

D E A F - B L I N D M E N T O R S T O R I E S

# *hawai'i & pacific* **DEAF-BLIND** *project*

## **Reflections of a Deaf-Blind Advocate: Pursuing dreams to make wishes come true**

by: Kerry Thompson, a friend of the Hawai'i & Pacific Deaf-Blind Project

### **THE DEAF-BLIND WAY**

Diagnosed at three years old with profound deafness, I later learned at ten that I was also going blind due to a progressive blindness disorder called *Retinitis Pigmentosa*. This form of deafness and blindness is called Usher Syndrome, which affects 1 in 25,000 Americans. During Deafblind Awareness Week, I like to reflect on lessons and experiences learned as a Deafblind individual.

Receiving such a diagnosis as a child, many of my questions took a childlike view – will I go blind? When? Do I have to tell my friends? Will it hurt? Why me? As I grew older, the questions remained the same but new questions arose – should I tell my teachers? My best friend? Anyone I might have a crush on? With each life development stage, the questions became more complex – should I take the honors and advanced placement classes? Should I go to college? Should I date a guy who is Deaf or hearing? What should my major be if I would eventually go blind? Do I prepare now or do I wait until my eyesight gets worse While the future did seem bleak at that moment, a few days later the future did not seem so bleak as I witnessed on television President Bush signing the Americans with Disabilities Act (ADA).

Over the years, I learned to keep many of my questions to myself because any time I asked any questions aloud, the answers from my doctors and/or parents was always “I don’t know.” For many of my questions, only I could answer, but I didn’t know how.

Upon learning that I was deaf, my family learned sign language, which was my first language. Up to kindergarten, education was a bit of a trial and error process. We tried to find the right setting that would work best for me. I also began receiving speech therapy and learned how to lip read.



From kindergarten through 12<sup>th</sup> grade, I was fully mainstreamed with no sign language interpreter, not because my folks were anti-sign language, they wanted sign language to be a part of my life and it was, outside of school. The difficult choice they had to make was if I were to have a sign language interpreter for school, I would have to attend the school for the Deaf, which was 100 miles away. Not only were they concerned about the distance; they were concerned about the lack of a quality education at this particular school. So the decision was made to enroll me in the same school as my older sister.

My childhood was a joyous one, playing with my siblings after school, going on family vacations, slumber parties with friends, and many educational achievements. Some of my friends signed and some did not, but my immediate family signed so I *always* had a balance of hearing and deaf worlds.

### **COLLEGE**

College was the next stage. I wish I could tell you that the answer to what my major or my field of study should be was an easy one. Even now, I still cannot decide what I want to be when I grow up. College did expose me to many experiences I never thought I would have, the opportunity to study abroad, volunteer abroad, and to become a student leader.



*Dancing salsa with a friend*

The most important and impacting lessons I learned in college were not in the classroom, but rather outside of the classroom. *Discrimination* was a hard lesson to learn about. College was not my first taste of discrimination but it was certainly where it was the most profound. Many of my advisors, despite my good grades, encouraged me to keep my career expectations low.

I approached graduation with trepidation, as I still had no job lined up. But the words spoken by my commencement speaker left an impact on me. “Wherever life takes us and whatever challenges we meet, each one of us has much to be grateful for. And the proper measure of response of a grateful heart is service.” My hero, George

H.W. Bush, signer of the Americans with Disabilities Act, spoke these words.

Shortly after graduation, I made the most difficult decision of my life, a fate decided by a coin toss – Heads/ New York City or Tails – Boston. Despite my accomplishments in Louisiana, there was widespread discrimination and a lack of opportunities for people with disabilities. My parents always believed in me and worked hard to give me opportunities. I had learned that life does not always hand out opportunities – you have to fight for them even if that means moving 1,500 miles away from all that is near and dear.

## **BOSTON**

I found myself in Boston with no job, no friends, and no idea what snow was like. My plan was to work with a temp agency while looking for a permanent job. After four months, I landed my first real job at Brigham and Women's Hospital as a Research Finance Specialist. The call to service was a strong one. One that I felt I could serve by helping those with disabilities, so I decided to return to school to pursue a Master's degree from Harvard University. Yes, *that* Harvard. I have always thought about disability rights as disability rights but I soon had an epiphany that disability rights is a *human rights* issue. Looking back on all the barriers and challenges I endured, despite the ADA, I thought about what the lives of those with disabilities in developing countries were like, without any legislation remotely similar to the ADA to protect them.

I would soon learn that there are one billion people with disabilities worldwide, 80% of who live in developing countries. Education, employment, social justice, and healthcare are virtually non-existent for people with disabilities. While the numbers may sound discouraging, there is a shift now in that people with disabilities are standing up to claim their rights. Upon receiving my Masters degree, I began working for an international non-profit that works to advance the United Nations Convention on the Rights of Persons with Disabilities.

## **GLOBAL DISABILITY RIGHTS**

I must confess that I entered the world of global disability rights with some naiveté believing that a disability movement would be inclusive of *all* people with disabilities. That the motto- *nothing about us without us*- was practiced not just preached.

In the seven years that I have worked in international disability rights, I have only met two people who were Deafblind in the field. Individuals with deafblindness are being excluded from having a say about matters that impact them and excluded from a larger movement due to their "lack of capacity." While learning these lessons, my eyesight was deteriorating significantly.

I have another confession. I did believe that I had to live life to the fullest and squeeze in as much as I could do and see *now* before I could no longer see. I was wrong to think that. My mindset changed and I realized that I have the power to fight for the future I want.



*Moderating a Global Advisory Panel on removing barriers to participation for people with disabilities*

## INCLUSION

25 years later after the signing of the ADA, my fight for access has evolved to a fight for inclusion. As a person with Deafblindness, access to education was my first hurdle towards access but I would learn that access and inclusion means two different things. Access may mean that someone provides an interpreter for me but Inclusion means that people learn sign language for me. Inclusion means instead of special programs for people with disabilities, there are programs that bring together both the world of disability and non-disability.

I have not yet mentioned that I am a salsa dancer and the Founder/Director of Silent Rhythms, which has taught more than 2,000 individuals with disabilities the art of dance while including them in dance socials held for people of all abilities. I loved dancing and initially was told that because I could not hear that I should not pursue dance. Eventually, I did learn Latin Dancing who wanted to include me in their Rhythms came about because I dance for people with disabilities. me to use dance as a fun way to bring together – those with disabilities and

That moment really struck a chord to when I was that age. I am happy young age and that I was included in me. Knowledge is power, and the learned is to give yourself the best every tool possible (Braille, Sign Language, Braille Display, the latest medicine, etc.). The second most is you never know unless you try.

If I could have three wishes, this is learns how to include people who are those who are Deafblind to feel being Deafblind, and three, that those who are Deafblind know they should dream big and pursue those dreams.



*Scene from Wheelock's Theater's Pippi Longstocking in which Kerry proffers a dance she choreographed that includes sign language, salsa, and bachata.*

with the help of patient teachers dance classes. The idea of Silent wanted to remove barriers to This was also an opportunity for two different communities those without.

with me and I remembered back that my parents told me at a knowing what was happening to most important lesson I have chance in life – you should learn Language, Tactile Sign research in technology and important lesson I have learned Never let fear hold you back.

what they'd be. One, that society Deafblind. Two, that we allow comfortable being open about

These are the lessons learned from a Harvard Graduate - Marshall Memorial Fellow - Salsa Dancer - Marathon Runner - World Traveler - Louisiana Native - Current Boston Resident - Dance Teacher - Guest Lecturer - Author Entrepreneur - Disability Advocate who just happens to be Deafblind.

