Assistive Technology Supports for Self Determination and Community Inclusion

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Abstract: A description of media techniques that "give voice" to people with disabilities to engage in assistive technology problem solving, including video collages, interviews, walk-abouts and "how to" demonstrations. Ethical considerations related to publication and dissemination are addressed.

Key Words: assistive technology, digital storytelling, creative problem solving

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The "Tech Act": An Invitation to Come to Hawaiʿi

In 1988 the U.S. Congress authorized the "Technology-Related Assistance for Individuals with Disabilities Act," otherwise known as *The Tech Act*. This legislation was a forerunner to the *Americans with Disabilities Act*, giving voice to the growing civil rights movement within the disability community. The Tech Act was reauthorized and amended in 1994 and again in 1998 when it was renamed the *Assistive Technology Act.*

The intent of the *Tech Act* was to raise awareness and "pave the way" for widespread dissemination of technologies believed to hold the promise of "leveling the playing fields" in our schools, homes, work places and communities, for persons with disabilities and their families. The *Tech Act* also affirmed the federal role in promoting assistive technology devices and services for all American citizens. It recognized the considerable barriers to technology acceptance and adoption, including lack of access to information, assessment, training, customization, maintenance and repair. The *Tech Act* represented a leap of faith that a truly inclusive society could be constructed with the appropriate application of technology tools (Alliance, for, Technology, & Access, 2002). The *Tech Act* came to Hawaiʿi in 1992, as did this author.

In summer 1992, I was invited by the Hawaiʿi University Affiliated Program for Persons with Developmental Disabilities (now called the "University of Hawaiʿi's Center on Disability Studies") to become Hawaiʿi's *Assistive Technology Outreach Trainer* for this new *Tech Act*. My job was to deliver assistive technology "awareness" and "training" to any audiences in Hawaiʿi who should request them, including the production of community television programs to be aired through our local public television network.

This essay describes this writer's story of service and discovery, with the intention of promoting creative partnerships among professionals and persons with disabilities and their families, to attain self-determination and community inclusion in the Hawaiian islands utilizing *assistive technologies (A.T.),* or what we came to call *technologies for voice* (Skouge, 1993).

Consumer Driven and Consumer Focused Supports

The language of the *Tech Act* was challenging and perhaps unsettling for those of us with traditional training in special education or rehabilitation. The *Tech Act* called for "consumer driven" and "consumer focused" initiatives and supports – notions which were somewhat contrary to the "medical" and "expert" models espoused in the professional literature (Alliance et al., 2002).

I read the Congressional Record in its entirety regarding the debates and ultimate passage of the *Tech Act*, moved by the testimony of families and individuals with disabilities sharing anger and frustration, hopes and dreams that assistive technologies could transform their quality of life. For the first time in American history, augmentative communication users spoke out in the U.S. Congress. Steven Hawking was becoming a household name.

"Leveling the playing field" was the phrase that stuck with me. Filled with enthusiasm and trepidation, armed with a fist full of airline coupons, I struck out on a great inter-island adventure, speaking with any community group that would invite me.

What is A.T.?

What is "assistive technology"? This was an important first question. Unlike rehabilitation engineering, or physical therapy, or special education, this new field did not fit into traditional textbooks or professional domains. A.T. was (and is) required by law to be "considered" in the development of individualized service plans, including *Individualized Family Service Plans* (IFSPs), *Individualized Education Plans* (IEPs), and *Individualized Work Rehabilitation Plans* (IWRPs) (Alliance et al., 2002). But, who was to do the "considering" and how was this "consideration" to be accomplished? The law defined *assistive technology* as any technology that supported a person with a disability to function more independently at home, in school, community and work place. The definition was expansive.

At one of my first talks on Maui, I tried brainstorming with the audience about the meaning of A.T. A well-traveled gentleman of the Pacific noted that eye glasses and hearing aids were lacking on many of the islands. "Perhaps we should begin there," he suggested. "What about electric can openers," "television remote controls" and "baby alarms" suggested others. Every suggestion sounded reasonable. The list grew. The need for a working definition become increasingly evident.

The *Tech Act* defined *assistive technology* in terms of "devices" and "services." Devices were to be understood as *tools to improve human functioning.* In Hawaiʻi we began calling them tools for life. *Devices* were described as ranging from "low tech" to "medium tech" to "high tech." *Tools for life* could be home-made, "off the shelf" or custom built. Services included a broad range of supports such as assessment, funding, training, maintenance, advocacy, and even systems change (Alliance et al., 2002) .

The conventional wisdom was to consider the lower technologies first, moving to the higher technologies only as needed. This wisdom had a certain appeal in terms of cost savings, not to mention training, repair and upgrade. It also presented risks. Would a letter board and a typewriter really substitute for an electronic "talker"? Would a "mouth stick" substitute for a head mouse or voice dictation on computer? We learned early on that money affects many decisions, sometimes at the detriment of respect and empowerment.

The law made it clear that assistive technology included *more than devices* (Alliance et al., 2002). It became abundantly clear that just knowing about a device (perhaps seeing it on television, or reading about it in a catalog or magazine) or even acquiring one, rarely prepares the user to integrate it successfully into daily life. Technologies may alter how we look, how we fit into groups, perhaps even our sense of who we are. No wonder it is difficult to predict in advance how they will work out. Many technologies require training. Many involve the support and acceptance of family or teachers or employers. Technologies cost money. They break. They disappoint. They are abandoned. In fact, for every successfully adopted technology, it is now recognized that there are many in disrepair, in closets, symbolizing disappointment and failure.

One thing became certain, assistive technology was to be understood and explored in terms of individuals with disabilities and their families, as they lived and functioned within the daily contexts of their lives. Assistive technologies are not “things.” They represent a process of partnership, risk taking, becoming and empowerment (Alliance et al., 2002).

Halona Farden, a wheelchair user, who was to become a role model for many of us, closed his front door by tying a dog leash to the knob, so as he passed over the threshold he could grab and pull. "Assistive technology is creativity," Halona explained. We began working from that premise.

Broken Promises

Within several months of my arrival in Hawaiʻi, I had acquired wonderful films from the U.S. mainland, depicting all manner of persons utilizing technologies for joy and independence – blind children riding tandem bikes with sighted partners, paraplegic skiers using sit-skis, and youth with cerebral palsy using electronic talkers for communication and switches to control toys and the environment. Many of these films were being produced and shared by the *Tech Act* projects across the United States, as part of a growing realization that people needed to visualize possibilities.

“Seeing is believing,” I thought, as I stowed a 30-pound video projector as carry-on baggage with Aloha Air. I also equipped myself with a few devices of my own, including an Alpha Talker, an Intellikeys Keyboard, and a laptop computer with voice synthesis and picture symbols (*BoardMaker*, *Intellitalk* and *Speaking Dynamically*). Aloha Airlines gave me a waiver to exceed their carry-on limit, agreeing with me that my bags were too breakable for check-in and my mission too important to abort. I flew with them weekly, appreciating their aloha spirit.

One evening I gave a talk to a parent group in Kona, on the Big Island of Hawaiʻi. Although I had no first-hand experience with augmentative communication, I had acquired a film produced by the American Speech and Hearing Association, depicting kids in the most awesome wheelchairs imaginable (little fork-lift trucks) - communicating, even singing, through their electronic talkers. After presenting the movie, I demonstrated how to record voices on my Alpha Talker, passing the device around for the parents to touch.

Several parents began to speak tearfully about the lack of services on their island for their children – tears were mixed with outrage. I stood alone in front of 25 “consumers” feeling powerless and hurt. We were not celebrating technology. We were expressing broken promises and pain.

One mother invited me to return to Kona the following week to spend a school day with Allen, her son with Down syndrome who did not speak. She wondered if I might spend a day with him, observing how things were going at school, to see if I thought an augmentative communication device might be helpful. Ignorant of what I might be getting into, I agreed. The family would host me at their home. They would make all arrangements with the school administration. All I had to do was arrive at the airport. It seemed easy enough. (Perhaps this is what the *Tech Act* meant by being *consumer responsive*).

A week later, on a Monday morning, I arrived at the school promptly at the start of the school day, parking my rental car close to a building marked “office.” My intent was to spend the day observing Allen’s communication strategies and opportunities, to make positive suggestions to the family and his teachers. This intention was not to be realized.

I was greeted in the parking lot by a grim-faced school principal who gestured me into his office. “I know why you are here,” he intoned in a cold voice after I was seated. “You are here to cost me band uniforms and athletic equipment. Technology costs money and you are here to sell technology.” I was frightened.

It proved to be a long and fruitless day, marred by cold receptions and hurt feelings. That evening on my plane ride home I realized that “leveling the playing field” would not be as simple as showing movies and demonstrating devices. I needed a team and a voice that was stronger than my own – a circle of support, perhaps, anchored in persons with disabilities who could join me in the story telling.

“Perhaps we could do video vignettes,” I wondered aloud, “Profiles of people. Nothing to embarrass – local folks, talking story” (to use the local vernacular). I closed my eyes and rested my head against the cold window, listening to the jet engine hum from the wing just outside in the darkness. We’d be touching down on O’ahu soon. I’d make it home, video projector and all, by bedtime. Exhausted.

The Touchdown

Hawaiʻi’s *Tech Act* project had a 12-member advisory board, with a majority of the membership representing persons with disabilities (as mandated by the law). The board had been formed several months before my arrival, so I was the new kid on the block – a project director still in his “honeymoon” period.

It was at our October meeting (I had arrived in July) that I made my proposal that we produce video vignettes of local people utilizing assistive technologies.

“I will use my camcorder to do the recording, and I can do all the editing myself. We will share the videos on televised forums, in which the person with a disability and his or her ‘circle of support’ (family, professionals and friends) talk about it and discuss its implications with the community.” My proposal was met with considerable doubt among the board members. Some feared that the production costs would be high. Others suggested that “local people” would either be too shy to be video taped, or so critical of the “system” as to be embarrassing. Dr. Richard Radtke, a professor of marine biology with quadriplegia, quietly interrupted the negativity getting everyone’s attention by inviting me to meet him at the University of Hawaiʻi pool the following day to film him swimming. I accepted the invitation without hesitation. The board meeting adjourned moments later, with the understanding that we would meet again two weeks hence to revisit the topic.

The next day, promptly at 2:00, I was standing waist deep in the U.H. Olympic swimming pool, with my VHS camcorder on my shoulder, filming Richard, his attendant, his wife Judith and his son David, as they laughed and played in blue water. As Richard floated, his attendant systematically rotated, first, Richard’s head, back and forth, then his arms, one at a time, around and around, and then each leg through what Richard called “range-of-motion” exercises. All the while, 8-year-old David laughed and splashed and played with Judith. Although totally paralyzed from below his neck, Dr. Radtke floated weightlessly. My camera lingered on every movement, including the hydraulic lift that lowered and raised this huge man into and out of the water and the wheelchair van that carried the family home.

That night I “edited” my video tape from camera to VCR. I didn’t know how to create titles. I didn’t know how to record narration or add music. All I knew was how to selectively dub the “good stuff” onto a new tape by pausing and un-pausing the VCR as my camera played. What I knew was enough. The story would more than compensate for my technical ineptitude.

The advisory board met soon thereafter, as agreed. Dr. Radtke was in attendance, as was his wife. We started the meeting by playing the video on a large television monitor, pausing it every minute or so to talk, reflect and enjoy. The blue colors of the water were vibrant. The hydraulic lift was awesome to behold. Laughter and joy filled the meeting room. Richard was dried and dressed. He was secured in his van, and the family departed, with Judith at the wheel.

When the tape was done, we talked about accessible transportation, access to recreation, the importance of attendant care, and the value of aquatics in people’s lives, and Richard’s near single-handed struggle to persuade the U.H. athletic department to install the lift.

Everyone on the board was animated. We all “got it.” We could tell local stories, and we didn’t need to embarrass anyone. Video vignettes could serve as spring boards for learning and sharing. It did not have to break our budget. It was so “local” – to watch and talk story!

The swimming pool episode marked the first of hundreds of video “pieces” that we have produced, all sharing snippets of people’s lives, proudly and sometimes shyly sharing one tool or invention or adaptation or accommodation (Skouge & Ratliffe, 2003; Skouge, Ratliffe, Callan, & Roberts, 2001; Skouge, Ratliffe, & Uesugi, 1994 - 1998). It marked the beginning of several hundred hours of programming for Hawaiʿi community television. We had stumbled onto a formula that worked. We scuba dived and sky dived and mouth painted. We cruised parks in powered wheelchairs, accessed beaches in balloon-tired beach chairs, sang songs and ordered “local food” using augmentative communication devices. We cooked with blind chefs, danced with the Deaf community, and explored myriad ways to access toys and computers, appliances and musical instruments. It was within this “crucible of story telling” that we learned that people want to speak for themselves, sharing their stories of life in the community.

Dare to Dream: Extending Digital Storytelling to Consumer Problem-Solving

By the end of our first two years our circle had grown to include perhaps 100 persons with disabilities and their families, in partnership with physical and occupational therapists, rehabilitation engineers, speech therapists, special educators, social workers, volunteer videographers, and a host of creative, handy people (many of whom were retired engineers). We had gotten the message that *assistive technology* required a circle of friends, engaged in creative problem solving. Assistive technology was creativity. It was human beings reinventing themselves and their world (Alliance et al., 2002; Skouge, 1997).

It was at this point that we began working with the *Hawaiʿi Centers for Independent Living*, developing an assistive technology self-assessment tool entitled *Dare to Dream*. The project extended our video techniques to individual consumers and their families engaging in assistive technology problem solving, focusing on 5 steps:

I WALK WITH OTHERS

- meeting role models on video

I CELEBRATE MY LIFE (profiling assets, strengths and resources)
- video mapping the people, contexts, activities and routines of daily life

I ENVISION MY FUTURE (clarifying values, hopes and dreams)
- video self-modeling: visualizing one's own participation and inclusion

I CREATE A PLAN
- identifying needs and challenges
- identifying partners
- identifying assistive technologies

I GIVE BACK TO COMMUNITY (acquiring a public voice; becoming an agent for social change)
- sharing my story in multimedia

The *Dare to Dream* self-assessment tool was developed in partnership with more than 50 families in Hawaiʻi, living on Kauaʻi, Oʻahu, Maui, Lanaʻi and the Big Island. It extended and systematized many of the visual and "talk story" components that played well on our television programming. This time, however, the purpose was not for dissemination on community television, but to empower people within their personal and local communities to own the process of self-determination (Skouge, 1997). In the following sections, I describe some of the techniques we employed.

Video Collages: Visions and Dreams

This activity is most often conducted in small groups, either with focus groups of people with disabilities or with circles of support. Team members are provided poster paper, marking pens, scissors, tape or glue, and a stack of magazines rich in illustrations. The first step, quite simply, is to produce a collage of hand drawn pictures and magazine clip art illustrating an agreed upon theme from the person's life.

Themes are positive in tone, focusing on hopes, dreams and visions for the future as related to independent living, mobility, communication, education, recreation, employment, friendship, community service, lifelong learning or the like. The collage is to contain a title and a tapestry of pictures and text captions. It takes perhaps an hour to complete the activity.

The second step is the presentation of the poster to a video camera. Typically, one or two team members hold the poster by its edges as a designated speaker stands or sits to one side, pointing in turn to each of the collage elements, while describing, reading and elaborating. As the speaker points and talks, the designated camera operator records each of the picture elements in close-up.

The resulting video product consists of a narrated, thematic "slide show" with each of the picture elements magnified to the size of the screen. Both the paper poster and the video recording become gifts to the person about whom the hopes and dreams are expressed. As possible and appropriate, the person with a disability is the speaker.

As simple as this activity may be, it can be powerfully moving, perhaps especially for adults for whom picture making is an activity long-forgotten from childhood. Many people have stopped dreaming about their futures, choosing instead to live in the present "state of stuck."

Recorded Interviews: Profiles of Accomplishment

An important component of our *assistive technology* problem solving consists of structured interviews. These interviews are often conducted "one-on-one" in the family home (living room, kitchen, patio). The interviews are "formal" in the sense they follow a protocol of questions, encouraging open-ended dialogue. Interviews are typically one hour in duration. They are audio recorded. Interviews are "strengths based" rather than "problem based." The goal is to "profile" the individual in terms of his or her unique history, beauty, strengths and to do so in their own words and voice. For people who cannot speak for themselves, we convene a "circle of support" to facilitate communication.

The interview focuses upon values, strengths, interests, likes, aptitudes, skills, gifts, hopes and dreams. The theme of the interview has *absolutely nothing to do with disability,* but with sharing a great day. Preparing a meal with friends. Describing beauty in nature. Giving a gift. Overcoming an obstacle. Feeling pride. Helping someone. Something to love.

We focus the conversation onto *details or events* that can be *visualized*. "Describe helping someone?" "Describe a meal you would prepare to make a party for friends?" We listen and show genuine interest. This is not a "counseling" interview; nor is it an effort to gain a client "history" which professionals might be expected to write in case studies or reports. Rather, it is a process of breaking the pattern of focusing on deficits, helplessness, dependence, loss and disability, which so often become the focus of professional-client relationships. It is an effort to "break through the wall" – to dare to imagine and dream. When the interview concludes, we leave the recording with the client that she might reflect on her own words (Skouge, 1997).

Video Walkabouts: Mapping, Photographing and "Talking Story"

We produce visual maps of daily routines and activities, beginning with getting up in the morning, preparing for the day, leaving the house, experiencing school or work, recreating in community, and life at home (including chores, meals and leisure). It is easy for people to talk about routines. Routines present a structure for conversation. We listen. We ask questions. We try our very best to visualize the details of the routines of the day.

As we "map" we are attentive to physical and social contexts or "environments." These, too, are easy for people to visualize and talk about: at home it is the kitchen, the living room, the bedroom, the bathroom, the yard; at school it may be the bus, the playground, activities in the classroom, lunchroom, recess, and so forth.

Typically, we conduct a "walk through," visiting each of the contexts with the family, seeking to get a first-hand visual orientation. After this *walk through*, we take a digital camera and retrace the steps, taking pictures of elements of each scene. We take pictures of details representing both "successes" and "challenges" – the ramp neighbors built out of good will; pliers that have become indispensable in the kitchen to open bottles; stairs in need of a railing; the fire extinguisher out of reach to the wheelchair use; the telephone too difficult to dial. These *little things* bear further scrutiny.

On yet a subsequent visit, we display the pictures either on a computer screen or living room television, encouraging the family to celebrate accomplishments and think about needed accommodations. We always ask the family for permission to show the pictures of their successes and “lessons learned” with others. They almost always agree (Skouge, 1997; Skouge, Ratliffe, & Guinan, 2001).

Showing and Telling: Video “How To’s”

During our initial years when we produced materials for community television, we learned people enjoyed showing, telling and demonstrating their skills, accomplishments and handiwork. We are all teachers at heart. It does not really matter whether we are 5 years old or 80 years young, there are things that give us great pride in showing and telling. Over the years we have produced many hundreds of simple “show and tells,” usually keeping them to 5-7 minutes in duration.

For example, Jamie is a medically fragile youth who receives his education at home. He teaches us how to use a favorite piece of software. Michael is quadriplegic from muscular dystrophy. He shows us how to grow herbs in the raised garden beds in his backyard. Artis is blind. She invites us into her kitchen to make spaghetti and salad. A family of a child with severe physical disabilities takes us swimming with the boogie board they’ve adapted for their son. A father shows us how to adapt a battery toy with switches.

Our video techniques are simple. We shoot with one video camera “up close and personal.” We do not use a microphone, nor any special lighting. Sometimes we shoot *over the shoulder* to get close-up shots of people working with their hands. We ask people to talk about what they are doing, as they are able. In recent years, with more technological sophistication, we pour the video onto our computers, add a title, credits and background music and “burn” to DVD (Skouge, 2004; Skouge & Boisvert, 2004).

Many videos are shown only to the family of the person with a disability. Sometimes, however, we incorporate them into our teaching at the university or share them at conferences and meetings. They function to give people with disabilities a voice; and to put us as professionals into a partnership. We always ask if we might share the videos with outsiders, and the families almost always say “yes.” These videos, by the way, are enthusiastically received within the disability community. People are proud to serve as role models for others; and eager to learn from one another’s experiences. This may especially be true here in Hawaiʻi, where people in the local community know one another.

Occasionally our videos are shown in client-centered planning meetings. They provide clients the opportunity to show and say “first hand” what they can do. It is one thing to report to a committee that an individual can take the bus and work at a grocery. It is quite another to produce a music video depicting the same. Pictures are worth a thousand words.

Considerations for Professionals-in-Training

Assistive Technology is not a linear process of assessing and locating devices and services. It is instead a process of engagement and encounter. It is recognizing that human beings are both “social animals” and “tool users.” We engage the world through extensions of ourselves as we live and thrive in community. We are programmed to be included in the construction of our world. Nothing less works.

As professionals we are in a position to value these tools and apply them in our work. This requires commitment, however, since media and multimedia are still mostly seen as the tools of "others," rather than ours. We are taught to maintain "professional distance" from clients, to write reports and present case studies.

The values and tools described in this article lend themselves to new possibilities, in which professionals engage in partnerships with persons with disabilities and families to create and share stories of discovery, experience and becoming. This represents a shift in thinking: Our mission becomes one of supporting persons with disabilities to find their own voices.

None of us can accomplish this alone. It requires vision, re-training, equipment and commitment. Old paradigms of "teacher-student" or "counselor-client" relations must give in to notions of role transcendence, shared ownership, collaboration and teamwork.

Imagine our *tool kits* to include cameras, voice recorders and multimedia computers. Imagine "stories" rather than "case studies," and our partners to include the very people about whom the stories tell.

Creating Virtual Communities: Creative Possibilities and Significant Risks

Technology means "change." Nothing stays the same. Opportunities widen. The digital revolution provides increasing opportunities for community building and sharing, transcending the obstacles of "time and place." Digital information can now be disseminated almost instantaneously wherever the high speed Internet is in place, including text, picture, sound, movie and "real time" imaging. The opportunities to interface people in creative dialogue are limited only by our imaginations.

With this opportunity, however, comes our responsibility to council and protect the privacy and confidentiality of the people with whom we partner. For those of us who work for "professional" agencies, it is likely that procedures and legal protections are in place, requiring "informed consent" from people to permit information sharing. These legal protections are important, but *they may not be sufficient*.

The implications of the digital revolution are new and largely unimagined by us all. For example, the power to broadcast video information over the Internet that is recorded in our living rooms 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), little realizing 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 consumers of the possibilities, the risks and realities of such digital communications, including safeguards to review, delete and edit digital information before dissemination.

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