

## Finding a Voice

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In Fall 2002, I was working in partnership with the Hawai'i Department of Education producing a series of video profiles of exemplary persons with disabilities in Hawai'i (Skouge & Ratliffe, 2004). Brian Kajiyama was nominated as a candidate. He was twenty-six years old; an honor student in his senior year at the University of Hawai'i, majoring in *disability studies*; and intending to pursue graduate education in counseling. Brian has cerebral palsy. He uses a powered wheelchair for mobility and communicated, at the time of our first meeting, through writing—word processing, e-mail, text messaging, and text telephone (TDD). Brian has the functional use of his right hand, permitting him to type with relative speed and ease. He chose not to use an augmentative communication device, as he did not like the robotic sounds of the electronic “talkers,” depending instead on the written word and, on occasion, having his words read out in class by his “note taker.”

Brian and I communicated via e-mail. He agreed to the making of the film, and he also agreed to write a twelve-minute script describing the milestone events of his life (Skouge, 2005). The plan was to keep the format very simple: I would film Brian rolling into a meeting room at the university, and he would acknowledge the camera with a smile and then turn to a keyboard to type his story. I would focus on his hand and face and the computer monitor as he communicated. Later, in post-production, I added my own voice, narrating Brian's words. We met three times. On the final visit, I brought an augmentative communication device that I borrowed from a friend, asking Brian if he might end the video by speaking a few words using the talker's voice. He agreed. This is what he said:

Now as I grow and have to think of communicating outside of this ivory tower known as school, I realize I will need some device, for people won't be as patient to read my thoughts and will want to hear them. So I try to keep up with what's out there in terms of augmentative devices. Ideally, it would be something very compact, without a robotic sound.

This device definitely has potential. It's compact and seemingly easy to transport. The only minor drawback, and, again, maybe this is something I'll need to learn to accept, is the robotic voice. I'm still hopeful, though with the extreme progression in technology today, synthesized voices will be available that will compare with human quality speech. My critical view of the speech quality on such devices is something that I need to accept. And quickly. I must learn to not be so picky. As they say, beggars can't be too choosy.

This was our final “shoot.” Brian and I parted company. Several months later, when I attended his December graduation, I learned that he had not yet been accepted into graduate school and that he was still uncertain about his future studies. Later that spring, I received an e-mail from Brian asking if he might volunteer in my office some days each week, helping me with clerical work such as filing, word processing, and keeping inventory. I immediately said, “yes” although neither Brian nor I had any idea where this arrangement might lead. He had never been in my office before, and we did not know one another beyond the brief experience of the video project. But I did know that Brian was intelligent, goal directed, mobile, and pleasant to be with. We set up a schedule. Brian would work three mornings each week, beginning immediately.

### An open space: Building around perimeters

I teach educational technologies in the Department of Special Education at the University of Hawai'i. The year prior to Brian's offer to work with me, the department had invited me to relocate my office in what had been the departmental conference room. It was a large space (perhaps twice the size of a typical office), windowless, inordinately cold (due to the air conditioning system), and lit by a few fluorescent lights. And in spite of the room's size, a large portion of its space was taken up by an over-sized, two-pedestal conference table. But I saw the room's potential, and I enthusiastically

cally accepted the offer, with the understanding that I could remodel it as a *studio*. I envisioned a digital environment with workstations around the perimeter and, in the center, a space that would be open and inviting to all comers, including wheelchair users.

The first order of business was to dismantle the immense conference table. Counters were constructed along three walls to accommodate computers, television monitors, printers, and scanners. Peg boards and shelves were hung on walls to maximize floor space. Light-weight furniture was acquired, including stools and tray tables. The fluorescent lights were replaced with spot lamps. Arts and crafts of the Pacific were displayed on the walls. Photographs and videos of marine life and island scenes were played on the monitors to the accompanying strains of Island music.

The open central space allowed Brian access to all essential equipment: computers, VCR's, cameras, a printer, and a scanner. We acquired a Telecommunication Device for the Deaf (TDD) for telephone communications; we disconnected the hydraulic "door closer" and tied a sash to the handle so Brian could pull the door closed while driving through. The lamps were plugged into power strips so they could be turned on and off with a single switch. And we constructed Brian's workstation in a corner of the studio, angled in such a way that he could back in to gain full view of the space.

Digital access proved to be easy to accomplish. Brian was capable of manipulating every key and button in our studio, bringing home the fact that the digital world essentially requires just one finger for near full control. We acquired trackballs for the computers, though Brian preferred the standard mouse. We purchased camera tripods that allowed full control from the handles (zoom, tilt, pan, and pause). Within days, Brian joined our video production team as they worked together on filming and editing interviews.

Brian's presence added to the welcoming atmosphere. He was young and "tech savvy." He loved sports and was a diligent student. We agreed that Brian should come and go as he liked and carry his own key to the office. Soon Brian had his picture and office hours posted on the door, with the caption, "Brian Kajiyama, Digital Media Associate." But I also had other plans to help Brian in his work as a digital media associate: I felt strongly that Brian's work would be more easily accomplished if he had an audible voice, and that meant a "talker," which was something I suspected Brian would resist.

## The DynaWrite and the "blog"

Not many weeks after Brian's start, we met Bruce Flemming, the Hawai'i "rep" for the Dynavox Company, which is a major manufacturer of augmentative communication devices. Bruce had recently been assigned to the Pacific region and was eager to build his reputation and client base. We heard that he was on island and invited him to our studio for a video interview. The "set" was simple: two chairs and a folding table. I acted as the host. Bruce demonstrated his equipment. Brian handled the camera. During the interview I proposed to Bruce that he lend Brian a DynaWrite for a two or three week "try out," suggesting that he might gain no better product endorsement, should Brian choose to embrace their product. Bruce agreed to leave his demonstration model with us that very day. It was perhaps a bit of an ambush to ask this of Bruce while the office cameras were running; but we did it nevertheless, and Bruce took it all in good spirit.

Brian fell in love with the DynaWrite. It was small in design and fit easily into his backpack—an important consideration for Brian. It also produced a deep, commanding voice—robotic, yes; but at least not the childlike robotic speech of earlier versions. Before long, Brian was answering the telephone, shopping at the bookstore, delivering messages, and taking over many of the management duties in our office. It was not long after that that he was admitted into the master's degree program in educational counseling; after which he began counseling "clients" in our office using his new device.

Little did we imagine that the loan of the talker would stretch from weeks into months, and finally into more than a year before the Hawai'i State Division of Vocational Rehabilitation (DVR) saw fit to buy Brian a DynaWrite of his own.

The story of Brian's eighteen-month quest with DVR for the purchase of the DynaWrite was one of persistence mixed with a certain amount of exasperation. There were face-to-face meetings between Brian and his counselor(s); letters of documentation and justification; formal "assessments" and the exchanges of many e-mails. Attempts were made to steer Brian to local providers even though they did not sell the device he requested. Patiently and repeatedly, Brian expressed that he had made his choice. He knew what he wanted. Time and again, Brian's initiatives were postponed or thwarted.

Midway through this protracted affair, Brian discovered blogging—a form of Internet journaling. Brian is an avid

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writer. So I was not surprised that he immediately took up blogging with the same passion that he invested in all his endeavors. Soon Brian was posting a weekly Internet entry entitled “Brian’s Ramblings.” The journal was marvelously written, and provided interesting and detailed accounts of the daily events of Brian’s life—including his struggles to obtain a DynaWrite.

**On January 24, 2005, Brian posted the following report:**

A very rare time that I’ll compose an entry on consecutive days. But it’ll be an interesting read, I assure you.

I like to think of myself as a nice person, I always try to do good, do the right thing, treat people with respect. I certainly don’t try to be mean or do bad to anyone. You’d think I should have good karma, or whatever you believe in....

Last night I received an e-mail regarding my augmentative communication device. It wasn’t a bad note, in fact it was a positive one. Someone had received a DynaWrite through the Department of Vocational Rehabilitation (VR). “Great!” one should think.

It’s great except for one minor detail...I’ve been patiently waiting for over a year to receive my device, all the while trying my best to convince VR that they should support this. Finally VR is convinced, but yet there’s a bunch of hoops that I was asked to jump through. I DO all that they ask of me....now it has become a waiting game, “pass the buck” if you will. Come to find out, a VR counselor was able to order a device for someone in less than a week’s time! How can there be such a huge disparity in this idea of “delivery of services”?

What exactly am I missing here?! Something is definitely askew in this picture. It’s like someone has punched me in my gut or played a very sick joke on me.

I’ll openly admit to literally feeling sick after processing all of this. I write this entry as I cope with a migraine headache, definitely brought on by self-induced stress. What do I take away from this? I MUST learn to deal with stress better, don’t let situations affect me so much.

I am very grateful that DynaVox has been extremely supportive of me. They have and continue to believe that I benefit greatly by using

a DynaWrite. Thus, I AM happy that I could help them in serving another individual who will benefit from their product. I look forward to the day that I can proclaim, “I have my OWN DynaWrite!”

Does this mean that I’ll start being not nice, more “mean” in my attempts to advocate for myself? Probably not. However, I will question my competence in advocacy until I receive the support I am entitled to. A year plus, in my eyes, is NOT considered “timely” in terms of delivery of service.

At this time, Brian was serving an internship as a teaching assistant in one of my technology in education classes. In this capacity, Brian gave occasional lectures and provided hands-on assistance to student teachers in a computer lab. Midway through the semester we determined that the students should learn something about Brian’s ongoing struggle to obtain the augmentative communication device. During one class session, we projected Brian’s blog site onto a screen and read it aloud together as a class. The students were incredulous. Proposals were made to initiate a petition. Both Brian and I cautioned the students to exercise restraint.

**One of the students, summarized the collective thinking of the students in our class as follows:**

While growing up in a small Alaskan fishing village, I never had the opportunity to meet people who were not able to utilize their natural voice. Brian was the first person I ever met that communicated with the aid of a tool which put his thoughts into speech, therefore one of the first things I learned about those in his situation was that not having a natural speaking voice does not at all mean that a person does not possess a very powerful mind. As soon as Brian started speaking through his external device, I knew that the guy was incredibly smart and was going to be a great teacher. Since then he has proven to me that I was not mistaken that day.

On top of being very intelligent and knowledgeable, Brian has a compassionate heart and utilizes it to relate to and help others. Although having an augmentative communicator is not necessary to put his intelligence and kind heart to work, I have seen how it allows Brian to work closer to his full potential and help turn his hopes and dreams of helping and inspiring others into a reality. By having an audible voice, Brian is able to change

the minds of those who may doubt him and show others who are in his same situation that they have the power to do the same...

After Brian explained his situation to us in class, I immediately started brainstorming ways I might be supportive and help him out. As anger and fear were some of the first emotions that I felt after Brian gave his explanation, my first thoughts were to somehow rebel and protest against the situation. After sitting and talking with Brian however, I realized that getting angry and oppositional was not the best way of handling a situation like this. What would be effective, however, is showing and telling those with the authority to provide devices like the DynaWrite what a difference such tools make in all of our lives. If certain groups cannot be considerate and empathetic on their own, perhaps they needed other people to do the job for them.

As professionals we have the capabilities and connections required to perform such tasks and we're long past the deadline to start doing them. We need to start using our imaginations and creativity to create our own assistive technologies and inspire others to do the same. Most importantly, we need to stay committed to doing what educators do: helping others realize their full potential no matter what.

In Brian's case, I believe that his augmentative communicator only played the role of a tool, yet that tool serves as a bridge linking a mind with limitless potential with society at large. (Wright, 2005)

This story of the DynaWrite came to a rather abrupt conclusion. Sterling Kryslar [a man with quadriplegia who is a role model for assistive technologies (Skouge, 2004) who served on the advisory board for the Division of Vocational Rehabilitation] took it upon himself to contact the DVR Director to ask him to read Brian's blog. The Director instantly realized that Brian Kajiyama had gained a powerful, public voice. Soon, Brian received a communication from his counselor that she had authorized an immediate purchase of the device.

### Digital storytelling: Brian gets a job

Brian started out in our studio as a volunteer. His mother dropped him off by seven o'clock a.m. on her way to work, returning in the afternoons at five. The family had

a wheelchair accessible van. Brian had "proven himself," having learned the technical skills required for video, multimedia, and telecommunications. He combined all this with marvelous interpersonal skills and a strong desire to help and serve. I felt strongly, however, that his volunteer status should end and that we should find a way to include him as a paid employee.

In fall semester 2004, Dr. David Leake, with the U.H. Center on Disability Studies, inquired whether we might be interested in producing "digital stories" of *culturally diverse* college students with disabilities, highlighting cultural variables that contribute to success in college. Dr. Leake left it up to us to define *digital storytelling*, which was wonderful, because it inspired us to develop an expansive definition: "digital storytelling" would include *technologies for voice* in which people are empowered to find their voices and to speak for themselves.

Digital story telling stood for any creative application of technology used to celebrate life experiences and to enhance communication. It included a wide array of "visual" applications such as photo essays, audio interviews, narrated slide presentations, video documentaries. It also made use of telecommunications technology such as audio and video conferencing and internet publishing (Skouge, 2005). Dr. Leake embraced our definitions and offered Brian a graduate assistantship to share his stories and assist in the production of other people's stories. It was a perfect job for Brian, and one that challenged us to explore the potential of technologies for voice using the DynaWrite.

Brian began by producing video poetry (music videos), inspired by the work of Norman Kunc in Canada. We published his work on Video CDs (Kajiyama, 2004a, 2004b). By this time, a growing demand was taking place for Brian as a public speaker, first to student groups at the University of Hawai'i and then at state and international disability conferences. Brian's presentations evolved into multimedia "events" in which he spoke through his DynaWrite while projecting his slides and captioned videos on large screens. The effects were electrifying. Brian Kajiyama's voice was one that people were eager to listen to. He was soon invited to serve on the Hawai'i State Disability Access Board.

### Working with Others to Create Digital Stories

In Fall 2005, Brian was admitted as a master's student into the rehabilitation counseling program in the U.H.

College of Education. Dr. Brenda Cartwright became his advisor. She encouraged Brian to integrate our digital storytelling initiatives into his counseling internships. It was as a result of this work that we came to know Sharon and Eulalia—two deaf women enrolled in their first year in the Gallaudet Regional Center at Kapi'olani Community College. They were from Pohnpei in the Federated States of Micronesia. Far from home, they were experiencing the loneliness and anxiety of being far away from their families. But they were also thrilled at the novelty of living and studying in Hawai'i. This was their first experience of being immersed in a deaf community and, at the same time, adapting to a western lifestyle. They were busily acquiring American Sign Language, and struggling with the demands of developing their English literacy. Brian was assigned as their counselor in training, and I was assigned to be his internship supervisor.

We wanted Sharon and Eulalia to join us in a project that included working with role models, technologies for voice, self-advocacy, and community service. First, we constructed opportunities for them to interact with role models and, in turn, to become role models in their own rights. Brian invited an associate named Steven Wichilfil to join him on the project. Steven was a college student from Yap, a sister state of Pohnpei in the Federated States of Micronesia. Like Brian, Steven loved technology and embraced diversity, including disability culture. He was also keen to learn American Sign Language from the young women. A productive working relationship quickly developed among the four. Brian communicated with Sharon, Eulalia, and Steven by means of messages displayed on his DynaWrite. They responded in ASL or in writing. They all took great pleasure in these interactions so that it became unnecessary to hire a professional sign language interpreter.

Our first project was a photo essay. Sharon and Eulalia were given a digital still camera, with the expectation that each week they would take pictures on a variety of themes—drawing on aspects of their life in Hawai'i such as friends, shopping, going to school, the scenery of Hawai'i, apartment life, and transportation. They brought their camera to each of the weekly sessions where they transferred their pictures to a computer and made thumbnail prints on contact paper. During the following week, Sharon and Eulalia took the contact sheets to school at Gallaudet where their teachers and friends helped them to compose sentences to go with the pic-

tures. At the next meeting with Brian and Steven, they typed their sentences into photo essay software on our computer. The photo essays were then printed in color on photographic paper that they could insert in a memory book.

The project served several important functions. First, it provided Sharon and Eulalia with a “visual” voice that they could use to communicate aspects of their world to others. Secondly, it taught them such skills as digital photography, photo cropping, and lay-out, which they were able to use in developing and communicating ideas. Finally, it provided them with multimedia support in presenting their ideas to an audience through public speaking and self-advocacy.

In Spring 2005 Sharon and Eulalia were invited to present their story to delegates at an international conference on disabilities in Honolulu. Their circle of support, which included faculty from the Gallaudet Regional Center and the U.H. Center on Disability Studies, joined them at the presentation. Their photographs, projected from a laptop computer, were the centerpiece of their presentation. Representatives of their government were in attendance, and afterwards expressed enthusiastic support for their project and applauded the educational contribution that they had made. When students like Sharon and Eulalia become empowered to share their work in public forums, an important new lesson is added to the value of the media project. They become agents of self-advocacy as informed contributors who are able to improve community awareness on an important educational and social issue.

In the final step of the project, Sharon and Eulalia were able to return something for the support they had been given by their community by producing a DVD that interpreted their essays in American Sign Language (Skouge & Boisvert, 2004). This DVD and the photo essays were then distributed to deaf educators in Micronesia to share with deaf children and their families.

## Looking to the future

The story of Sharon and Eulalia illustrates our belief that digital storytelling must be interventionist and empowering. Like Brian's experience with the DynaWrite, it tells a story about finding a voice. Our strategy is to employ role models and technologies for voice to empower young people to gain confidence that they can participate more fully in their communities (Skouge, 2005; Skouge et al., 2003; Skouge et al., 2004).

Perhaps the story that Brian related on his blog points to a new future for persons with disabilities who have found their voices through media. Brian regularly posts his photographs and writings to his blog site; and soon, we hope to add video and audio projects by utilizing video streaming and podcasting. We are also exploring live teleconferencing in which virtual communities can see and talk to one another and share their multimedia expressions.

These technologies present new opportunities to create peer support and consumer advocacy networks and, as in Brian's blog story, they permit a "public voice" with all of the opportunities and responsibilities that go with publication.

## Brian's Epilogue

As I worked on editing a video in Dr. Skouge's office, a complete stranger came in and introduced himself.

"Hey I'm Robert. What is your name?"

"Hi Robert, I'm Brian," I communicated through my DynaWrite.

"It's nice to meet you Brian; this is some office you have!"

"It's not my office, I share it with a professor but I agree it's pretty cool."

All of a sudden, I realized what was transpiring. I was having a conversation with a complete stranger. This was a foreign concept to me until I had my augmentative communication device that enabled me to verbalize my thoughts.

"It was nice chatting with you, Brian. I'll see you again!"

"Okay, Robert. It was great meeting you. Have a great day!" I replied. The ability to wish someone a nice day provided me with a sense of joy, for I know how good I feel when someone wishes me well. This was just the start of many opportunities to come because I was now empowered with a voice that could be heard.

After the University of Hawai'i's women's volleyball team was denied the opportunity to host a regional playoff in 2005, the team's sports psychologist, who was my friend and teacher, called me with an urgent request.

"Brian, I'd like you to address our women's volleyball team and deliver a message of hope and inspiration to them because they're at a very low point," Dr. Michael D'Andrea explained to me in a phone call.

I agreed to speak to the team as they prepared for regional tournament play, realizing that their hopes of contending for a national championship hinged on their ability to persevere over this perceived slight from the NCAA selection committee. They were to leave for the continent in the morning.

The locker room for the volleyball team was very quiet and somber as I entered. I shared a little background of my growing up as a person with a disability. I explained how I learned to turn the question of "why me?" into one of "why not me?" and proceeded to explain how I used this positive outlook on life to get through any struggles in life. I challenged them to take on this attitude as they entered tournament play, explaining that "champions win regardless of where they're asked to play."

The reaction from the young women seated in front of me was powerful. Some were crying, some smiled, and some came up to me as I ended and thanked me for taking the time to inspire them. I parted ways by saying, "I look forward to seeing you back here as national champions!"

After their season concluded, the head coach for the team, Dave Shoji, found me at the athletic complex and expressed his gratitude for my taking the time to speak to his girls. None of this would have been possible without my DynaWrite.

In 2006, I connected with one of the assistant coaches for the University of Hawai'i's Warrior football team. Coach Jeff Reinebold quickly learned of my love for the university's team. I was attending practices regularly since Coach June Jones began his reign and knew many of the players. However, this was a new time, a new opportunity for me to express myself in a way that could be heard. Coach Reinebold heard me loud and clear, recognizing that I had abilities that could help the team in tangible ways. Verbalizing my thoughts and ideas allowed me to be seen as more than the "inspirational" figure who loved to support the team. I soon found myself working with other coaches, communicating information that could help in preparation for games. These

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experiences led to my earning a graduate assistant coaching position in 2007.

During that season, the Hawai'i Warrior football team went undefeated and earned their first Bowl Championship Series (BCS) bowl berth. My family and I were able to accompany the team to the Sugar Bowl in New Orleans, Louisiana. I received a Western Athletic Conference (WAC) championship ring. This ring is a constant reminder of all of the hard work, sacrifices, and great experiences we had throughout the season. More importantly, the ring epitomizes the value of having a "voice" in contributing to a winning team.

All of these experiences have allowed me to discover that I am a social being. I enjoy conversation, fellowship, and helping others; I enjoy people! My ability to be heard has such an important role in being able to relate to people. Society is so fast-paced; many people do not have the time or patience to wait for someone to write thoughts on paper and then read them, which was how I communicated prior to obtaining my DynaWrite.

My career goals have changed because of my "voice." No longer do I envision myself doing work requiring little or no interaction with other beings. Had I continued on this path in life, I would have felt empty. Sitting at a desk, typing away on a computer all day would not have been fulfilling. The lack of interaction with people would have left a void.

I now aspire to become a college professor, as my passion lies in helping and teaching others. In order to accomplish this, one needs to be able to communicate with a voice—a voice that can be heard.

In the fall of 2007, I was accepted into the exceptionalities program of the College of Education's Department of Special Education. This acceptance was the next step in my journey to follow in the footsteps of my mentor and friend, Dr. James Skouge. A professor needs to be able to communicate with his or her students, as well as with colleagues, in an effective manner. The most effective and efficient means of communication occurs when it is audible.

As I look ahead, I cannot help but reflect upon my silent past. The silence was deafening, but because I was able to find a "voice," my horizons

are endless. People can finally hear me...loud and clear. I hope to enable others to find their "voice" as well. It will be at that point that I can truly say, "I have been heard."

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