Technologies for Voice:
Video and Multimedia Communication Supports for Self-Determination

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Abstract: Video and multimedia technologies that support the self-determination of persons with disabilities are explored in a series of three stories. Young adults with disabilities clarify their values, visualize their futures, and speak for themselves, utilizing readily accessible consumer technologies. Professionals and critical friends are challenged to re-tool their technology skills to keep up with people with disabilities who are making decisions that impact their own lives.

Key Words: self-determination, technology, multi-media, video

Introduction

Young people with disabilities are assuming increasing responsibilities for their own goal setting, transitions, and life planning. Self-advocacy includes public expressions of one's hopes and dreams, strengths and assets, support needs, goals, objectives, and career plans (McGahee, Mason, Wallace, & Jones, 2001; Test, Fowler, Brewer, & Wood, 2005). In support of this effort, youth are expected to participate in their own circles of support and to find and share their own voices in the planning process (Agran & Hughes, 2008; Karvonen, Test, Wood, Browder, & Algozzine, 2004; Meadan, Shelden, Apple, & DeGrazia, 2010; Skouge, Kelly, Roberts, Leake, & Stodden, 2007). Regardless of disability, it is the young person, him or herself, who is at the heart of this evolving social value called *self-determination* (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Mason, Field, & Sawilowsky, 2004; McGahee et al., 2001).

Concurrent with the *self-determination* movement is the growing recognition within the American public education system that everyone must acquire video and multimedia communication skills, along with broader technology literacy and skills (NCLB, 2001; PCAST, 1997). In order for a free society to survive, its citizenry must become literate in using the readily available technological tools that support creating, problem-solving, communicating, and decision-making (PCAST, 2011). This movement to re-tool our society stems in part from the recognition that communication now extends beyond merely speaking and writing. Universally-designed information delivery systems, including tools that incorporate visuals, audio, and graphics, enhance communication and provide access to content that previously was unavailable or difficult to access (Ayers & Langone, 2008; Rose & Meyer, 2005). Cross-cultural understanding is enhanced by such technology as it delivers diverse stories, experiences, and perspectives. We call the various multimedia tools that support self-determination and self-advocacy by the phrase *technologies for voice*.

This paper explores the overlap between the two social movements, self-determination and the re-tooling of society, both of which impact youth with disabilities. We share three stories

in which young people with disabilities, all of whom are from culturally and linguistically diverse heritages, attained positive outcomes by employing video technologies to clarify values, visualize choices, and communicate those choices with family and critical friends.

We hope to inspire service providers and other critical friends of persons with disabilities to embrace video and multimedia tools of communication and expression. These tools are no longer new. In fact, the young people whom we support have been immersed in commercial media and digital technology since their births. Furthermore, video and multimedia technologies have more recently emerged as tools for self-expression and self-determination within the disability community (Dowrick & Skouge, 2001; Held, Thoma, & Thomas, 2004; Kelly, 2008; Kelly, Skouge, & Thomas, 2005; Lancaster, Schumaker, & Deshler, 2002; Skouge et al., 2007; Wehmeyer et al., 2011). For those of us who support persons with limited communication skills, we are well-advised to become adept at using the emerging technologies for voice. The stories that follow illustrate something of our experience.

Constructing Environments

Bandura (1997) identified three contexts for persons with disabilities. The first and most restrictive context consists of environments without choice (this environment could be exemplified by the commands: "You will live with us. This is the way it is. It is for your own good"). The second context, and the one that is most widely promoted today, offers choices that are typically pre-determined for the person with the disability (e.g., "You will live with us; or you will live with them. You will work here or you will work there"). The third, and potentially the most liberating, context promotes *constructed* environments in which people are challenged to visualize possibilities that are not readily apparent, as in the phrase, "Can we envision a future that realizes your hopes and dreams?"

Constructed environments are the most challenging contexts to actualize, but they are potentially the most rewarding (Dowrick, 1999; Dowrick & Skouge, 2001). Video self-modeling (VSM) strategies utilize a form of constructed environments to support self-advocacy, communication, and learning (Bellini & McConnell, 2010; Delano, 2007; Dowrick, 1999; Mechling, 2005). In VSM, multimedia technology is used to explore strengths, skills, and a vision for the future through carefully edited videos to create positive self-images. Empirical research suggests that when people construct their futures using multimedia, and participate in the processes of planning, rehearsing, producing and reviewing, they are far more likely to realize their goals (Bellini & Akullian, 2007; Hitchcock, Dowrick, & Prater, 2003).

In the three stories that follow, we illustrate simple video techniques to construct environments with young persons with disabilities. Typically, our projects are completed in three meetings: a planning meeting, a day of production and editing, and a gathering of showcase and celebration. Our techniques, however, are secondary to the stories themselves. In our experience, as young people become empowered to speak for themselves utilizing multimedia, the technologies become tools of expression to be employed in a wider variety of ongoing ways.

Story #1: Marcus "This is who I am"

This story is consistent with a growing body of literature suggesting that young persons with disabilities and their families can become active, positive, contributing partners in transition planning. Marcus produced videos of self-expression and presented them at the beginning of his monthly inter-agency meeting. In so doing, Marcus transformed from an insolent resistor of change to a contributing team player.

The authors were employed by the University of Hawai'i to engage youth who had disabilities in video projects to promote self-advocacy and self-determination. Typically, the videos were 8-10 minutes in duration and were intended to be shown at the beginning of planning meetings, in order for parents and professionals to hear the youth's voice first. The youth involved were often considered troubled; they were bouncing through the human services systems, including foster care, mental health, special education and juvenile justice. Our intention was to assist them in becoming enthusiastic, contributing members of their own support teams, instead of passively resisting and barely tolerating the personnel who attended their inter-agency meetings.

Working with Marcus was one of our first assignments. He had a history that included truancy, failure in school, and gang activity. He had recently been involved in an automobile accident which had left him partially paralyzed on one side and slower in speech, and had exacerbated his incorrigibility. Although he was physically self-conscious when we met him, he had begun to reconnect with his peer group and to reengage in risky behaviors. Marcus lived at home, in a rural valley on Oahu.

Although Marcus had been attending his monthly inter-agency meetings, he did so under duress. At the meetings, he spoke little, if at all, while slouching in his chair next to his mother, who looked pained at her son's resistance. The participants talked about Marcus, but not with him. The meetings were expensive to convene. The paperwork was intensive. Everyone believed that Marcus had the potential for a good future. But the process was unsatisfying and discouraging to everyone involved.

Our connecting with Marcus was problematic from the start. Because he was a juvenile, his multitude of services was shrouded in confidentiality. His counselors and therapists were accustomed to delivering services behind closed doors. The idea of inviting two digital storytellers (us) into Marcus's life to support him to produce and direct his own video was a foreign idea. Nonetheless, after some months of wrangling, Marcus's psychologist persuaded the team to give us entrée. Marcus's social worker arranged for us to meet with Marcus at her office. The date was set. We arrived with our tool kit, which included a video camera, a digital still camera, a tape recorder, a mixer and a title maker (note: these days a laptop with editing software would replace the latter two items). Marcus listened to our idea about telling his story, and expressed interest in "producing a movie." We planned to begin the following weekend.

We met Marcus in the front yard of his parents' home, amid chickens and dogs, rusting cars and farm implements. Marcus's father was sitting in a nearby shed. He did not emerge to greet us, nor did Marcus make any effort to introduce us. Marcus wanted to go to a nearby beach, which he called the most beautiful beach in the world, where he had surfed before his accident, and which he wanted to highlight in his film. We drove to the beach, walked to the edge of the sand, and mounted the camera on a tripod. We showed Marcus how to pan and zoom. He asked

to be left alone, so we sat at a nearby table. After about a half hour, Marcus signaled that he was done. On the way home, he shared his excitement that he had caught some "awesome" waves and surfers. We arrived back at the house and left our slippers [sandals] on the porch.

Marcus invited us into his bedroom, which was a tiny spaced filled with a bunk bed, a dresser, a single chair, and a small patch of floor. Clothing was scattered about. There was one small window covered with a tattered curtain. A rotating fan hummed annoyingly. Marcus sat on the lower mattress of the bunk bed, rummaging through piles of cassette tapes trying to locate the perfect music for his video. "It's here," he said. "I just need to find it." It was hot and stuffy. The lights were off. Marcus found the tape, and after much rewinding and fast forwarding, cued it to its beginning. I (Jim) sat in the chair. Mary volunteered to sit on the floor.

The camera rolled. Marcus introduced the song as a "true love song" which he dedicated to his girlfriend. We listened. Marcus rocked on the creaking mattress while cradling the boom box. Reaching under his mattress to retrieve a half smoked cigarette, he lit it with dramatic flair and dragged with a deep inhalation. The song ended. We suppressed the urge to cough. Marcus looked straight into the camera and took another drag. "This is for my parents," he said. "They don't want me smoking, but they know I do. It's how I relax."

"It's how I relax," he exhaled and repeated. The smoke hung heavy in the room. The camera kept rolling. I found myself wondering if I would soon be fired from this job. "What in the world were we doing in this young man's bedroom?"

We spread our editing equipment on the floor. We plugged in our extension cord and power strip, and we worked together to edit the video right then and there, complete with titles, surf images, music, and smoke. Marcus narrated a portion from the beach scene, expressing once again that it was the most beautiful place in the world. The finished VHS tape was named, labeled, and presented to Marcus. We offered to help him produce another when he was ready. Marcus asked for our phone numbers, assuring us that he would be ready to create another video very soon.

As we drove back to town, drained from a day full of activity, I recall thinking how amazing it was that a kid so troubled (and so expensive to society), could be satisfied with taking us to a beach, playing a love song, and smoking a cigarette in front of a camera.

The next day Marcus was on the phone. "This is who I am," he said. "This video is who I am!" We set a date for two weeks hence to produce his next video. This time it was to be a Christmas gift to his family and a piece to be shown at his upcoming transition meeting. Mary went to the mainland to visit relatives. Marcus and I (Jim) were left to make the movie alone.

This time, Marcus had a much different plan. I arrived to find the living room arrayed with photographs on the sofa, chairs, table, and floor. Marcus had raided the family photo albums of their contents and had even removed pictures from their frames on the walls. I gulped as I surveyed the scene: "What will your mother say?" "What if she comes home to this?" "How will we ever get things back?" "Don't worry," Marcus assured. "She'll love this project." I wanted to believe.

Marcus had a shooting sequence in mind. We recorded each photograph for just 10 or 12 seconds, with Marcus holding up each photo, close to the lens. We had a bit of an assembly line, and the process didn't take more than an hour or so. When we were done, Marcus used a microphone to record commentary about each picture.

He had something loving and positive to say about each of the many people whom we recorded that day, including his parents, brothers and sisters, and the many nephews, nieces, cousins and such. He took great pride in commenting on his family's ethnic diversity, recognizing family members as Pilipino, Chinese, Vietnamese, Hawaiian, and Haole [Caucasian]. "We've got it all," he said.

We added a title and background music. Marcus knew just what he wanted. The photos were returned to their proper places, and by late afternoon when Marcus's mother and sister appeared, we were done. I greeted them; they acknowledged me, perhaps with some suspicion. I expressed how much I had appreciated working with Marcus, and packed the car to leave. I had never been part of a project that was so uplifting. I found myself wondering how a kid with such a bad reputation could express such love and feeling for place and family.

For several months thereafter Marcus would phone to tell me that he watched the videos every day. "That is who I am," he repeated often. "It is who I am." Both videos were shown at his planning meetings. Marcus insisted on showing up a half-hour before the meetings to cue the tape and insure that there would be no glitches. He introduced his work and expected everyone to pay close attention. And, of course, they did. They applauded him. They saw a person totally different from the resistant youth, fidgeting in a chair, who had resented being there.

In the months that followed, the cloak of confidentiality resettled over Marcus's life. Eventually, we lost touch. We can report, however, that the ice was broken within the local mental health establishment as regards video storytelling. Mary and I were supported to continue our work with other youths, one of whose stories was in fact shared publicly at a major mental health conference some months later, representing mental health case workers from across Hawaii.

Story #2: Chef Ryan Makes a Party

In this story, a youth with disabilities and his independent living counselors were challenged to clarify values and see beyond boundaries. The video was initially created to display Ryan's independence as host and chef. Its surprising outcome, however, was to show the value of interdependence and community inclusion.

The first author (Jim) was hired by the Hawai'i Centers on Independent Living to work with their counselors to support consumers to engage in self-advocacy. On the Big Island I met a man with cerebral palsy who enjoyed being with people but spent an uncommon amount of time alone. He lived in a marginally accessible apartment, and was able to independently cruise through his hometown using his electric wheelchair. His sister prepared his meals and brought them to his door at suppertime.

He expressed to us that he would like to learn to cook and host a party for his friends, but his kitchen was too small for him to negotiate. So, he had never acted on the idea. "Let's do it," the counselor and I suggested. "We'll bring adapted kitchen aids and we'll make a party." Ryan

was on board. We sat in the living room to formulate a plan. We decided to produce a slide show that would depict Ryan living out his dream.

The next week I returned, camera in hand. We by-passed Ryan's kitchen altogether by running an extension cord to a card table in his front yard, plugging in an electric skillet and a toaster oven, both of which became accessible under these circumstances to Ryan in his wheelchair. We brought the ingredients. Ryan pulled up to the table and went to work. We all helped. I functioned as the photographer, taking digital pictures of every step, carefully framing each shot to display *Ryan as an independent chef.* Photographs included:

- Ryan at the grocery store with his shopping list.
- Ryan pressing meat patties between his hands.
- Ryan slicing tomatoes with the adapted cutting board and knife with "L-grip" handle.
- Ryan frying patties using tongs as grippers.
- Ryan salting fries with the shaker with the adapted handle.
- Ryan serving his friends.
- Ryan and his friends feasting and laughing.

As we set up and photographed the shots, I found myself questioning our rationale. "Why are we doing this? Isn't it false? What do we gain from this?" The reality was that Ryan was not cooking independently. We were helping him every step of the way, just out-of-frame of the camera. There were perhaps 8-10 of us in attendance, including nearly half the independent living counselors in town. Doubts or no doubts, we stuck with the plan.

Later, when the picnic was over, we watched the pictures in Ryan's living room, displayed on his television. We were all laughing. Ryan was always slow to speak, but when the performance was over, with great determination he expressed his truth. "I want to have more parties," he said. "It is fun to work together."

We stayed connected with Ryan throughout the upcoming year. He watched his video many times, and he hosted numerous parties, sharing joy with his friends. What I learned from the experience was a simple lesson that inclusion does not mean "independence." Inclusion means sharing and participating in community.

Story #3: Keoni's "Great Race"

This story brings home a vision to a family. The parents see great joy as their son realizes his dream, as depicted in video, of a single constructed event. They act on it by cutting through red tape and delays to purchase their son an amazing bicycle.

We were asked by several physical and occupational therapists to videotape a physical assessment of a young man who was being evaluated for a tricycle. Keoni was without speech, and he had severe physical disabilities, including hemiplegia. He was 12 years old and physically large. He refused to walk more than a few yards without sitting to rest. Everyone including his family thought of Keoni as a bit lazy. He loved tricycles however; and his teachers thought a 3-

wheeler might motivate him to move and exercise. His family was from Micronesia and struggled to manage in the Hawaii economy. Keoni was too big for a children's tricycle, so efforts were underway to "fit him" for an adult version.

We were invited to produce the video to be sent off island to several therapist trainees so they could evaluate from a distance. The assessment was to occur at a public school, where tricycles of various sizes and styles were available. We arrived at the school at the end of the school day, just at the same time as Keoni and his father. Keoni slowly got out of the car, walking cautiously with braces, holding his father's hand. Keoni did not speak and carried no means of augmentative communication. The resident occupational therapist greeted us with a number of different styles and sizes of tricycles at the ready.

The assessment was conducted. Keoni's range of motion was observed. His strength and stability were measured. He was asked to mount and dismount, pedal and brake. I was doing the filming. Keoni's father, wearing dark glasses, stood off at a distance, uninvolved. Keoni was obviously delighted to see tricycles, but disappointed he was not riding. I (Jim) whispered to a physical therapist friend that this was soooo boring for Keoni: "Ugh." She agreed.

"Hey," I suddenly exclaimed. "Let's film a bicycle race! Let's put Keoni up against the fastest bike racer on Oahu and film a race! We've got the bicycles. We've got the track. All we need to do is recruit some competition!"

And so it happened. A girl about Keoni's size, far too old for tricycles, was innocently walking past the door just as my idea was gaining acceptance. Her name was Marcy. She was heading home from school, a book bag over her shoulder.

"Hey," I said. "We're making a movie of a great bike race. Would you take a few minutes to help us? We need you to race Keoni." "Sure," she said. We were all laughing. We were making a movie!

Keoni's father, always shy and reserved, became animated. He placed his ball cap, in reverse, on top of Keoni's close-shaven head. He slipped his sunglasses onto his son's beaming face. I took out an Alpha Talker and recorded a few quick messages, like "Let the race begin" and "Come on, let's get going" and "Beep, beep. Out of my way." We set up a starting line. Marcy and Keoni were positioned head-to-head, excitement mounting.

I got the camera rolling. Keoni pushed the buttons on the Alpha Talker. "Beep. Beep. Let's get going." A starting signal was sounded. The race was on. Keoni and Marcy were neck-to-neck. Keoni was straining every muscle. This was real. "Go, Marcy, go!" we screamed. "Go, Keoni, go!" we shouted.

Down the parking lot they raced, wheel-to-wheel, inch by inch. Keoni's father trotted beside his son offering words of encouragement in Micronesian language. I, too, ran alongside, camera rolling. Then it ended. Marcy won by a hair. There were high fives and shaka signs [Hawaiian gestures of solidarity]. Keoni took off his glasses and tossed his cap in exuberance.

That evening, I edited a short seven-minute piece, adding music and titles, and delivered it straightaway to Keoni's family. The Big Race, along with the assessment footage, was sent to

the therapists and their trainees. Reports were to be written and recommendations to be made. But, before the documents could be produced, we learned that Keoni's family had purchased a beautiful 3-wheeler for their son, entirely on their own. It was a recumbent bicycle they had seen in a catalog. The family had seen all they needed to that day, and they had acted.

Keoni lived for that tricycle. He would sit on it outside their front steps every day after school. He would ride it to the park whenever his parents allowed. One day I filmed him at the park. His family was with him, including his little brother. Keoni pedaled right up to the climbing structure, parked in the sand. He dismounted and indicated to his father that he wanted to climb up to the platform and go down the slide. He did it. The climbing took forever, with his dad pulling from above, and his mom pushing from behind. I filmed it. Keoni did it. A 13-year old boy taking the biggest risk of his life.

Clarifying Values, Asserting Identity, Exploring Inclusion

Perhaps a common thread to these stories is that all of the central actors (Marcus, Ryan and Keoni) were searching for ways to clarify their values, to assert their identities, and to become participating, contributing members of their communities. The videos were constructed to illustrate these themes. In each case, the first audience for each video was the individual and his family. The videos were viewed and reviewed numerous times at home, reemphasizing that his constructed choices were in fact attainable. As Marcus expressed it, "This is who I am!" The second audience for each video was critical friends and professional support teams. The videos enabled Marcus, Ryan, and Keoni to present a "first voice" to the families and teams committed to supporting them. This experience was new for each of them, as each had challenges with oral and written communication.

Re-Tooling Technology Skills

The video technologies employed in this paper are not difficult to learn. It is likely that you or the young people with whom you work are already engaged in digital storytelling in one form or another – often by taking digital photos and showing them on computers, tablets, smart phones, or social media sites (e.g., Facebook). Our presentations are often enhanced with text and music. Some people are even making short videos that are shown on personal television sets and computers or shared more globally on sites such as YouTube. Both digital still cameras and digital video cameras are fairly inexpensive and commonplace. In addition, many phones and mobile devices include these as standard features, and computers even come with free software to edit videos (e.g., iMovie, MovieMaker). All the tools for multimedia expression are now within reach.

If you are new to this, we suggest that you begin by assisting just one person to share a hope or dream. You might start with PowerPoint or some other familiar presentation software. You can share meaningful photographs, add text to explain the significance of the pictures, and add music to set the tone. Or, use a video camera to record important moments that can be shared with others, and perhaps add photographs, text, and music. Then, when the project is complete, encourage your client to be the "first voice" in their planning meeting. It is a start. You will be entering into new partnership with your client to explore tools for voice and empowerment (Held, et al., 2004).

Honoring Privacy and Confidentiality

Technology can provide change, globalization, and access. The digital stories described in this paper were intended to empower Marcus, Ryan and Keoni to find their own voices for change, for use within their own private and confidential circles (be it within their families or within agencies). For Marcus, who was enmeshed in the social service system, issues of confidentiality almost prevented us from engaging in the project at all. It was easier to obtain media release waivers for Ryan and Keoni, as they had legal guardians who could give consent. In all cases, however, issues of confidentiality and privacy should be considered paramount.

Digital information can now be disseminated almost instantaneously wherever the high-speed Internet is in place, including text, pictures, sound, movies, and "real time" imaging. The opportunities to engage people in creative dialogues are limited only by our imaginations. With these opportunities, however, come our responsibilities: we must counsel and protect the privacy of the clients with whom we partner. For those of us who work for professional agencies, it is likely that legal procedures are in place, requiring the informed consent of the client or guardian to allow information sharing. These legal protections are important, but *they may not be sufficient*.

The implications of the digital revolution are new and beginning to be better understood by us all. For example, the power to record video in our living rooms and broadcast it over the Internet calls for serious consideration. We say and do things differently in the privacy of our homes than in public arenas (even when cameras are recording). We seldom realize that an audience of strangers may see us completely out of context. As professionals, it is essential that we develop and practice techniques to fully inform clients of the possibilities, the risks, and the realities of such digital communications. We should discuss safeguards to privacy, such as reviewing, editing, and deleting digital information before dissemination.

Marcus's and Ryan's videos were gifted to each of them, with the understanding that they owned the material and could share it with audiences of their own choosing. All of the out-takes and original footage were erased. In Keoni's case, the "Great Bicycle Race" has been broadcast on Hawai'i Community Television and throughout the Pacific Basin as part of technology outreach training by this paper's first author. This was accomplished with the enthusiastic support of Keoni and his family.

Finding Voice

Video and other multimedia tools present exciting opportunities for self-determination, self-advocacy, and systems change. Youth are drawn to technology. Now with digital video and still cameras, laptop computers, cellular phones, tablets, and other portable devices, the opportunities are as never before to engage young people in authentic expressions that are anchored in their homes and communities.

As young people find their voices, it is our experience that they do not become rebellious or careless. Instead, they empower and synergize their circles of support to engage in vision-crafting and problem-solving. Fundamentally, when given a chance, young people want to express gratitude and love to the people who support them. They want to share the beauty of the

world as seen through their eyes. They want to live in community, to love and be loved. They want to prepare for a career. And they want to give back. As young people become self-determining, parents and professionals will find their work of guidance and support far more satisfying.

If there is a single lesson from our work, it is that young people with disabilities must own the full process of digital storytelling, from planning their messages, to producing and directing their stories, to editing their final pieces. Finally, they must be fully present at the showing – sharing their voices as natural expressions of who they are, what they want and need, and how they will get there.

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