a short while, I found I had broken my leg. I broke my left femur, where there was no hip. I had so much pain. Thank you Jesus for the shots I got in my leg. After that, I could still use my left leg, but not as well as my right leg. I needed more help. All of my strength is in my legs, but with only one hip my balance was thrown off. So I could no longer get out of my chair on my own and stand like I used to or move about well. Also I had a tumor in my arm and when they took it out, my arm was weak and I broke my arm. I needed more help.

Before that time, I felt like I did not have a "disability". Instead I would say I had a "handicap". To me, "handicap" means I can do things for myself, just dif-

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ferently from other people. But disabled means I need more help to do things. To me, now I'm more disabled. When I was handicap I could take myself to the bathroom. I could get out of my bed. I could stand up on my own. But now that I'm disabled, I'm not able to go to bed on my own. I'm not able to get out of bed on my own anymore. I can't walk with a walker on my own. I am not able to stand up on my own. And that's how I see the difference. When I was young, I could get around with barely any help. I could walk a little on my own, or with a walker or cane, or grab the wall. Yes, my family would walk with me and help me. But I could move freely by myself. Mom and Dad saw that I needed to try to do stuff for myself. But that all changed after I had my hip removed. So on February 1, 2004 I had to move to a home that could help me more. I moved to the B Home, where I am now.

Now I live in a huge group home with twelve other peers, and I hate it a lot. Twelve residents in one home means you might have a lot more staff, but you can never have enough. Because when you have twelve peers in one home, a lot of the time we all need help at once. You need to go to the bathroom, but you need help in the bathroom and so does everyone else. Sometimes after you wait your turn, the urge might be gone. If you complain, depending on what staff it is they might be mean back. So you try to keep your mouth shut.

I miss the smaller EW Home very much. I grew up in a large family of

eight kids- I'm the eighth child- so for me living at EW was no problem. But when I had to move in with twelve people it was quite overwhelming. There's a huge difference between eight people twelve people. With eight or nine people, if a few people go out, things quiet down. But when you have twelve people in one home, it's always noisy. Twelve people all have different behaviors and personalities, and have different needs. You can't get away from it all. With so many people with different needs, sometimes I feel like I'm in a hospital. A hospital is not a home. That's the way I feel, and I won't apologize for feeling that way. It's really hard to live in a huge group home. Not everyone can live in a group home. It takes a lot of perseverance.

This group home is a hospital way too huge and with too many people in one home. In our group home, because the house is so huge, I asked them to put bells in the bathrooms and in the bedrooms because it's really difficult to call out all the time. But sometimes the bells are a pain in the butt too. You still have to wait for the staff... sometimes I think they just make you wait, because they are being butt heads and are being lazy.

I feel like I moved into an old folk's home. It's not easy living in this group home. It's what I call an old group home. Some of the people are much older. And they have problems that older people have and that gets hard for me. Sometimes to me I feel like this is a nursing home, except one where the residents need even more help. I guess you have

to be here to experience what I feel. Yeah, after my hip was taken out, I needed more help too. I still have my own bedroom like I had at the EW Home and I have to keep it clean like I did at EW. I do my best. I have two hands, but a lot of times I use my feet for hands too. But still, I need more help than I did at EW.

One of the worst parts is that where I am now is a big group home with no sidewalks and a lone-way bridge. I feel like I live in a cage. I only go from home to program. We do go out of the home but it would be nice to go for a long walk. I lived in Webster all my life before the group homes. Where I lived, we had no sidewalks. So for a long time I couldn't go out for a walk by myself. Over time, I did go out for walks, but usually not by myself. When I was thirty-four, and moved to the EW Home, after a while I got a power wheel chair and around the EW home they had sidewalks, and I could go all over the place by myself. It was heaven.

August 16, 1995

My first power wheel chair at the age of 34 years old. August 16 1995. My life will change now. I want to get a volunteer job outside of program and outside of the house. I want to go places with my new power wheelchair. Most of my life I have wanted a power wheelchair. But the opportunity never came up until now. I lived at home for 33 years with Mom and Dad. Mom and Dad's house did not have a ramp for me, so I could not have a power wheelchair. The only regret that I have is not being able to see

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my mom's face. I know that my Mom sees me but I can't see her, and that bugs me. I know some people can share and I can see those faces. I wonder what my Mom is saying to Jesus right now.

But now I'm stuck at this cage. At the B. Home I do not like the neighborhood at all; you really can not go far. How can you go anywhere when there are no sidewalks? The B Home is not really made for me. I am not comfortable in this house like I was at EW. At the B Home I cannot reach things like dishes, cups, and food. The house is way too huge.

I feel like I have lived a double life, because I used to be able to do a lot more for my self. When I lived in my home, in my real home, I was free and could do whatever I wanted. But when my mom died, I had to move to a group home, where there were bureaucratic rules to follow, and where there were people that were difficult to live with. And then when my left hip died, I had to move again into a big group home, a home that is not a home. This is a home that I never wanted. It's an old folk's home with no side walks. I hate it.

But I can't just leave, or find a different group home. Let me tell you how you get into a group home. First, you have to apply and fill out many forms before you get on a very long waiting list. Sometimes you can be on the waiting list for years, I'm sorry to say. They have to find you the right home for you, and sometimes you get in that group home only find out that it's not the

right home for you. What can you do? Can I move out? Where will I go? Is there another home or another place? Or sorry, you just have to put up with this home. We did our best. Wait until there's another opening at another home.

I'm trying to get back to where I used to live, the EW Home, with God's help. Or maybe it's just a pipe dream that I have. I am getting a lot older. I'm pushing 50. Some people are trying to show me it won't be easy. People with cerebral palsy age more quickly. I guess it might have to do with the way we move around.

Oh, I do have some good and wonderful times too. I don't really care for the B Home, but this is what Jesus had in mind for me all along. I am grateful for what God gave me; that I have a roof over my head and a warm place to stay. Every human being needs a place to live. Sometimes in life we are given a cross to bear. I wanted to have a home like my family does, but for various reasons I had to give up that dream. God gave me this cross to undertake.

Afterword

I'm writing this essay to help the general public to understand about group homes and how they work, and I want it to become a book.

A group home is a unique home with people who have special needs. It's for people who can no longer live at home, because they need twenty-four hour care. Their family members or other people who were taking care of them placed them in a group home, for peace of mind,

so that they would know they were getting the care they need. The person who has special needs may be in a wheelchair, and as they get older might not be able to help themselves as they were able to before. Or other people with special needs might have behavior problems, or be blind. There are so many reasons why people move into a group home.

Depending on what the problem is, you have to make the best of where you are living for the time being. And be blessed that you have a home. It may not be what you wanted or need, but in time something will come for you.

The first home I lived in was a smaller home which had only nine residents in it. That home was a great home. Not too big and it felt like a normal home. The ones who worked in that home made it homely. But the home I live in now is too big. It's not a home. There are too many people, and the home is in a neighborhood with no sidewalks, so we have no freedom.

Group homes come in all shapes and sizes. But the consumer's ability to pick and choose what home they live in is very limited. This is an injustice.

Note: The names of homes and people were changed to protect them.

My Life

By Kathy Hendrick

In Collaboration with Taylor McCabe

I was born in Rochester on December 10, 1953, but not in a hospital, in my parent's apartment. My uncle was there, but he didn't cut the cord—the doctor did. I weighed five pounds, a little tiny thing. I had six brothers and sisters.

My brothers were named Tommy (the oldest) and Bobby (the sixth). My sisters were named Betsy (the fourth), Maize (the third), Patty (the fifth), and Chrissy (the youngest). I was the second oldest.

We had a lot of pets growing up: dogs, parakeets, one kitten, a lot of pets. I also had a guinea pig, named Rolling Paully, but it died. I had to put it to sleep, because it had been sick. That was hard.

Now, Tommy has a wife named Robin. He has two kids named Mikey and Joe. My brother Tommy likes to hunt, which means there is always a lot of food at his house. Tommy went turkey hunting for last Thanksgiving, and my whole family ate turkey at his house.

Maize has a son named Danny, and two daughters named Kim and Stephanie. Danny has a wife named Sue, and they have two children named Chastity and Crystal.

Kim has a husband named Patrick who has a little girl, but I don't remember her name. Danny and his family come up to Rochester every

summer, so I get to visit with them. We always watch a lot of movies when Danny comes.

Betsy has a roommate named Linda, and Linda has two kids named Mikey and Robbie. Mikey is getting married soon. Betsy has a dog, named Bella, who had puppies who were born on February 26—there were seven boys and one girl.

Betsy always has puppies, but she always sells them. I go to play with the puppies every Easter. I love playing with them, since they're so cute! But they do grow up fast!

Linda is a chiropractor, so she helped me out when I had a problem with my back. I don't know how she did it, but it helped a lot. Her office is at Betsy's house, since it's cheaper to have her office at home.

Patty married Steve, and has two sons: Chris and Kyle. She has three daughters: Tracy, Jessica, and Jenny. Tracy has a husband, Aaron. Bobby has a wife, Cindy.

They have two boys, named Robbie and Tommy, and a daughter named Chrissy. Chrissy has a husband named Matt. They had a dog, named Zeke, but he died.

Patty used to work in a restaurant, but now she's a nurse. She hasn't been a nurse for a very long time, though. She has always liked helping people, even when we were

young.

It was fun growing up with so many brothers and sisters. Sometimes we fought, but you know how kids are, everybody fights sometimes. The fights were always playful, and a lot of them were pillow-fights. We went to the movies a lot and we went to the mall to go shopping. My favorite movie is *Sleeping Beauty*. We went to the *Phantom of the Opera*, which was good. I also like the movie and I own it. We saw it in Toronto, Canada. We stayed at a really big hotel when we went to go see it. The trip was fun.

We also went to Niagara Falls, and took all the tours. We went up in the CN Tower, which was good. We went in the summer. I was about twenty years old. I went with my whole family.

I went to school at Longridge School, in Rochester. I switched to a lot of schools to take Special Ed, because they moved the program around, I don't know why. I don't remember the names of the schools, just Special Ed and Longridge. I was on the honor roll three times. I was good in gym. I had a little bit of a hard time with science.

I graduated from Greek Athena School in 1973. My best friend there was Kathy Spring. We played games together, like Twister. She

was in Special Ed with me.

I was the school bus mail girl after I graduated, but in a different building, for extra credit. I stamped mail for the school. I had to quit, because it was time to move on. Then I went to another school, called Alsign 1. I worked there with camera parts, putting them together to make cameras. I didn't like it, because it was hard for my hands. That's why I quit.

Then I went to U.C.P., which is where I go now. I live in a house for U.C.P. in Irondequoit, on King's Highway. There used to be just one U.C.P. house, but now they have

seven. I live in one of the newer ones, but I used to live in an old one, but that's a long time ago. I like the new one better.

My favorite thing about living at U.C.P. is that we go out. We go bowling, and we go out to play bingo. We go to the University of Rochester, and we go shopping. I like shopping for clothes. My favorite store is sometimes Target, but it depends. We go a lot of places. If you ask, they will take you where you want to go.

I also like about U.C.P. that we celebrate holidays. On St. Patrick's Day we have corned beef and cab-

bage. On Christmas we have ham, and we have turkey on Thanksgiving. We exchange gifts on Christmas, and have Easter Egg Hunts on Easter. On Valentine's Day, we make cards for each other and for our families. For New Year's we have snacks and stay up until midnight to watch the ball drop in Times Square on T.V. It feels the same as holidays with my family.

I am the president of a club. It's called Kwianis, and our group is called The Aktion Club. In the club, we have meetings, where we talk about where we want to go, and we have soapbox car races. The club



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makes the cars for us. I drove one, and it was fun, and I'm going to go to drive it again, in June. The race will probably be by Lake Ontario.

We go to ball games, and the club pays for it. My favorite team is the Red Rings, a team from Rochester.

We go out and have dinners. My favorite food is spaghetti, and sometimes I eat it when we go out, it depends on what I feel like.

One of the programs we do is art. I like to draw. My favorite things to draw are birds and horses. We do art every Monday, and we've been doing it for about a year.

We have a teacher to teach us math. I like math. We have another teacher who teaches you spelling. That's helpful when I use my DynaVox.

My DynaVox is a machine I can use to type out words to help people when they can't understand me. The DynaVox will say out loud what I type. It helps me talk to the doctor and my teachers. I've had it for five years. I like having it. I can use it to send emails.

The teachers only sometimes understand when I'm talking, so I have to take my time when I'm explaining something to them. In our spelling class, we read about famous people and have tests on them. Frederick Douglass is my favorite famous person because he is from Rochester. I also like Susan B. Anthony, who is also from Rochester.

I went a long time ago to see their graves at Mount Hope Cemetery. It's a really big cemetery. I went there with my old group home,

which was called Elwood. Elwood was okay, but I like U.C.P better.

I like the people I live with at U.C.P. We do programs together. I have a roommate named Rita, she's a good roommate.

About four years ago, I went to Florida with my family because my dad was going to die. We went because he wanted to see everyone. We went to Walt Disney World, it was great. My favorite part was the It's A Small World ride with the different countries singing. Then we went swimming. It was good. Then we went back home.

We went in the spring, so it was still cold a little bit when we got back to Rochester. When we were in the airplane, my ears cracked. It hurt.

One time, I went to Hersey Park with Betsy. It was great. We took a tour there of the chocolate factory. At the end we ate a lot of chocolate. The tour was in a kind of train that worked almost like a roller coaster. They had games there, too, like throwing darts to pop balloons. I was pretty good at that, and I won a prize. It was a big, blue stuffed whale, and I still have it. Blue is my favorite color.

I use email to keep in contact with my family. I talk to all my siblings a lot, but I talk to Betsy the most. She lives in Irondequoit, and she comes visit me a lot. When she comes to visit me, we go to the movies. I went to go see all the Harry Potter movies with Betsy and Chrissy. I like Harry Potter a lot, he's cute! We just went to go see Rango. It was funny,

I laughed a lot.

When I go to the movies with Betsy, I usually just get Coke, because I can't chew very well. My favorite actor is Johnny Depp, he's cute, too, but he's married. Too bad! I have seen his other movie, Pirates of the Caribbean, but only the first one.

There are have been hard times and easy times, but as I get older, I realize that I am doing fine. I think about my family a lot—they're all I think about!—and I'm very glad to have them. I hope that the rest of my life is just as happy as my life so far has been—but I'm pretty sure it will be!

Dignity: 22

I Am a Dreamer

By Toni Montgomery

In Collaboration with Ripa Chowdhury

20 Lone Oak Cir. is where my new home is at. I moved in there in 2008. Wow! It has been two years and four months! My times here have been truly blessing and I am thankful for all the support that I get from the staff. They are like my family.

The most important place to me is my home. My bedroom is pink. Pink is the color for cancer awareness. I like colors, especially light colors—pink and red, that's it. There is a big bed, a dresser, a wooden white desk, and a chair. The desk and the chair are my most favorite furniture in the room since this is where I enjoy writing in my personal dairy. But sometimes I actually like sitting on my bed while writing in my diray since the chair is very hard and uncomfortable. My bed is very comfortable. It is decorated with comfy pillows and a bed sheet that has a mixture of pink and blue colors. I also have a Hello Kitty blanket that is all pink. I love it! I got it from a friend on my birthday. There are pink and white curtains on my window too. I open the curtains in the morning, a little bit, not a lot. I don't like the bright light of the sun. When I get up in the morning, I look at the pictures on my desk. I look at the picture of Oprah. She signed it with a black pen! Then I put my clothes on and get ready for the day. I eat breakfast. My favorite breakfast is Special K Chocolate Delite. I like the little pieces of chocolate bar! Then

I go to different classes like writing, acting, painting, sewing, and physical therapy depending on which day it is.

During my free times I watch movies and listen to my favorite church music. My favorite singers are Shirley Caesar, Kirk Franklin and Fantaisa Barrino. I have a flat TV on the wall, a small CD player, and a laptop where I saved lots of movies and songs. I love Tyler Perry and Jamie Fox. Tyler Perry is a good actor because he can play so many different parts and talk in so many voices! He is cute too! Jamie Fox is also very funny. Both of these men are so fine! I really liked watching the movie "Dream Girls" and Jamie Fox was in it. I got this movie in my collection. I also watched "For Colored Girls." I liked this movie too but the ending was sad. Both of these movies were inspirational. It inspired me to dream. You know . . . I like dreaming, especially when I am sleeping.

I sleep like a baby at night but I have a machine that helps me breathe because sometimes I have trouble breathing when I am sleeping. I think this is because I am overweight. I am trying to lose some weight by dieting. I want to live healthy. I don't want to die! NO way! I want to live and explore life. I am a fighter! I am a dreamer!

I have many dreams and I like to imagine a lot of things. My goal is to have my own apartment. I want it to be like a pink wonderland and it will

be Toni's. I like to imagine it. My apartment will have a table this big, as wide as my arms when I hold them apart. There will be dishes. I have my mom's special dishes in a glass chest. There's a candy dish with a Christmas tree. There are dishes and cups with gold around the edge. And there are dishes with green flowers. There will be a pink Lazyboy chair and a little couch. My kitchen will be small, with a low counter because I'm short. I've seen the kind of stove I like on TV. It has knobs that turn and flat burners. But I won't cook. People will help me. I'll plan the meals, though. I'll make good choices! I'll have salad, tomatoes, a little low-fat cheese, Italian dressing. I'll put lemonade in the refrigerator to keep it cold! My bedroom will be a big one, with a big bed, my dresser, and a wooden chest for blankets. I'll put my desk in the living room. I'd like to have some visitors, like my best friend Amanda, and Kia. I'll have staff coming in each day to assist me. One day I'm going to have a housewarming party—with girls, no boys, no boys! Power to the girls! First I'll decorate the apartment, I don't know how. I'll think of something, maybe some small flowers in the kitchen. Then I'll get some Diet Pepsi and Coke, low-fat chips, and onion dip. We'll play some name games. Maybe we'll paint my bathroom. We'll paint it pink and white! But what I really look forward to is the quiet time when I can draw pic-

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tures to put on my wall. I'll also put up photographs of my family, my nephews and nieces, my dad and my stepmother, my stepsisters, my sister Ki-Ki. When I look at the pictures, I'll think about my family. I love them and I always will.

I love art. I paint Oprah pictures. I go to the art shows in the library. I will soon have my paintings in the library exhibit. I am very excited! I want people to buy my art. I don't know but I hope they will. I don't want the money for myself. I want to give it to the program so that they can have

enough money to buy more paintbrush, crayons, and sketch books. I dream to have my own studio one day where I will have lots of drawings on the wall. There will be many different colors and paintbrushes for me to use. I will put my signature on the drawings and have my own art exhibit where other artists and people from all different places will come to visit.

Finally I dream that my story will inspire other people and let them dream too. I want my story to be in the news, on TV, and on Oprah Winfrey show where I can very much wish

to be a guest and talk about my experiences in life and how I struggled and came this far. I never gave up; I kept fighting. Despite all the troubles I faced when I was younger and dealing with the deaths of my mother and my little brother, both of whom I love and miss very much, I am glad and very thankful to god, the staff in my program, and my friends for helping me daily. I am also very happy about getting to share my story with others. I will keep living, fighting, and dreaming just like Martin Luther King did!



Dignity: 24

Poems from the Chair

By Thuan Nguyen
In Collaboration with Tyler Sowcroft

My Journey

Saigon, Vietnam

A summertime filled
With unpredictable weather,
I spent this time mostly in bed
Wishing to see the world
That existed outside
The walls of my home and beyond
Saigon.

Without a wheelchair,
I made the most of my time
Speaking with family and close friends.
Soon my luck changed and my wish came true.
I was interviewed in an office somewhere in Saigon
By a representative from America, who offered
Me an opportunity to move to the great
United States.

I left Vietnam in December
And went to the Philippines;
It took four hours on a plane.
I landed in a big city.
I stayed there for three months
To learn English.
A bus took me four hours
To the camp,
And, after school.
Took me four hours back.

After I went to school,
In the Philippines, I went
To another country,
For a couple of hours,
And then, seventeen hours later,
I arrived in the United States.

I flew two hours from Seattle, Washington
To California. I lived with my sister
For one year before I moved out.
I went to Los Angeles.

Los Angeles, California

I went to the program
To learn how to act,
To learn how to speak English,
To how to be in the play.
I lived with one-hundred and fifty people.

I went to Santa Catalina Island on a boat.
I went to Disney Land;
The water park
Had different boats.

I went on city walks, in my wheel chair.
There were shops, they sold t-shirts,
Shell necklaces, water bottles, and
Hats with pictures of Disney's Cars.
I went to the movies in California;
Spider Man was my favorite.

Once, I drove five hours
From my home to Las Vegas.
I went to a concert that played 90's music.
My supervisor gave me money
To play the five-dollar slots—
I won twenty dollars.
My favorite casino was New York-New York.

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The Philippines

I go to school,
To learn English.
My teacher lets me in.
I see the white wall with letters A to Z,
I see the big window.
Outside, there are children and trees,
I see the table covered with papers
My teacher wrote.
My teacher says, "Hello."
She has long hair.
She likes to teach me how to talk.
She is beautiful.



The War

To the President and Congress of the United States,
The White House and the Senate:

I'm concerned for the safety of our great country.
Please listen to what I have to say
This is very important.

In Libya, we are fighting for the people.
Gaddafi's government is wrong
They are using their military to slaughter
The innocent people of Libya.
Someone needs to stand up for them.

We need to bring them
The doctors, nurses, and medicine
They need to heal.
Although some of our soldiers were hurt,
We need to help.
We need to give our help to everyone
Who asks the United States for help.

We need to save the people from harm.
We need to stop the war and put
Him out of power now, Gaddafi
Must go, must go in peace and the world
Will go in peace, we go in peace together,
All as one.

I Open the Door for you to Come

You come to me with happiness,
You know how I feel about you.
You make me feel good,
Like you've opened the door to my heart.
When will we be together?

I'm thinking about you
When the sun sets. And when it sets,
I go to the ocean thinking of you.
You are a flower, a red rose.
When will we be together?

I sit by the table with a lit candle.
The candle makes me think of you,
The white wax is like your skin.
Communicate, let me know.
When will we be together?

Sometimes, I get upset and need
Someone to talk to.
If you were my girlfriend, I'd talk to you.
We'd go to Alaska, to the frozen ocean,
Surrounded by the power of God,
We'd be together.

When will that be?

Message for Congress

To the Congress of the United States:
I write to you
About Medicaid and Medicare.
I advocate not just for myself
But for everyone;
Politicians are people too.

Without Medicaid and Medicare
I can't see the doctor.
Without Medicaid and Medicare
I wouldn't have my wheelchair.
Without Medicaid and Medicare
We couldn't put food on the table in our group home.
Without Medicaid and Medicare
The agencies that help people with developmental disabilities would disappear.
Without Medicaid and Medicare
I wouldn't have medicine.

People get sick.
People in the hospital need help.
Help the homeless, who have no place to live,
No food to eat,
No medicine to take.
We need to go back to the way it was before.

If helpless people don't have work,
They don't have money.
They used to work for companies;
Now we are putting factories in other countries.
They used to work in group homes
And schools. Why are teachers' jobs gone?
Our troops are overseas;
Bring them home to their families.

We need to fund daycare programs.
We need to get everyone working.
We need to help the college students,
People like you and me –
We need money to go to school.
We need to move forward.

You tell us to tighten our belts:
I cannot tighten mine anymore.

Dignity: 30

The Fictional Life Story of the Lovely Latrice

By Latrice Person

In Collaboration with Joanna Scott

Let's talk about a girl who just got out of high school and goes to her program. She just graduated from high school. Let me think of her name. Her name is Angel. Angel is in a wheelchair and she has four older brothers, Matthew, Derrick, John, and Christopher. Her brothers are all grown up and married. Angel wants to move out of her parents' house to get some independence.

She tells her service coordinator that she would like to move out of her family house and try living independently for her life. She knows it will be an adventure, it will be challenging, but she knows that it could be fun, too.

On a cold snowy day in December, December 27th, she moves into a house with five girls. Some of the girls can walk, and some of them can't. Some of the girls can't see, and some of them use sign language. The girls who can't talk use their hands, along with a box that has pictures in it. The box talks for them. It's called a Dynavox. They find the picture that they want in the box and then press the button, and the Dynavox talks for them. Angel thinks that's very cool.

On the day she moves in, she's nervous at first because she doesn't

know anybody. At first the girls are quiet. Angel knows sign language, so she makes the sign for friendship, which is two fingers crossed. Yeah. One girl is named Sophie. Another girl is named Tonisha. There's Tanya, and Millie. Oh, and Rachel! It's easy to forget about Rachel because she's very quiet and she keeps to herself. But when Angel makes the sign for friendship, Rachel gets happy because she has finally found a friend.

Tonisha is kind of shy at first, too. Tanya likes to talk a lot. Millie doesn't talk at all. She's the one who uses the Dynavox. She can't feed herself and she can't walk. She needs lots of assistance. She reminds me of my friend Alex, who can talk but you really can't understand what he's saying. He uses his eyes to communicate. He's supposed to use a Dynavox but he doesn't like it, he'd rather talk right to you. He doesn't think he has a disability. I don't think so either because he likes to do a lot of stuff and he's a very happy person.

I have this other friend named Anna. She can walk, but sometimes people don't understand what she's saying so I have to interpret for her. If she needs help with something and people don't understand her I tell them what she really wants. Sometimes I do that for Toni.

The girls who live with Angel—they're made-up people, but they're inspired by my friends. I haven't told you about the girl named Sophie. She is blind, she's in a wheelchair, and she goes to college. She's learning how to become a counselor to work with children. How I came up with that is my and Toni's friend Melissa is in a wheelchair, and I also have another friend named Rebecca who is in college and she's blind, and she's in a wheelchair, so I put my two friends together to make Sophie.

Let me say that Sophie was in a car accident. She was in a coma. She got out of the coma and she became blind and unable to walk. Angel can't walk, she's in a wheelchair, but she's a very good talker. She's very good at expressing herself. Here's something that Angel said once:

"I can believe in my dreams, my aspirations, anything I can do in my life. I'm a very hard worker and try hard in everything that I do."

Angel has a learning disability and a reading disability, but she doesn't let that stop her from going after her dreams. One day, a few weeks after she moves to the new house, she goes to her brand new program. She never got into a walker before, but she tries it for the first time, and she runs down the hallway and her physical

therapist named Amber has to chase her.

That really happened to me once! I'd never gotten into a walker in my life before, and I ran down the hallway while my staff was chasing me. I think the feeling was awesome because I never really thought that I could walk. Once I did ride a bicycle when I was in middle school, at Jefferson Middle School. The bicycle was in the PT Room, and I used my arms to peddle.

When Angel runs down the hall in her walker she is very excited because she had thought she'd never be able to do that. She is nervous, too. She stops at the end of the hallway, and when she's done she gets back in her chair, and she feels like she accomplished her dream to walk. I feel like that when I'm in my walker, kicking up my legs. I'm tired when I'm done, but I'm happy that I accomplished my goal. I love walking, I really do! Each time is like the first time, and I have to learn all over. But once I get the feeling of it, it comes more naturally. The more I do it, the better my body feels.

Angel starts a group called The Sunshine Inspirational Leaders. That's like the group we started in 2008. It's called The Handicapables. What we're really trying to do is bring awareness about people with disabilities. We're showing that they can go to work and go to college and do whatever they put their minds to. Society has a stereotype when you have a disability. You have this voice in your head, everybody is saying you can't do this, you ain't gonna be able to read, you ain't gonna be able to walk, you're stupid, you're

dumb, you're slow. And we know it's not true. My dad always said that you could do whatever you wanted to do if you put your mind to it and believed it. That's my motto. That's how I want to live. I believe in my dreams and aspirations. When I get frustrated about what people say I really don't voice my opinions. I just think about what my dad said and what my grandma taught me, to live my life to the fullest and don't worry about what other people say because what they say is not always true.

When Angel starts The Sunshine Inspirational Leaders, she wants to bring awareness to help change the stereotypes of people with disabilities. All the five girls in her house join her group. They don't like when they go to the mall and people stare at them and talk about them behind their backs, saying something like, Look at that handicapped girl, she can't walk, she can't read, she's dumb.

Tanya says, "Let's start doing an advocacy program. We could do a video about how to treat people with disabilities."

Millie says, "We could have our teachers help us."

Rachel says, "We can show how to treat people with disabilities. We can show them how to say hello, how to talk to us like normal people."

"Cause we are normal people!" says Angel. "We just have disabilities. We can do stuff by ourselves, but we just need extra help."

That is true. I can do a lot. I can feed myself, I can put dishes in the sink and bathe myself and brush my teeth. I need help with transferring from my chair to the bed or the couch and going to the ladies' room. I need

assistance with cooking. But I can help stir the batter when we makes brownies with Kristy. I can tell her what to do. When I have new staff, I help to train them. I can do a lot. I have strength, God-willing.

Angel and the girls start the video by writing a script first about what they want to say. They talk about it with the entire group. Millie does the writing. The other girls are in the video. Angel shoots the video with the camera. This is what they talk about in the video:

They talk about the stereotypes and about how it's important to treat people with disabilities like everybody else. They talk about how people with disabilities just do things normally like everybody else—they go to school, to program, get jobs, go to college, get married, have kids, and drive cars. People with disabilities are people, too and they need to be respected. They shouldn't be called bad names. They should be called by their real names and not their disability, like, "that handicapped girl" or "that quiet girl" or "that slow girl" or "that blind guy." We want to be called by our names and not downgraded.

My nickname is "The Lovely Latrice." I named myself that to give myself confidence. Sometimes being independent can be difficult and challenging, but if you have a good outlook on life, you will get through it.

In the video, Millie brushes her teeth to show that people with disabilities can do stuff, in different ways. Rachel helps with the laundry. She puts the soap in the slot and presses the button and turns on

the washer. Tonisha and Tanya help their staff with cooking and making egg salad sandwiches. Sophie helps open the door for people. Angel films it all!

My favorite things to do are cooking and doing laundry and putting dishes in the sink. What I really like to do is make the grocery list and go shopping for food cause I get to pick out what we have for the week. It helps me become independent. At the store I help find things like cookies and cereal and yogurt. I know yogurt is in the dairy aisle. If you want to get a shirt you go to the clothes aisle and if you want to get fruit you go to the fruit aisle. I'm a big kid so I like to get toys, but I'm trying to grow out of that and get clothes and stuff that I really need! I like to

help bring the things home and I feel proud when I get to put them away.

In Angel's video, the girls go to the grocery store and they pick up fruit and vegetables for their dinner. Angel has her license, and they have a handicapped van she can drive. She feels independent when she drives. She is very careful because she knows she could get in an accident. The girls put their seatbelts on before they leave the parking lot, and Angel drives away. At home, they take their seatbelts off and get out of the van very carefully one by one. They put the groceries away in the refrigerator and cupboards. Angel films them making their dinner. They make spaghetti and then they eat it, and that's almost the end of their day. They relax and watch TV and play games

and read books. Before they go to bed, they make their lunches for the next day, and then their staff assists them with their showers.

They like their group home but they have challenges emotionally that affect them in their daily lives. Not every day is perfect but you try as hard as you can to get through the challenges.

Mind you, I've never been in a group home before. I was in foster care and in emergency respite. I went to respite before but I never really experienced being in a group home so it's been an emotional rollercoaster, but I'm trying every day to succeed. When I am at program and around a lot of people, it's a little bit challenging. And at home I talk a lot, I talk a lot more than Toni does,



I'm used to talking to my sister and my mom and my dad and my cousins and my nieces. And I'm used to seeing them all the time. But now that I'm in a group home maybe they think I'm not in their family. Sometimes they answer the phone but sometimes they don't answer the phone when I call them. I do try my best to call them every once in a while and say, How are you doing? I think I'm a responsible family member like my grandmother was, but my grandmother died.

My grandmother was like me. She was sweet, but she meant business when you messed with her. Like me—I'm sweet, and I'm assertive. My grandmother liked to dress in suits and nice clothes, she liked going shopping. She liked ordering clothes for me and my sister from magazines. She did a lot of stuff for us. She bought us school clothes. Anything we basically wanted she would give it to us. She was a caring person like I am. Sometimes I think I'm too caring. I try my hardest to be positive about everything I do, but sometimes I think that positive stuff is like a shadow because when something is wrong I just block it out.

Like this weekend is hard because it's Mother's Day, and I'm trying to keep as busy as possible, trying not to think about the negative part. I'm learning to worry about myself and not worry about my family. But I end up breaking down, I end up crying because I'm trying too hard to be perfect. I always do that, I try to be motivated and kind. It's hard to do that all the time, but I try to be a positive person.

Everyone can't be positive all the

time in their life. And that's why I relate to the people in my story because they try their hardest to accomplish their goals and try to do the best that they can do to the best of their ability. But it doesn't always work out because life is not perfect.

Angel is trying to do the best that she can do with the video but at the end of the day she feels that she's burnt out. She tries so hard to do her task and it doesn't turn out the way she wanted it. When she watches the video, she sees that one girl said a sentence wrong, and it doesn't make sense. And in another scene, Angel was holding the camera in her wheelchair and she shot it the wrong way. The camera wasn't focused on the person correctly. She is mad at herself because the video isn't perfect.

She is upset a little bit, but she knows that she has to learn to accept stuff, so she sleeps on it. In the morning she is proud again of what she and the girls have accomplished, because even if the video isn't perfect they are trying their best.

When they're done making the video they show it to their managers and he says it's a good video. They go out into the community with their staff and they show the video to students, from first graders, all the way up to college students. They really feel proud of what they've accomplished cause they succeeded in their dreams. They've changed their lives forever.

Me personally, I'm proud of myself. I've gotten a little quieter and calmer since I've been here. I've gotten better at vocalizing my feelings and advocating for myself. I have more confidence. I've grown up a

little bit more. I wrote a note to my sister saying that I feel left out of the family because nobody calls me, and she wrote back. We're still a close knit family. My mom came over the other day with my little nephew and my sister. My dad called me on the phone. My other sister called the day my mom was here.

And I want to mention that I have a boyfriend! His name is David. I remember seeing him for the first time. My staff said, "Here's a new consumer, his name is David." And I was thinking in my head, but I didn't say it, Wow, he's cute! He knows how to play the piano, and I love the piano. We like art and acting. I love singing, and he loves singing. We've got a lot of interests in common. We elected David the vice-president of my Handicapable group. We were talking about him when my mom was here. She said, Go ahead, Tricey, have fun!

I do have fun, but I realize that you have go through some hard times to be a stronger person and appreciate the gifts that God gives us. Do you understand what I'm saying?

I know that it's hard to be independent, but I try to take one day at a time because that's all I can do. It's very difficult, but you have to have that drive to be successful. Life is like a roller coaster, it goes up and down and around the corner, you never know when it's going to stop. So you have to put on your seatbelt and pray to God that the roller coaster will stop. But it never seems to stop because your journey never ends.

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