

PHASE II (MS#029d(1)-H01)
PRODUCT OF STUDY #14
Richard Radtke and James Skouge

University of Hawai`i at Manoa Center on Disability Studies
National Center for the Study of Postsecondary Educational Supports
A Rehabilitation Research & Training Center

Personal Perspectives From Professionals
Mentoring and Role Modeling in the Ocean of Potentiality Program
Its Impact Towards a New Paradigm

Preface by Richard Radtke

In 1981, I first began realizing that I was becoming disabled. My strength was waning. It was becoming increasingly difficult to hold onto things or lift my legs. I was tripping and falling. My father had died eight years earlier of pneumonia due to complications from Multiple Sclerosis. I had always wondered if I would be next. And so it was. In that year, I too was diagnosed with the disease. My self-esteem plummeted on a path to total disintegration. After a wild gallop, I was quickly the operant of a wheelchair. By 1985, I was a quadriplegic and have been so ever since.

In youth, much of my self-worth was grounded upon physical attributes. I competed in college football and was the friend often called upon to relocate sofa bed couches. The journey from being a defensive end that hunted quarterbacks to a quadriplegic in a wheelchair incapable of movement from the neck down was formidable.

At first I thought that I could no longer contribute to society or mankind. My self-esteem had evaporated (many people take a similar kind of pilgrimage). To my salvation, over some period of years, I discovered that I could still contribute, albeit in other than physical ways. Eventually my obligations to mankind became greater than ever. I discovered that we all have a responsibility to one another even if one has a disability. The method to fulfill that obligation differs for each of us.

For me, role modeling is not an academic approach. It is giving of myself so that others and I can move forward and make a difference in the world. It requires some bearing of self and soul. We all have talents and some are well hidden. A mentor's job is to foster talents and often times to demonstrate, firsthand, that dreams are attainable.

I believe that people learn the easiest by example. Our activities with people with and without disabilities have shown this to be true. We have taken groups of youth with disabilities out into field conditions where few have been before. When they see a quadriplegic being placed into a rubber raft, propped up by life jackets and cushions so that he can lead in research, and paddled out into the stream or lagoon, something stirs within them. Those who doubted now want to join the adventure. Role modeling requires that we give of ourselves. We stretch our boundaries in order to help others stretch theirs.

Most youth long to be engaged in the activities of life. A true role model shares himself, his knowledge, his time, his energy, and his efforts. We believe that young people see and feel that sharing and will, in turn, engage it.

Richard Radtke

Supporting Youth with Disabilities through Role Modeling: Oceans of Potentiality

In 1996, the authors of this paper submitted a proposal to the National Science Foundation (NSF) to explore outdoor education opportunities for youth with disabilities with the mission to motivate youth with disabilities to stay in school, move on to college, and consider careers in math, science, engineering and technology. Initially, the NSF funded a one-year pilot project to involve youth in stream and reef research on the North Shore of Oahu, Hawaii. A year later the project was expanded into a three-year effort to involve youth with disabilities in camping and wilderness experiences across the state of Hawaii.

Richard Radtke is a practicing scientist, a marine biologist and oceanographer. He is also severely disabled, paralyzed from the neck down by Multiple Sclerosis. Jim

Skouge is a special educator with a background as a camp director for youth with disabilities. Both are experienced in assistive technology and media. Both are faculty at the University of Hawaii. Both believe in the power of story telling - which explains why the stories that follow are written in the voice of the first person.

From the outset, we (Rich and Jim) both agreed that the Oceans of Potentiality Project, although complementing the math and science curricula of public schools, would be wholly different from what youth might experience in the classroom. Our goal was to design experiences in which youth with disabilities could join a community engaging in great and challenging adventures. Our dream was to create interdependent experiences that could be transformational, in which youth with disabilities discover that they can do and be anything that they choose to be. We wanted to plunk kids right into the middle of great stories that could touch them at the very core of their attitude about themselves.

We started by recognizing that Rich has all the right stuff to become a hero and a role model for youth. He is a big man - ex-football player. Paralyzed from the shoulders down, controlling computers with voice and head movement. Living with pain, but physically fit. A vegetarian, who swims every other day and exercises with discipline every morning and evening. Family man who travels with his wife Judith and daughter Ocean. Supported by youth attendants who, themselves, are college students pursuing careers in marine sciences. A Golden Retriever service dog that turns on and off lights and computers and even calls elevators!

Rich is a field scientist who scuba dives and works in remote and romantic places - Greenland, Antarctica, Norway, Alaska, Hawaii, Samoa, and the Arctic. Surely, we have here the stuff of a hero and role model for youth. Someone who could penetrate the chains of disability and light a spark in youthful eyes. We were determined to create experiences in which Dr. Radtke could touch and be touched by youth.

We also wanted to celebrate science within the context of culture and the arts. Recognizing that a great strength of Hawaii is in its cultural diversity and Polynesian

ancestry, we invited Angela Zangerle and Makia Malo to join us, both proud Hawaiians and powerful role models in their own rights.

Angela and her family live in Waianae on the island of Oahu, a local and proud Hawaiian community struggling to find and maintain its identity. Angela is the mother of a teenage girl, Lia, who was hit by a car seven years ago, and suffers severe traumatic brain injury. The family fought back from financial ruin, overcoming tremendous odds. Lia is now in high school, out of the wheelchair and succeeding in school with special education supports. Angela is now recognized as a statewide advocate for parents of children with traumatic brain injury. In partnership with the University of Hawaii, Angela and her family, and many youth from the Waianae community produced a film on Lia's accident promoting traffic safety and the need for traffic signals in Waianae. This award-winning film, entitled *Watch it, Don't dodge it!* is now shown in public schools throughout the state. Angela would be a perfect role model for parents of youth with disabilities. Not to mention that teenagers of all sorts love being around her for her humor and boundless energy. Angela grew up on the ocean (her father was a fisherman), speaks local pidgin; teaches traditional arts and crafts, and her cooking is da bomb.

Please join us, Angie; we can't do it without you.

In no time at all, Angie was to become our camp cook, crafts lady, and auntie to countless youth with and without disabilities.

Makia Malo is a storyteller. He is now world-renowned, but his anchor is in the classrooms of Hawaii's public schools. He is joyous and utterly incomparable, telling stories that make kids jump with fear, scream with laughter and struggle to hold back tears. Makia grew up on Kalaupapa. He was taken from his family when he was 12 years old because a spot was discovered on his skin indicative of what was then called leprosy (Hanson's Disease). Makia tells his stories of growing up both before and after the exile. Hilarious stories of the local kids growing up on Punchbowl, working in taro patches, skipping school and swimming naked in the Nuuanu Stream. Poignant stories of the exile to the inaccessible peninsula called Kalaupapa, with its sorrows, terrors, and joys of

coming of age: hunting wild pigs with his dogs, shooting sharks from the pier, picking opihi, diving for octopus, playing piano in the community hall, drinking beer with friends in the moonlight, and daily tolling of the church bells for the dead. The legacy of Father Damien. The medication and the cure. Leaving Kalaupapa, blind and disfigured. Marriage. University and graduation. Divorce and re-marriage. And staying forever connected with Kalaupapa, living both in Honolulu and back home. We held our breaths as we phoned to invite him to join us in our Oceans of Potentiality adventure. We told him that we wanted to inspire youth through heroes and role models.

Would you join us?

Without a moment's hesitation, nor any request for additional information, Makia said, "Of course." Makia would become our folklorist and cultural broker. None of us would be left untouched.

So, there we had it. Our core faculty consisting of Rich, Angie, Makia and Jim, each with our circles of support. Since that time, four years ago, we have challenged more than 100 youth with and without disabilities to think about their lives and futures, striving to engage them in transformational experiences. What follows is a brief sharing of some of those events. As you read, we hope it becomes clear that we are not engaged in a formal prescription for youth empowerment. Instead, we are uncovering some of the ingredients for deconstructing the disability paradigm.

Our ingredients for youth empowerment in science, math, engineering and technology include:

Hero building and story-telling

Role modeling and mentoring

Interdependence, cooperation, partnership, community building and service

Cross-cultural sharing and the arts

Camping, outdoor education and adventure in majestic places

Media, computing, assistive technology, and the Internet

Career education and visioning

The ingredients listed above are not technical or scientific terms. Nonetheless, each has become loaded with meaning for us. In the vignettes that follow we will try to illustrate each, given that the activities we support are intended to be fun, challenging, connected with nature, technology enhanced, universally designed, culturally referenced, and community enhancing.

We believe in community building through universal participation. Activities are challenging and purposeful for everyone including the adult volunteers. No one stands back. Adults and youth, alike, help one another with chores and, on occasions, activities of daily living, helping those who cannot feed themselves, pushing wheelchairs, and volunteering as sighted guides. As appropriate, we even help with transfers, bathing and dressing, respecting one another's privacy, but appreciating that camping is a unique experience in which personal and public boundaries sometimes dissolve.

We also believe in public reflection and expressions of gratitude and commitment. Our camps include circles of sharing in which everyone expresses what touches them and commits to community service.

The organization for the vignettes includes selected stories from (a) our Through the Viewfinder youth-produced television series, (b) our day camps on the North Shore, (c) our three-day camps in Waianae (Oahu), Kalaupapa (Molokai), Koke'e (Kauai), and Waimanu (Big Island), and (d) reflections on the disability paradigm as we have ourselves have changed and been transformed.

Through the Viewfinder (Youth-Produced Community Television)

For some years, Jim (one of the authors) had been active with his colleague Mary Kelly, working with troubled adolescents living in Waianae and along the Leeward Coast of Oahu and supporting them to produce video letters and video celebrations of their lives. Music videos were a common genre, but after several of the youth elected to document community events (cultural festivals, local musicians, and so forth), it seemed a natural progression to build a bridge with Hawaii Public Television (O`lelo) to create a youth produced television series. A production company was formed, naming itself "Through the Viewfinder," with membership consisting mainly of troubled youth, their parents and siblings, and the occasional special education teacher and mental health counselor. As a company (we preferred calling ourselves "family"), we completed the necessary training to access the O`lelo production studios and borrow their field cameras and equipment.

For reasons unfathomable to this author, O`lelo offered "Through the Viewfinder," a live half-hour television spot shown once a month in which our youth were to be behind the cameras, in front of them, and even in the control booth. We accepted the offer. This was LIVE television, available in thousands of homes statewide! A guarantee of gray hairs for any of us old enough to feel responsible. The youth were in heaven.

We were scheduled to go on the air at 8:00 p.m., the first Wednesday of each month. On the broadcast day, we were allowed into the studio by 4:00 (four hours before air-time), which was good because it gave us ample time to set up and rehearse. It was also bad because it was a school night and we were pretty well worn out by airtime. Kids got cold. No food was allowed in the studio. And there were plenty of buttons and wires to invite kids to get into trouble. By the time eight o'clock rolled around some of our more "active" youth (special educators called them "hyperactive") were off the wall. But all in all, we did fine. We all knew that we were engaged in something very important and very complicated. Additionally, all the kids knew their friends from school were

watching. Not to mention the fact that this writer feared that his friends from work might be watching too.

Jim and Mary alternated being floor directors or managing the control booth, and other than the time that Teresa (an emotionally disturbed teenager) broke down crying as she was controlling one of the cameras, things were upbeat and working. The kids invited the guests. We rehearsed the questions. The guests showed up. The 30-minutes were over before they started. And, the show was being watched. The kids were gaining notoriety in the community, which was good, as they had been totally invisible or worse, before.

But then came the Christmas show when the stage was set, the tree was lit, and the guests (local musicians) didn't show up. (It's possible Margaret had forgotten to invite them.) It was 30 minutes to show time. We phoned and they weren't coming. Perhaps 20 or more of us sat on the cement floor of the over air-conditioned studio wondering what to do. It came to a vote. This author voted that we call it a bust and ask O'lelo to substitute anything on tape perhaps even a cue card announcing, "show cancelled due to no guests." But the kids were not to hear of it. It was Christmas. We owed the community a celebration. They voted that everyone who had talent was to sit on a carpet in front of the tree to tell Christmas stories, sing carols and offer Christmas wishes to the community.

"Are you a chicken?" they asked me. Yes I was a chicken. Absolutely. "Cluck, cluck." (My friends might be watching.)

The show went on. We did as voted. The lighting was good. The audio was fine. The content was as you might imagine, rough and unrehearsed. But we made it. We sang songs to which many of us did not know the words. We made up stories. The kids called me "uncle" and insisted that I start a round robin Christmas story. We each shared something for which we were grateful. And then it was over. "All clear on the set." Pinch myself, we had survived. The kids were elated. We had overcome great adversity. We had bonded, and we all agreed that we would never again produce a live show in that oh so cold studio.

By January, we had accumulated enough lights, tripods, mixers, microphones and cameras to open our own "mini" studio in Angie's garage. It was tight, but it worked. What had been cold at O`lelo, was warm and friendly at Angie's garage where we produced one new live-to-tape television show per month for more than a year to come. Our programs were still aired on O`lelo, it's just that we now delivered our shows "in the can." The formula worked. Soon we became quite a community sensation. The garage door remained open. Neighbors and on-lookers standing in the driveway, peering in. "Quiet on the set."

We explored all kinds of things in Angie's garage including puppet shows, story reading, and no end to music and entertainment. But we kept coming back to the interview format. V, a blind high school student, became one of our lead hosts. She was a great listener, always nodding and leaning into her guests, reading her notes from her Braille notebook computer. Among our guests, we started interviewing more and more people with disabilities. It is as though we were all discovering and rediscovering that our first mission was to explore, discover and celebrate the culture of disability. This fact truly hit home the day V interviewed Cheryl Nelson a blind community activist. V, also blind, was interviewing a woman who was a personal role model. Cheryl described growing up in an institution for the blind. V listened and questioned in disbelief. Together, they shared examples of prejudice they had experienced. The interview was electric. At its conclusion, V thanked her guest and we knew to a person that this was role modeling at its best. Our kids had the power to give voice to their role models.

Soon afterwards, the youth invited Dr. Radtke and his service dog to appear as guests. He showed up with his entourage. Raised roof van and lift, Judith and Ocean (wife and daughter), youth attendant and service dog. A big man in a floppy hat, wearing a passion pink T-shirt, his arms folded gently on a bright blue pillow adorned with fishes, and a leash draped over his forearm attached to a Golden Retriever so beautiful you couldn't take your eyes off her.

"Make way for Dr. Radtke!" Cameras and cables were pushed aside as Rich was pushed and positioned next to Lia and Tim, his interviewers. "Quiet on the set."

With halting speech and all the struggles associated with traumatic brain injury, Linda guided Rich and the audience through questions about his work and his dog. Then, as part of the plan, she made her own presentation on ocean pollution asking the audience to throw wads of paper, one piece at a time, into an inflated plastic swimming pool, to demonstrate the overwhelming damage caused by overpopulation on the fragile ocean environment. Rich sat patiently at her side, commenting on her presentation, and supporting her as she answered questions from the audience.

Inviting Rich had been Linda's idea. Some weeks previous she had begun participating in our Ocean of Potentiality day camps on the North Shore of Oahu and had embraced Rich as a hero and role model. Already she was saying that she wanted to become an oceanographer. And here Dr. Radtke was her guest on our own "Through the Viewfinder!" After that day, the stage was set. Most of our "Through the Viewfinder" youth wanted to join Oceans of Potentiality. In turn, the Oceans of Potentiality became a co-sponsor of our company.

Field trips on North Shore Oahu

In 1996, we received our first NSF grant to support youth with disabilities to explore careers in science, math, engineering and technology. We were given one-year's pilot funding to create a science club in which all manner of youth would engage in field-based science with Dr. Radtke. It was a simple and inauspicious beginning. Rich's daughter was named Ocean. He was an oceanographer. We named the project Ocean of Potentiality.

The work scope was most definitely "do-able" and it was honest. Kids would see and experience the very kind of work Rich and his colleagues do. Rich knew of a stream that fed into the ocean at a park on the North Shore of Oahu in a location that was accessible to our beach wheelchairs (which were built of PVC pipes and balloon tires). Kahuku High School was located nearby with science and special education teachers already known to us, with unbridled enthusiasm for any project promising to get students into field experiences. As an added plus, the Center for Independent Living operated in

partnership with the high school supporting young adults with disabilities who had recently graduated, but had failed to make the transition to work or postsecondary education. It sounded like the perfect pool of students. So we held a meeting at the school, laid out a plan, and reached a consensus that we would meet six Saturdays over the ensuing several months at the mouth of the stream to engage in basic field research. The Kahuku folks were to supply the kids and Dr. Radtke, and his graduate students would deliver the curriculum. Rich had limited experience working in field conditions with youth with disabilities. Jim had no experience with stream biology or marine science. Together we figured we'd make a fit. The die was cast.

It was rainy and a bit blustery. Rich was sitting in the beach wheelchair covered in bright yellow rain gear, wired-up with a head-set microphone connected to an amplified speaker propped against his footrest, making his voice loud enough, but perhaps a little tinny, and with the occasional squeal of feedback. Three inflatable boats were in various stages of readiness, angled with their bows to the river's edge. The ocean surf played against the sand dunes just behind. All kinds of scientific paraphernalia were strewn about: nets, chemistry sets, rope and floats, cameras and binoculars. Graduate students standing with their hands in their pockets probably wondering what Rich had dragged them into. Rich's family, Judith and Ocean, his attendant Josh, and the service dog, two sign language interpreters, an independent living counselor, and the high school teachers were in attendance. The youth included four of whom were deaf, one was blind, several with traumatic brain injury and associated learning disability, and then a number of teens from the Kahuku High School Science Club who had no disabilities at all, but aimed for careers in science and technology and were hungry for the learning opportunity. We probably could not have been a more diverse group. Rich called us to order. We did our round-robin introductions. And before much else happened we were forming cooperative teams. The teams dispersed. The wind and rain slackened. Blue sky and blue water reigned. An auspicious beginning for the first day.

Rich's graduate students were to act as team facilitators showing the kids what to do, how to set up the equipment, what to observe and how to record. The projects were varied: inventorying life forms on the beach, netting fish, photographing leaves and

plants, measuring water, salinity and other chemistry. The truth is that Rich's students knew a lot. They were Master's and Ph.D. level scientists in their own rights, but they were not teachers. Further, they most certainly did not have a clue how to organize or manage their groups so as to insure the cooperation and interdependence of the diversity of members. The tendency from the beginning was to assign or default the leadership to the gifted kids from the science club with the kids with the more severe disabilities assuming more passive roles. This challenge, by the way, continues to perplex us to this day having tried many strategies with more or less success.

A second reality that hit us early on was the general preference of the Deaf students to stay together as a team. This is perfectly understandable (as they do speak a common language), but troublesome nonetheless exacerbated by the fact that we are usually limited to just one or two interpreters. Our strategy to date has been a form of reverse mainstreaming in which one or two hearing students are included on the Deaf student team.

Perhaps what intrigued us most from that first day, was the apparent ease with which some youth with disabilities accepted passive roles on their teams. Oftentimes they were the ones sitting on the outer edge, not volunteering, deferring responsibilities to others. What to do? Again, we certainly do not have any one answer, but the strategy that we began using, right then on that very first day, was what we call role modeling: Rich would participate in every activity. The kids would see, firsthand, that one of the most severely disabled members of the group actively participated in everything, no matter how extreme or creative the accommodation. If Rich could do it, couldn't Vicky?

Case in point, one afternoon we were sending teams out of our line of sight, around a bend in the stream where there was noticeable current. The teams were using the inflatable canoes and kayaks, accommodating 2-3 persons in each boat. The team was to paddle to the site, anchor a net on one shore, then paddle across the current or in some way pass the net to a boat on the opposing shore to anchor it there. The stream was perhaps 20 yards across. The team was to wait some minutes and then check and inventory the contents of the net placing any live critters into zip lock baggies to share

with Dr. Radtke, observe and record, and then return unharmed to the stream. It was a seemingly simple enough task. The kids had been doing it with joy and enthusiasm all morning. But when it came time for Vicky's team to embark after lunch, Vicky quietly but firmly declined to participate. She was blind. A senior in high school. And very strong willed. I don't care to join in. I'm not feeling well. Please go without me.

That was when we decided that Dr. Radtke should head-up Vicky's team. We would put him into one of the inflatables along with a strong kid who could paddle solo.

Would you help us, Vicky? You steady the boat while we transfer Rich.

It took us a half hour or more to get Rich into a boat! In fact, the first boat didn't work out at all. We couldn't stabilize Rich's torso, no matter how many cushions and life jackets we jammed between rib cage and rubber. Rich is a big man (6 feet, 4 inches), with nearly 200 pounds of dead weight. By the time he was loaded, Rich was laying in the bottom of the boat except for his shoulders and arms that were draped over the inflated gunnels, his head resting against the bow. Michael, the youth who volunteered to paddle, sat facing Rich with their legs intertwined. Judith fitted Rich's floppy hat, rubbed suntan lotion onto his bare shoulders, and Vicky extended to him a water bottle that he might suck from the straw. We were exhausted and holding our breaths.

The boat was launched. Mike, himself a youth with special needs, clenched his jaw, forced a smile, and said to Rich I can do this. Rich said, Of course you can. And ever so slowly, low in the water, the boat edged away. Before many minutes it disappeared from view.

Those of us remaining on the shore had pretty well sat down by this time wondering collectively what we had just witnessed, when Vicky asked if there was yet another boat.

I think I'll go, she said. He may need water.

Vivian was blind. She had not visually witnessed any of this. But she knew. And Rich knew that she had never been in a boat before and that she didn't know how to swim. He hadn't pushed her. He was just determined to go himself. We helped Vivian put on a life jacket and she and another youth took their paddles and launched.

Jim had the opportunity to drive Vivian home later that afternoon. It was an hour drive or more. Plenty of time to debrief. For Vivian, it wasn't that she had done science (although that was interesting). It was that she and Rich had gone out in boats. Vivian has since graduated high school, gotten her Internet connected and embarked on college. Paddle on.

Residential camps

It wasn't many months later that NSF awarded us a three-year funding to develop residential science and technology camps for youth with and without disabilities. It is one thing to orchestrate Saturday field trips. It is quite another to run 3 and 4 day camps. To date, we have managed six of them, both on Oahu and the Neighbor Islands. Of course, we have many stories we could share, but in the interest of brevity we will tell just a few.

Rich has it in his mind that if we are going to do camps, we should do them in the most beautiful, spectacular, and sometimes sacred places in Hawaii – nothing simple here, where we go down the street to our local Y-camp. Jim is the more conservative wishing that we could just lease a camp and perhaps even hire its core staff. Not to be. Rich wins.

We've taken reef walks at night with flashlights and clear-bottom viewing boxes. We've ridden in small planes and the beds of pick-up trucks. Told ghost stories where we probably shouldn't. Flown kites in winds so gusty as to propel Brandon in his wheelchair across the grassy meadow. Hiked and pushed and pulled and groaned through mud flats, sand bars and lava fields. Taken thousands of pictures. Eaten local kine grinds. Bumped Rich's head on more doorways and shower stalls and overhangs than any one man should ever deserve. Danced and cried and bonded in ways that could not have been imagined.

And so far, knock on wood, come out pretty well unscathed. Sore backs. Sleepless nights. Warm hearts. Kids that keep coming back for more.

We mentioned in the introduction that we look for peak experiences or moments of transformation. The challenge of this is that such things are often unpredictable and require change and growth on the parts of everyone involved. So that when we have a closing circle (which is now part of our camping ritual) and Rich, the stoic Germanic type gets a catch in his throat, and tears streak his cheeks, we realize that this is not a project for youth, rather it is a community that touches us all. Through it we change and grow. This phenomenon is difficult to describe and near impossible to replicate, but we believe there are ingredients that when judiciously applied lead as often as not to transformations. It is this belief, in fact, that motivates us to write this article. In that light, we will share a few more stories.

Camp Kalaupapa

When Makia Malo joined our team we began seriously exploring the dream of taking young people with disabilities to Kalaupapa (the once-termed leprosy colony) to spend some days with Makia and the members of his community. The peninsula is now part of our U.S. National Park System, but it is in the unique status of being on-hold until such time as the final resident (patient) dies or moves away. The community is aging and has dwindled now to 50 or so living members.

Because of Kalaupapa's history as a place of forced exile and isolation, it holds a special place in Hawaii's history, never to be forgotten. It is also one of the most uniquely beautiful places on earth. A tiny village on a remote peninsula, accessible only by the occasional boat and small plane; surrounded by sheer cliffs with only one switchback trail to the top, some thousands of feet above.

The citizens are growing old. Many are disfigured. They cherish and deserve their privacy. Kalaupapa has been their home since the day as children they were snatched from their families. It was Makia's home from the time he was 12 and although he moved to Oahu in his thirties, after becoming blind, it will always be his home. Two of his

brothers are buried there. They too had been exiled by the disease. Makia continues to live on the peninsula some months each year and intends to be buried there.

For all of these reasons, Rich wanted to organize a camp on Kalaupapa. Notwithstanding the fact that there were many good reasons not to do so. Youth had to be 16 or older to get a permit. And many residents were wary remembering the day some years prior when a young visitor fell off her bicycle while riding through the village only to be terrified by a resident who instinctively reached out to help with a hand that was disfigured. The youth had screamed and ran. Soon thereafter the village counsel voted to ban youth visitors. But, all told, Rich wanted our youth to go.

It's a special place, Jim. Our kids need to experience it. And, who knows, maybe the patients need to experience us.

We arrived in small planes – 25 of us or more. We were warmly received by Makia and three of his lifelong friends. Suffice it to say, the kids were on best behavior. We all knew that this was once in a lifetime. One night, Makia took us to the place where the caskets had been made. As he grew up, the church bells tolled almost everyday for the newly dead, the just departed. We sat in the darkness and he told us stories. Some really scary, the way only Makia can tell them. But then he'd make us laugh and tell us some crazy story about the way his eye was plucked out by an octopus. We wrote journals and edited photos in the town hall: the place where Makia and his friends in bygone years watched movies on Saturday nights and crooned the Big Band tunes in the moonlight. There was an old piano in the hall. Makia hadn't played it in a long, long time, but he did with the kid, every night. One of our youth, hard-of-hearing, sat on the piano bench and filmed Makia's hands as he hammered out the tunes.

He plays so good. And he doesn't even have all his fingers! Billy whispered. At our closing circle Billy confessed that he wanted to take up the piano too.

We did science, also. We inventoried the litter on an uninhabited beach, littered full of plastic and Styrofoam, to enter the data into an Internet database of ocean pollution. We transected a quarter acre of a high plateau to measure the encroachment of

foreign plants into the ecosystem. We visited a lava tube that snaked its way under the cinder fields to open on a cliff face far above the sea, a place where ancient Hawaiians stood guard against invasions. But most of all we felt the presence of culture, history, and continuity through Makia's eyes.

It was at Kalaupapa that Jim and other youth first began to realize how much work it takes to get Rich up in the morning and to bed at night. It is one thing to think about these things in the abstract, quite another to live them firsthand. Our living quarters were small. The bathroom and shower were utterly inaccessible with stalls so narrow there was barely room for an able-bodied person to turn around. Rich's attendant needed help. This was no place for privacy or embarrassment.

One night, after dinner, Rich asked several of our young men (kids with emotional or behavioral challenges) to help with the showering. These young men struggled to undress Dr. Radtke, transfer him into the tiny stall, wash him in the cold water, brush his teeth, dress him for bed, and transfer him yet again onto a mattress placed on the floor in a room down the hall so that he wouldn't fall out of bed as he had the night before when the mattress was on top of the box springs. Jim stood back, watching one of those transformational moments, when young men are allowed to touch and in turn are touched. Two years later, one of those young men, a local youth with a legacy of a painful childhood, straightened out his life and became Richard's attendant. He has now traveled with Rich to Alaska, Samoa and Philippines and speaks now of going to college.

On the Saturday morning after our arrival on Friday afternoon, we held an orientation in the town hall introducing one another, meeting some of the town folk, and orienting ourselves to our cameras, computers, and journal materials. S, from Kauai was good looking, able-bodied and proudly Hawaiian. His special education teacher had brought him hoping the camp would open his eyes to his own possibilities. We had hired a videographer named Tom to document the camp. We gave S a digital camera and asked him if he might like to work with Tom to act as a camp documentarian. S took the challenge and under Tom's care began to shoot the most beautiful pictures, mainly

patterns, petals of flowers, old stonewalls, stained glass windows in the churches, lava formations. It was art. By Saturday night, as Makia played piano, we began downloading Seth's stuff to the computer for all to see. It was good. Everyone knew it. Since then S has become a photographer at all our camps. His work has been shown on community television. And as he confessed one day not long ago, I think I've found a career.

Camp Koke'e

Some months after Camp Kalaupapa, we organized a major undertaking at Koke'e National Park on Kauai, one of the rainiest places in the world. By that time we had expanded our scope to include increased numbers of youth in wheelchairs, including kids with cerebral palsy who use augmentative communication devices. Four kids in wheelchairs participated, two with electronic talkers. We also invited two youth with autism who absolutely loved our cameras and computers. This was in addition to Makia, D and V who were blind, deaf kids and their interpreters, a fair share of able-bodied youth who faced learning, emotional or behavioral challenges. The most diverse group we had ever orchestrated.

We arrived from all over the state to the Lihue airport on a Friday morning. Organized our stuff into seven vans and departed for the mountain jam-packed with people, wheelchairs, computers and cameras, backpacks, three service dogs, and all manner of paraphernalia. Our food and basic supplies had been delivered by truck the day before. Our principle goal at Koke'e, besides visiting the look-outs to appreciate the grandeur of Waimea Canyon, was to hike in the Alakai Swamp, something Rich had always wanted to do because of its utter uniqueness as a cloud forest with flora and fauna (especially birds) to be seen no where else.

We arrived at the camp late Friday afternoon just as it was turning dark. It was raining and it was way colder than the weather we were used to at sea level. Supper was ready, as Angie had flown-in the day before to get the kitchen in order. The food was ono. Spirits were high.

The facility was definitely too small for our group of 35 and it was only minimally accessible for persons in wheelchairs. There were no dormitories and no beds, futons to put on the floor. We all slept in two common rooms, one of which doubled as the dining room and kitchen. We decided not to separate the sleeping quarters by gender – everybody picked a spot that would work for him or her. Rich's family pitched a tent nearby. By 9p.m., we had located all the missing bags and were gathered in the dining room for opening circle. It was raining. No matter. We were dry. Spirits were high. The dogs were fed and the hike wasn't scheduled `til Sunday. And on Saturday if need be we could stay in-doors, as we had plenty of learning and preparing to do.

By 9:00 a.m. Saturday morning, our clean up was complete and our first naturalist (a bird and bug man) had arrived in his truck with all manner of specimens and magnifying glasses. We learned about birds and insects, medicinal plants and endangered species – even something about Hawaiian quilt making. By late morning the sun was coming out. We practiced using our binoculars and cameras and field notebooks to observe and record. Sean, a young man with autism, learned to use our digital video camera. He and Jim volunteered to videotape the weekend including on-the-scene interviews with the microphone beginning with the assembly of Rich's all-terrain off the road swamp cart which looked like a heavy-duty rickshaw that could be both pulled and pushed. Rich had gotten it direct from the inventor, a professor with paraplegia who lived in Alaska who used one just like it on the tundra.

In the afternoon, the Park Director paid a visit to talk with us about the Americans with Disabilities Act as it affected park planning. Using flip chart paper and brainstorming techniques we dialogued with her about ways to make her park more inclusive. We all had ideas. She was receptive to our suggestions. It was a wonderful dialogue and the sun came out.

By 4:00 p.m., we were ready to trek down to the Park Headquarters and museum. It was a half-mile away. The kids in wheelchairs needed to go by van, but most everybody else walked. The museum was great with plenty of exhibits that celebrated the ecology of the Alaka`i Swamp. Most fun, however, was the huge grassy meadow (acres

and acres) in front of the park headquarters. A strong breeze was blowing. We had brought all sorts of high performance kites, borrowed from a kite shop in Honolulu. Everybody flew kites. Brandon, a kid with a great sense of humor who communicated through an electronic talker, asked us to tie a kite to the arms of his wheelchair. A great yellow high performance kite danced and tugged and pulled Brandon's chair across the grass. Gleeful.

Sunday morning three local guides arrived in a 4-wheel drive pick-up. They had volunteered to lead the trek in the swamp. As they watched us load-up the vans, we detected some hesitation in their demeanor. This group was diverse. Rich's all-terrain get-up-and-go wheel chair was loaded last. It looked like something out of a Star Wars film.

The road will be passable but rough up to the mouth of the trail. We'll park the vans there. Bring plenty of water. There'll be a boardwalk but it'll be tough going.

After some discussion and negotiation, we decided that a few of our youth would take an alternative hike on a more established and conservative path. C's wheelchair just didn't look fit for the trek. To this day, we're not sure whether that was the right thing to do. The group took off. Skies were gray but no rain. Jim stayed with the back-up group. S found another partner to help produce his video.

The group did have a wonderful day. It did rain. Birds were spotted and flora identified. S made his movie. Folks got cold and wet and muddy, but by the time they returned in the mid-afternoon all that was forgotten. However, it had gotten tough. The boardwalk was fine at first. Rich's Star Wars chair was perfect for going up steps and around the trees. But then things got tougher. The boardwalk narrowed, so that Rich's wheels just barely, barely stayed put to the edges. In fact, it got so that youth had to walk along side the boardwalk, trudging in the mud, pushing up on the armrests to keep one or another wheel from toppling. Folks got tired. Rest breaks got longer. The bugs were coming out. Repellent or not, it's tough when you can't slap your own face. Rich, the indefatigable warrior read the handwriting on the wall.

We'll park under these trees and wait for the critters to come to us.

It was a unanimously accepted compromise. S made his movie. The sun came out, as did the birds. By mid-afternoon the group returned, exuberant. Sometimes the best way to see nature is just to be in it.

At the closing circle on that Sunday night we shared things that we were grateful for. Brandon, using his augmentative communication device, told Dr. Radtke that he'd really like to have a chance to fly that kite one more time. As we prepared for bed, the stars were shining. We left on Monday morning, under blue skies and brilliant sun.

So, what's to come?

We certainly plan to continue with the camps. Waimanu Valley on the Big Island is next on the schedule. Rich and some others will be ferried in by helicopter along with the gear. The rest of us will hike into the valley. Rich has done previous field research in this remote valley and paints a pristine picture of an isolated peninsula washed by the ocean, nourished by a meandering stream, rich with fish and other life forms beckoning for research. We will take our inflatable boats and nets and go as bona fide field assistants for Dr. Radtke eating field rations and sleeping on the ground in tents. A scientific protocol will be followed with the intention of publishing the findings, referencing the youth as co-authors. Everyone is to be a scientist in this our most rigorously scientific adventure to date.

It rains in Waimanu Valley. Wood gets wet. Fires are hard to build. Ahhh, boiled water and instant mashed potatoes. There'll be plenty of seconds, Rich assures.

Transforming a "disability paradigm" into a celebration of diversity and interdependence

So, where are we in all of this? What's the point? We have mentioned such notions as "hero-building," role modeling and mentoring, all of which we believe are the ingredients of youth empowerment. It is tempting, even in writing this paper, to portray Rich, Makia and others as a "super heroes" - excelling beyond odds and expectations. Youth with disabilities need heroes just like everyone else and we believe that in our

work we have touched this core need. What we want our youth to experience firsthand, however, is the fundamental truth that none of us, not even our heroes, act alone. The only honest paradigm for this new millennium is cooperation, integration, interdependence and the synergy that human beings generate when they work toward common purpose. Within this paradigm of diversity and interdependence there are critical roles both for persons with and without disabilities. We need one another and together anything is possible.

Some months ago we held our second camp in Waianae on Oahu. A parent on the Big Island asked us if we would include her son John, a boy with a history of depression and suicidal tendency. She had heard of our work and believed, along with his teacher, that a camp such as ours might be good for him. We said, "Of course."

John flew over on the Friday morning with his suitcase and no friends. We picked him up at the airport. He was cool, reserved, polite and without eye contact. We determined to watch John carefully that weekend.

By Friday afternoon, we had given John a digital camera and told him it would be his for the entire weekend. "We'd appreciate it if you would document the camp." "I like cameras," he said, as he accepted the offer.

John didn't interact much with the youth that weekend although he showed up at all the activities, took plenty of pictures, and even participated when we tore apart the computers. He would have been easy to lose in the crowd, as we had many energetic Deaf youth as well as five wheelchair users (including two using augmentative communication. All were engaged in an active regimen including horses, reef walks, campfires, and Hawaiian agriculture and spiritualism. But John was there, watching, taking pictures.

On the last night of camp (Sunday), we held our closing circle right after supper. It was already getting late and we had a dance and light show scheduled for later. It would be a late night. The circle was huge, perhaps 40–50 people, filled with tradition, including the passing of the microphone when everyone gives public thanks. We asked

John to videotape the event by standing in the center of the circle handling a camera on a tripod. It took the better part of an hour to get around the circle. Deaf kids spoke through their interpreters. B shared a joke through his "talker." Plenty of tears and laughter and thanks for acts of kindness. The last person to speak was to be Rich. He thanked Makia, Angie, and Jim, and all the counselors and volunteers, and especially the kids letting them know with sincerity how they had touched him and energized him to carry on with his work. When Rich finished speaking someone in the then teary-eyed room called out, "John hasn't had a turn." All eyes turned to John in the middle of the circle. There was nowhere to hide. S raced over to jam the microphone in John's direction.

"Thank you, Dr. Radtke," was all John said. Then it was time to clean up the dining room and make preparations for the dance.

Jim got up from his chair and walked up to John to thank him for his help. As the two of them put away the video gear Jim put a hand on John's shoulder and asked, "How was this camp for you?" With his eyes averted, John said quietly, "I didn't want to come here. My mother made me. I didn't want to be with a bunch of disabled people. It sounded weird. But it hasn't been that bad. These people are OK." We put away the equipment.

Perhaps everybody thinks that it's somebody else who has the problem. If true, our challenge is to come together in communities that celebrate the light that each of us shines. In that, there will be a mighty beacon.

During these past four years, we have increased self-esteem and evoked curiosity among youth with disabilities. Many of our participants now think and plan for college when they did not before. We have opened a door and invited youth to enter. In this process we too have changed. Rich is more erudite. Jim is more pragmatic. We get tired and frustrated. But, together, we have discovered a harmony and synergy in which both of us (with great help from Makia, Angie and many others) have extended beyond our self-defined boundaries. Role modeling involves community building and personal change. To touch youth is to be touched by them in return.

Symposium Contributors

Jennifer Aaron is the Student Liaison/Self-Advocate for students with disabilities at The Ohio State University. Ms. Aaron has a BA from Ohio University in Communications and a minor in Special Populations. As a person with a learning disability, Ms. Aaron frequently conducts workshops and presentations to educate employers, teachers, and students with disabilities on topics such as sensitivity, awareness, communication techniques, understanding and accepting disability, individualized adaptations, and self-advocacy.

Joie Acosta is a research assistant for the University Affiliated Program/Center on Disability Studies at University of Hawaii-Manoa. She is also a doctoral student in the Community and Culture program and is enrolled in the Disaster Management and Humanitarian Assistance certificate program. She has a B.A. in Psychology from the University of Richmond, Westhampton College.

Jim Beck is the Acting Assistant Chief of Services for the Alaska Division of Vocational Rehabilitation. Mr. Beck formerly worked as the Director of the Americans with Disabilities Act Partners Project and conducted ADA training for the Disability Rights Education and Defense Fund.

Lori W. Briel is a Research Associate with the Rehabilitation Research and Training Center on Workplace Supports at Virginia Commonwealth University. She has a Masters in Education and extensive experience providing supported employment services and coordinating community supports for individuals with disabilities. She currently coordinates the Career Connections Program for college students with disabilities and serves on several projects that are directly involved with the professional development of university faculty. She has co-authored several journal articles and a book chapter in these areas.

Dr. Sheryl Burgstahler directs project DO-IT (Disabilities, Opportunities, Internetworking and Technology) at the University of Washington. DO-IT promotes the success of students with disabilities in postsecondary programs and careers. Dr.

Burgstahler has published articles and delivered presentations that focus on the full inclusion of individuals with disabilities in postsecondary education, distance learning, work-based learning, and electronic communities. She is the author or co-author of six books on using the Internet with pre-college students. Dr. Burgstahler has extensive experience teaching at the pre-college, community college, and university levels.

Dr. Sharon Cramer is currently the Executive Director of the SABRE Project, an innovative student information services implementation, and a Professor of Special Education at Buffalo State College. Over the past 25 years, Dr. Cramer has been instrumental as a leader on her campus, as well as at the local, state, and national levels of the Council for Exceptional Children. Her publications include *Collaboration: A Success Strategy for Special Educators* (Allyn & Bacon, 1998), and numerous articles. Dr. Cramer serves on several editorial boards with distinction.

Lyla Mae Crawford is a Counselor/Coordinator for the University of Washington's DO-IT (Disabilities, Opportunities, Internetworking and Technology) program. She has a BS in Applied Psychology and an MS in Developmental Psychology.

Dr. Peter Dowrick is Professor of Disability Studies and Graduate Studies in Community and Culture Psychology. He is also Director of Creating Futures and Professor Emeritus at University of Alaska Anchorage in recognition of his 14 years there as founding Director of Center for Human Development (UAP), Chair of Psychology, and other program developments in the community. He began his research in the disability field with early studies on self-modeling in what was then known as the New Zealand Crippled Children Society (now CCS) in Auckland. Other related appointments include Research Fellow at University of London and Associate Professor of Pediatrics at University of Pennsylvania and Children's Hospital of Philadelphia. He has 120 publications including two recent special issues on disabilities in other journals. He was coauthor with Dr. Stodden and original Director of Research for the National Center for Study of Postsecondary Educational Supports and is currently focusing on issues of literacy development for all ages of children and adults.

Duane M. French is the Director of the Alaska Division of Vocational Rehabilitation and has served in that position for the past 5.5 years. French was formerly the Executive Director of Access Alaska, a Non Profit Independent Living Center. French serves on the Federal Interagency Coordinating Council and numerous State councils and boards.

Elizabeth Evans Getzel is Research Associate with the Rehabilitation Research and Training Center on Workplace Supports at Virginia Commonwealth University. She has worked for a number of years conducting analyses of federal and state policies to assess their impact on services and programs for individuals with disabilities, developing and implementing evaluation studies to identify effective strategies and programs within service delivery systems, and coordinating federally funded projects on accommodating students with disabilities in postsecondary education settings. Her research interests are in the areas of transition and postsecondary education. She has authored or co-authored journal articles and book chapters on transition, career development, postsecondary education, and employment.

Dana Scott Gilmore, MA, is a research associate at the Institute for Community Inclusion (ICI). His current studies include tracking employment outcomes for people with developmental disabilities.

Jennifer Graf is a research assistant at the University Affiliated Program/Center on Disability Studies at University of Hawaii-Manoa. She is a Ph.D. candidate in the Community and Culture Psychology program.

Debra Hart, M.Ed., is the School and Community Project Coordinator at the ICI and has experience working with children and adults with disabilities. Most recently, she has been the Co-Director for two statewide systems change projects. One project was designed to work with school districts on developing their capacity to assist a diverse student population in gaining access to and making progress in the general curriculum. The second project focused on working with high schools to better prepare their students with disabilities as they transition into adult life.

Jennifer Hertzfeld serves as Program Associate for the Partnership Grant at the Nisonger Center. She has a B.A. in Psychology and an M.A. in Rehabilitation Counseling from The Ohio State University. Currently, Ms. Hertzfeld is working on her Ph.D. in Rehabilitation Services. She has done extensive research in the areas of Universal Design, accessible curriculum, distance education, and assistive technology.

Mike Hoenig is the director of the IDEAS (Iowans with Disabilities Exercising Advocacy Skills) Project at University Hospital School, Iowa City, Iowa. He has a B.A. in psychology from Central College, Pella, Iowa, and an M.A. in Rehabilitation Counseling from the University of Iowa. He previously worked as a rehabilitation teacher with the Iowa Department for the Blind and as program director at the Illinois/Iowa Center for Independent Living.

Dr. Margo Izzo is the Program Manager for Special Education and Transition at the Nisonger Center. She has an M.A. in Vocational/Special Education and a Ph.D. in Special Education and Rehabilitation Services. Currently, Dr. Izzo is the principal investigator of two federally funded projects designed to enhance the quality of education and transition services for both secondary and postsecondary students with disabilities.

Robert Jahier, is at the National Center for the Study of Postsecondary Educational Supports in the Center on Disability Studies, University Of Hawaii-Manoa, and is a Ph.D. candidate in Exceptionalities in the College of Education.

Jennifer L. Schuster, BS, is a research data coordinator at the ICI. Her research activities include qualitative analysis of the experiences of individuals with disabilities using state employment services and Social Security Work Incentive use for transition-age students.

Evette Simmons-Reed is currently a 2nd year Ph.D. student with a visual impairment at The Ohio State University. She is currently a member of the Executive Support Team, whose goal is to improve the quality of postsecondary education of students with disabilities. Ms. Simmons-Reed also has a M.A. and B.S. degrees in special

education, with teaching certification in Developmental Disabilities. Before returning to school, she taught for four years at both the elementary and secondary levels.

James Skouge, Ed.D., is an Assistant Professor of Disability Studies and Graduate Studies in Special Education, specializing in classroom applications of assistive technology, media and computing, especially as they relate to community empowerment, cross-cultural learning and communication. Dr. Skouge works in Hawaii, American Samoa and Micronesia.

Dr. Robert Stodden is Director of the Center on Disability Studies and the National Center for the Study of Postsecondary Educational Supports and is a Professor of Special Education at the University of Hawaii at Manoa. Over the past 25 years, Dr. Stodden has served as principal investigator/director of more than 100 research and training projects spanning the areas of secondary school transition, postsecondary education and employment for youth with special learning and behavior needs. During the process of reauthorization of the Individuals with Disabilities Education Act (IDEA) of 1997, Dr. Stodden served as a Kennedy Senior Policy Fellow with the Disability Policy Subcommittee in the United States Senate. He currently serves on numerous association and editorial boards and has an active record of research in the field of disability studies.

Cynthia Zafft, M.A., R.N., is a Training Associate at the ICI. In her current position, Ms. Zafft coordinates a three-year demonstration project supporting students with significant cognitive disabilities; age 18 - 22 years, in their transition to inclusive postsecondary education options.