



A Journey to Independence

Second Edition

Tiffani Harvey

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Foreword

The reason for this book is to help people who want to make their own choices. The author writes about her own mistakes so readers can avoid making the same mistakes. She wants readers to learn how to make their own choices and know what kind of questions they should ask before making a choice. This book is written for:

Middle School and High School students

Victims of violence

People who have disabilities

Family members of people with disabilities

Powers of Attorney and Guardians

Payees

Advocates

Caregivers

She wants to help people learn to ask questions and get answers before making big choices.

She wants to help people get as much independence as their health will allow.

She wants to help everyone to save money and buy only what they can afford!

She suggests that you read and understand everything you are asked to sign. If you don't understand, don't sign or ask someone *you trust* if they understand and agree before you sign.

Acknowledgements

I need to start by thanking Mariaelena Wareham and her staff. It is from watching her organization that I felt the need to write my story.

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(If you know someone who proofread this book and was not listed, let Tiffani know so she can add them to the list. Thank you.)

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Finally, I want to thank the Author of Life—the Lord!

Practical Living: How to Make Everyday Choices (and Stick to Your Choices)

Introduction

As you read this, it is important to understand my view of life. Growing up, people told me I could not do things. Why? I was disabled. As an adult, I got to make my own choices since I had no guardian. I was able to make mistakes and learn from them.

Since 1992, I met people who had mental illnesses who wanted to be as independent I was. Since 1996, I met people who had intellectual disabilities come up and say they want to do things that people without disabilities do such as get married or have a paper route.

While growing up, I worked hard to get others to let me make my own choices! I know a lot of adults who don't make their own choices. I think adults should make their own choices. Adults that don't make their own choices have a guardian or a Power of Attorney make big choices in their life.

In the following pages:

First, I share my life.

Second, I explain how I make my choices.

Third, I write to the individual who wants to apply the information.

Fourth and finally, I write to the person who assists the individual in making choices.

I am a firm believer in health:

- Prevention
- Taking Vitamins
- Eating Healthy
- Exercising
- Taking prescription medicine

- Choosing your own doctors

I believe it's everyone's responsibility to be as healthy as they possibly can!

Being healthy includes avoiding:

- Drugs
- Alcohol
- Tobacco

Being healthy can include cutting back on:

- Salt
- Sugar
- Caffeine

I believe a Powers of Attorney and guardians can be good for medical and health reasons. A guardian can give messages to and from the patient and the doctor.

Be Safe

I support the right of adults with disabilities to make their own choices and make their own mistakes. I believe it is important to keep an open mind. "Keeping an open mind" means you are willing to change your mind if you find out someone has a better idea than you.

If someone is worried that what you are doing is unhealthy or dangerous, think about doing something else.

If you speak slowly or if it is hard to understand what you say, it might be best to have a power of attorney or a guardian. Why? People who can speak clearly and quickly can communicate your needs or wants *faster!* To a doctor and other professionals, "Time is money!"

I chose to write this book after many people who have intellectual disabilities asked me how I got to do things that their guardian wouldn't let them do. This includes:

- Getting married
- Going to college
- Handling my own money

I thought I could reach more people by writing this book instead of telling my story to one person at a time. I also thought people could go back and look something up if they didn't remember what I said.

I write from the point of view of a person with intellectual disabilities. If I don't know about something, I ask others who do know about that topic. Some information is constantly changing, but the source is the same. So, you can look up the latest information.

Practical Living: How to Choose

Childhood

I was born with partial seizures. I always felt them coming on. The left side of my body does not work very well. I have a rose colored birthmark on the right side of my face. I have vision issues. I also have a conceptual learning disability.

I had very few friends because my parents were embarrassed by other kids in special education. My parents wanted me to have friends who had no disabilities, but the able bodied kids teased me. I tried to be friends with all the adults my parents invited over including the professionals. I never understood why they never approved. I thought my parents would allow them to be my friend because they had no disabilities and my parents let them in the house. My parents were upset with me, but I never understood why.

I was on a lot of medicines growing up. I had lots of side effects. Side effects are unwanted things that happen as result of taking medicine. Side effects I had:

- Feeling half asleep
- Hard time focusing
- Hard time understanding schoolwork

A doctor told my mom I would not walk or talk. God proved the doctor wrong. I walk with a limp, but I don't use a walker or a cane, and I talk very well.

Family Life

One important thing my parents taught me was being faithful to each other and to me when life got hard.

My mom has Multiple Sclerosis (MS). She had a mild case of it. Over the years, her MS had gone in and out of remission.

“Remission” means the symptoms of a disability disappear. When the disability comes “out of remission” the symptoms reappear. When I was two years old, my mom had to use a walker because her MS was out of remission. There were times she would have double vision for a week or two, and then her vision was fine again.

When I was in grade school, my mom was a stay-at-home mom. When I entered middle school, she got a job. She worked for about 13 years but had to stop when she was no longer in remission.

Dad worked at Kaiser Aluminum. He rotated shifts. He worked day shift, swing shift, and the graveyard shift. He also worked a lot of extra hours. My dad has no disabilities. Growing up, Dad and I frustrated each other a lot because we didn’t understand each other. This was hard on Mom. For example, I always sang in the school choir. I would tell Dad 1-3 months *before* a concert thinking he could plan ahead to come to my concert. I thought God and family were more important than a job.

My value system was and still is that God and family are more important than a job.

As an adult, I started to understand—you can live in the same house, go to the same church, but still have totally different values.

I am an only child. My parents were afraid of having another child with disabilities. They have even said to me, “Do you want another disabled child like you in the world?!”

This is one of my beliefs: Stand up for what you believe in!

I learned to stand up for myself and voice my opinions. I always knew I was special in God’s eyes. Everybody is!

My Grandparents

We went and visited my grandma in Idaho a lot while I was growing up. She was always there for everyone. She was my dad's mom. As her eight kids grew up and moved all across the country, she stayed in contact with everyone. (These were the days before cell phones and the internet.) Grandma was great at having family reunions. She died in a hospital from heart failure when I was in the 7th grade. This was my first experience with death.

I was close to my grandparents on my mom's side. My grandpa worked on a farm. Grandma was a homemaker. We would go visit my grandparents more often than my other grandma. The main thing my grandparents taught me: family comes first. Whenever us grandkids came, we were the center of their attention. That helped me have strong family values. Later in life, Grandpa suffered from Alzheimer's disease and Grandma got skin cancer. She died at my aunt's house in 1990, a few weeks after I graduated from high school. My aunt and two cousins took care of them along with an agency called Hospice until Grandma died.

My family took care of my grandpa until it got *very hard*. My mom and aunt put Grandpa in an adult family home.

It is my belief that the women of the family should take care of their older relatives *if* the family can afford it. We could afford it and I wanted to.

There were a few problems with me taking care of him:

1. No one ever asked my grandpa.
2. I was being told, "You're disabled. You can't take care of him!"
3. My aunt and mom were assuming that my grandpa would be embarrassed if I took care of him.
4. His generation always made sure that the family took care of sick family members even if that meant that older

relatives had to move into another family member's home.

It would have been respectful *to ask* my grandpa before placing him in the adult family home and later moving him into a nursing home.

My grandpa died in early 1993. After all three of my grandparents died, there were no more family reunions. For a few years after they died, we stayed in touch by calling each other and by writing letters. Eventually, the letter writing stopped and later everyone stopped calling each other.

I never let my disabilities get in my way or stop me from doing what I wanted to do. I wanted to be like everyone else. I wanted to ride a bike, swim, sing in the choir, and play sports. As an adult, I wanted to do all the things other able bodied adults did such as being a wife, a stay-at-home parent, move away from my parents, go to college, get a part-time job, and have a driver's license. *I wanted to find out for myself what I could or could not do!*

As a kid, I never learned to ride a bike without training wheels, so I don't ride. I think swimming is fun, but swimming alone is dangerous. I remember I was seven years old in a friend's backyard pool and I had a seizure. A five-year-old neighbor was keeping my head above water while yelling for her mom to help. The neighbor's mom called my mom. After that, I only wanted to go to pools that were easy to get out of. Why? Safety: because I knew lifeguards were around.

Once you find out something is unhealthy or dangerous, find a healthier or safer way to do it or don't do it.

"Accommodation" means finding a way that works around your disability or disabilities that allows a person to do things independently. An example would be people who are blind using a white cane or a service animal to walk around.

Church Background

The only reason some of the kids went to church was, they were forced to.

When I entered 10th grade, I met my first boyfriend. He invited me to his church. My parents said I could go. That was October 1987, and I was 16.

**The last seven churches I have gone to have been my choice; I *chose* to leave my parents' religion. They have the right to choose their religion and where they want to go to church, and so do I! Their religion is different, but it's not necessarily wrong! I want you to feel good about your choices! My parents allowed me to change to my boyfriend's church and I went there as long as I wanted to—for ten years!

School

When I was in 3rd grade, a kid said, "Fxxx you," so I asked mom what does "Fxxx you" mean? She slapped me. That was the first time my mom ever hit me. I learned quickly, don't ask my parents questions, hide in the church, and stick with people who have disabilities. Why? Kids without disabilities use bad words. Using bad words got my face slapped. Since I never wanted to be slapped again, I stayed away from kids without disabilities. I was so sheltered that I didn't realize both people with and without disabilities use bad words.

My mom gave the school my medical information and that bothered me! I wanted to keep it private. I felt that only the doctors should have that information. I was afraid the teachers would treat me differently if they knew the specifics of my disabilities. I was right! They treated me differently. My parents and the high school never let me take driver's education! No one ever gave me credit for thinking safely! If I didn't feel safe, I would not drive.

When I entered 6th grade, my parents moved seven miles off the bus line. Even when I was too young to drive, I thought we should have been living on the city bus line so I could have a social life. I worried that I would never drive and that I would never have a social life.

Throughout middle school, I was mad at God, my parents, and the world. Why? I was so frustrated with my disabilities. I felt I was being left out at school and at church because I was not allowed to get a driver's license. Also, no one listened to how I planned to stay safe to prevent an accident.

In 8th grade, a group of female students kept calling me a virgin and I had no idea what "virgin" meant. I kept saying, "No, I'm not!" They finally asked me, "Who did you sleep with?" I told them, "Nobody! That's sick!"

They responded, "Then you're a virgin." I said, "Okay," and I accepted it, and wore the name proudly!

Choir, English, and math were my best subjects when I was in K-6. My grades in English and choir continued to be great in 7-12. My grades in history were always low. History was hard on me emotionally because of all the wars and death. I hate war, guns, and death.

Science and biology were also hard subjects for me. I did not understand formulas for science. Cutting up frogs and other animals in biology made me feel sick, so I tried to forget everything in that class. In the classes I had a really hard time in, I was given a "D" so I could pass and get to the next grade level. Physical Education was also hard. Why? Catching and throwing baseballs, footballs, etc. was hard for me. I had a hard time running because I sprained my ankle falling on the ice so many times. The only sport I liked in school was volleyball. Even though I got hit in the face with the volleyball, I was having fun.

1st – 8th grade: my friends were girls. In 9th – 12th grade my friends were boys. 10th grade was when I became interested in dating men who went to church.

Remember, if it's hard to do some of the things that I write about, there are agencies out there that can help!

If there are other things you need help with, look to see who can teach you. Who you ask depends on what kind of help you need.

What kind of help do you need?

- Advice
- Financial help (help with money) (energy assistance)
- Shopping
- Paperwork
- Something else

Who you ask depends on what it is you need. People or agencies that might be able to help are:

- Family
- Government Agencies
- Nonprofit organizations
- Your place of worship
- Organizations that help people of your faith
- Friends

For example, if I need to get something like milk, or go back to the doctor in the same day, there are a few people I can ask for a ride. If I need help with my homework, I have a different group of people I can ask.

Taking Medicines and Choosing Doctors

Before anyone thinks about living on their own, they might need to prove that they know how to take their medicines, when to take their medicines, and prove that they can be trusted to always take it correctly!

At age 12, my parents trusted me to take my own seizure medicine. In the summer of 1986, I went to visit my cousins. This went on for seven days. I *accidentally* forgot to take my medicines. When I realized I had forgotten to take them, I told my aunt. She asked, “Are you having any seizures?” I said, “No.” When Mom and I were driving home, I told her I stopped taking my medicines and she nearly drove off the road. Mom was scared saying, “And you are not having withdrawal symptoms or seizures?” I answered, “No! What are withdrawal symptoms?!” I *never* should have asked because I trusted God to heal me.

However, being the curious person I am, I asked, “What are withdrawal symptoms?” I got every symptom she told me about.

My parents let me continue taking my medicines because I admitted my mistake. No one thought I would stop taking my medicines again. After all, I’m the one who suffered!

If you are a slow learner, or if you learn by making the same mistakes over and over again, others may want you to have a backup plan.

I graduated in 1990 and I changed my medical doctor. Six to nine months after I graduated, I wanted to be on less seizure medicine. My new medical doctor didn’t know me that well and did not know much about seizures, so he disagreed with me.

Finally, six to nine months later, he decided to send me to a doctor who knew more about seizures.

(If your doctor listens to you and will work with you, follow your doctor’s advice!)

In 1992, I had an emotional breakdown. I willingly went into the hospital for 14 days and was on a new medicine for three