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FORUM: SHARING STORIES, AUTOBIOGRAPHY AND DISABILITY

Sharing Stories, In School and Out: An Autobiographical Forum

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I have always been fascinated by self. When I was in elementary school I read every biography I could find in the library. I still recall my excitement when one day I discovered a new biography of George Washington by an author named Carver. With great anticipation I plowed into the book, then became confused. It slowly dawned on me that I was not reading about the first U.S. President, but learning about a southern, black scientist named George Washington Carver, born in the 1860s, who invented hundreds of products from peanuts, as well as from other plants.

My disability experience, I believe, has had a lot to do with my compulsion to understand identity. As a young boy, who experienced almost indescribably painful bone crises, I did not know of anyone else who experienced my kind of pain (Brown, 2003). The only way I could imagine to explore my experience was to investigate myself.

I was well into adulthood before I met anyone else with the same disabling condition I have. Now there is a thriving listserv (The Gaucher Disease E-Mail Discussion Group) addressing Gaucher Disease (GD). From its inception, those who participated in it have shared their stories, or those of children or other family members. Few of us had any experience with others with GD until the past decade or so. We were all eager to learn about one another's personal journeys and the various paths we have trod.

In the past twenty-five years, as I have become immersed in what it means to analyze and live with a disability from a rights perspective, I have in some ways become even more eager to learn about how others have moved to their own truths about their lives. In the early 1980s, when I first became involved in the disability rights movement, I ventured to the local library and looked in the now antiquated card catalog for books about disability. The only one I recall finding from a rights perspective was Frank Bowe's *Handicapping America* (1978). Eight years later, Bowe published *Changing the Rules*, an autobiography that focused on his early years as a person learning what it was like to be deaf in a hearing world. As the recent controversy over who will succeed I. King Jordan as President at Gallaudet University demonstrates, this search remains an issue close to the surface of disability rights identity.

As I became absorbed in my own desire to understand what disability culture might mean I read as many autobiographies as possible. I have both discussed and reviewed many of these tomes (Brown, 2002). Examples include well-known authors and books, such as *My Left Foot* (1954), Irish writer Christy Brown's story that became the subject of an Academy Award winning movie, and the contemporary acerbic cartoonist John Callahan's *Don't Worry, He Won't Get Far on Foot* (1989), to less popular, but just as compelling memoirs, like Cass Irvin's reflections in the 2004 *Home Bound* and Greg Smith's *On a Roll* (2005). Two recent autobiographies detail experiences with pain (Felstiner, 2005; Wall, 2005), another with acquiring a disability as a young adult (Linton, 2006), and a fourth with moving through the world in an unusual way (Kuusisto, 2006). A commonality of all these autobiographies is that they are well-written, from the poetic (by the poet Kuusisto) to the rousing (the motivational speaker and radio personality Smith) to the more reflective and quasi-scholarly (the academics Felstiner, Wall and Linton). The reviews section of this journal

includes more detailed descriptions of a number of the books discussed in this paragraph.

As more people are able to write and publish about their experiences, coupled with the exploding avenues opening to writers, we will learn more about a diversity of lives. Our goal in this forum is to share compelling stories that reflect the goals of this journal: international in scope, reflective of emerging and more experienced scholars, and unsung voices. We hope readers will find these self-explorations as fascinating as we did. A brief word about each is in order.

Perhaps the most satisfying article, to me personally, is that of Joakim Peter. I first met Jojo, as he likes to be called, when he approached me in a hospital lobby and asked about the wheelchair I used. That initial exchange led to a friendship and dialogue that continues to this day. For several years, I could not understand the kind of assistance Jojo requested. Why was it so difficult for disability advocacy to make inroads in his native Micronesian island of Chuuk? His article, "Building Familial Spaces for Transition and Work: From the Fantastic to the Normal" eloquently alleviated my confusion. Further west, in Taiwan, Heng-hao Chang grew up in a family that included a sibling with a disability. In his memoir, "Seeing Through the Veil: Auto-Ethnographic Reflections on Disability," he explores his own personal journey of understanding his family's approach to disability and puts his findings into a broader social context. Both Brian Shaughnessy and Nathan Say, residents of my island home of O'ahu, explore and reflect on their own disability experiences. Shaughnessy, an attorney, actor, and comic, describes life with a medically-caused disability in an excerpt from his recently published autobiography, *The Squeaky Wheel* (2005). Say, a young man with cerebral palsy, relates experiences with personal assistants in his poem, "Hands of Another." Finally, Zosha Stuckey collaborated with the aging Devera Gordon, over multiple months at a nursing home, to develop the essay, "Steaming, Compressed Air."

In my poem, "Tell Your Story," (1995) I wrote:

We all have so many stories to bear

Cry, laugh, sing, and despair;

How will our children learn and compare

If we're too timid to dare

To raise the flare

Share that we care

It still seems to me that it is for all the world's children, of all ages, that we continue to need to share our stories with one another.

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Seeing Through the Veil: Auto-Ethnographic Reflections on Disabilities

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Abstract: This article is an auto-ethnography reflecting the interactions among society, my family and my brother who has Cerebral Palsy. The experiences of me and my family show the visible and invisible veils that segregate people with disabilities and their families from mainstream Taiwanese society.

Key Words: Auto-ethnography, family, disability

For sociologists, personal biography can be an important entry to an unfamiliar social context that is usually invisible or misunderstood within certain cultures or ideologies. Sociologists try to be "objective" in their research projects, but it is difficult to be alienated from sociological research projects that deal with social processes in which sociologists are also situated. Thus, an ethnographer in the field of sociology has to be self-reflective and aware of the boundaries and distance between her/his own experiences and her/his research. The process of researching and writing my dissertation, "The Disability Rights Movement in Taiwan: Modernity, Civil Society and Politics of Difference," has been a journey of self-discovery. It has given me a chance to re-think and give new meaning to my experience with disability.

I grew up in a middle-class family in Taipei. My dad was a successful businessman before he retired from a big corporation as a manager in charge of the export department. My mom is a housewife. She quit her job and committed herself to raising the family after she got married and had my sister. My sister (one year older than me) and I were considered good kids: we

did well in school and attended elite public high schools and national universities. In mainstream Taiwanese people's eyes, we were an ideal family and my mom was considered a fortunate woman—having a hard-working middle class husband and well-educated kids.

My brother, seven years younger than me, was born when my mother was thirty-nine. Unexpected news changed the "fortunate" life of my mom and had a dramatic impact on my family—my brother has a disability.

I can still remember that my family was excited and happy to have this new family member. However, after we had celebrated his first birthday, we found that he could still not sit up by himself. My parents decided to take him to see a doctor for close examination. He was diagnosed with Cerebral Palsy (CP). According to the doctor, CP could not be cured, but with proper rehabilitation, the condition could be improved. It was an unfamiliar "illness" that we had never heard of. The doctor's diagnosis and short explanations just left us with more questions and uncertainty. My family simply did not know how to deal with it.

Can he can be "cured?" How does CP affect his life? What can we do to help him? We kept asking these questions of ourselves and all the friends and professionals we could reach.

Among my childhood memories are frequent family visits to the "Children's Psychological Development Center" in the teaching hospital of National Taiwan University (*Taiwan da-syue Er-tong sin-li-fa-jhan jhong-sin*) and *Jheng-Sing* Rehabilitation Center. It was always my mom who took my brother for different visits. My father would give them a ride in the car on the weekends and my sister or I sometimes accompanied the family after school or on weekends. Visiting the rehabilitation center was a family routine.

At that time, early intervention and rehabilitation for children with disabilities were still underdeveloped. To some extent, they still are in Taiwan. There was always a long waiting list at different centers. My parents were always anxious to try to use different "channels," giving *"Hong-Bao"* (red envelopes with cash in them, that is, bribes) to get better doctors or physical therapists or more appointments. We even ended up paying a physical therapist who worked for the rehabilitation center to conduct private therapy at home for 1000 NT dollars (around $30 dollars) per hour, which was considered extremely expensive at that time. Although my brother's condition improved, there was no medical miracle.

When my family recognized that these "Western" treatments did not seem to work, we turned to traditional medical treatment. I suddenly discovered how many types of folk medical knowledge there are, such as acupuncture, Chinese herbal medicine, alternative healing, Chi-kung, and so on. We ended up visiting many parts of Taiwan, including Taichung, Tainan, Hsin-chu, and Kaohsiung. I can still remember one of the most difficult treatments. We had to drive for five to six hours to the southern part of Taiwan every week for six months to get a special herbal treatment.

Leaving aside the long wait for different treatments, we actually had great times together as a family. However, all these traditional treatments were the same; they did not work as the "doctors" claimed they should. After spending a lot of money and countless hours, my brother was not "cured." We gradually realized that disability is not only a medical issue, but a social and political issue as well. We had to accept his disability and look for a support system.

When my brother got older and his disability became more visible, my family members were forced into unexpected life journeys. Not surprisingly, besides my brother, my mom was the one who suffered the most. According to traditional cultural beliefs, my mom had been considered a fortunate woman, with a hardworking

and successful husband, and two "good" kids, my sister and me. It was an ideal life for a Taiwanese woman at her age. As part of traditional cultural practice, she was frequently invited to many weddings to share her fortune with newly wedded couples. But all of a sudden, when my brother's disability became more noticeable, she realized that she was no longer invited to weddings. Nor was she welcomed to gatherings among our relatives, such as New Years' dinners and birthday parties.

Not until the wedding of my cousin, when I was in college, did I see the invisible veil which separated my mother's and brother's lives from ordinary social life. She was the youngest daughter of my father's older brother. The two families used to live next door to each other. My cousin was six years older and babysat my sister and me when we were in kindergarten. However, when the time came for her wedding, we suddenly realized that only my father, my sister, and I were invited; my brother and my mom were not on the invitation list. My uncle and aunt apologized but did not give any explanation although my cousin desperately wanted my mom and my brother to be part of the wedding. Later, I found out that it was because they believed that the appearance of my mom and brother would embarrass them and make the wedding banquet look bad. My mom felt sad, but did not say much. What I noticed was that my mom and my brother gradually withdrew from the social life of our extended family. At many other family events, although the invitation lists might not specify the guests, my mom knew that she and my brother were not welcomed. She knew that their presence would be considered disruptive to the harmony of the family gathering.

The relationship between my family and my uncle's family was broken after we leased our apartment to a community home for the independent living of four intellectually-disabled residents. The apartment was right next to where my uncle's family lived. At that time, most people refused to lease their places to people with disabilities and there was no law preventing discrimination in housing. My mom was a member of the disability rights NGO that had initiated the de-institutionalization movement in Taiwan. My family happened to have an extra apartment for rent. The deal went through, but my uncle could not understand why we leased the apartment to a group of "crazy people" and argued that his grandson and granddaughter would learn "bad examples" from people with disabilities. The two families stopped talking to each other thereafter.

The invisible lines dividing people with disabilities and their families from mainstream society not only exist in Taiwan but also in other countries. Like many middle-class Taiwanese men who experienced the regime transition from Japanese colonial rule to the Nationalist Regime, my dad always felt insecure about the future of Taiwan and began contemplating emigration to another country. He finally took action and applied for "investment immigration" to Canada. However, after years of waiting, investing, and spending a lot of money on a lawyer, my family's application was denied. At the same time, my father's close friend, who went through the same process with the same lawyer and put the same amount of money in, gained Canadian citizenship. The reason was simple: there was one disabled child in my family. We were not qualified to be Canadians, although in its immigration law, every foreigner and his/her family should be granted Canadian citizenship, if she/he makes a certain amount of investment. My family had put most of our savings into "buying" citizenship. We just did not recognize the hidden rules separating people with disabilities and their families from the rest of society.

The immigration lawyer suggested that we could give it a second try by temporarily "removing" my brother from our family registration. We could "re-adopt" him after we gained citizenship. My father brought this message home. My mom, my sister, and I all said, "No!" We told my father that "if the Canadian govern-

ment denied our brother, at least we should not exclude him as part of our family." He was somewhat disappointed but certainly agreed with us. My family used to believe that Western industrialized countries have better welfare systems for marginalized groups and are more protective of human rights. I guess we realized that these "developed" societies only want money; rich able-bodied people can be part of their nation, not people with disabilities. There was a hidden rule that prohibited people with disabilities and their families from moving freely.

There was also a veil that segregated people with disabilities from mainstream schooling in Taiwan. Ironically, I was also a student in the special education system during my high school years. In Taiwan, under the "special education law," students who had IQ tests below or above two standard deviations would be categorized as "special education" students. Not surprisingly, students at the two ends of the normal distribution received very different and actually contrasting attentions and resources. Being labeled as a "special talented" student in high school meant endless schooling to prepare you to be a great scientist who would contribute to the development of the nation in the future.

This kind of "special education" was out of reach of most students, but because I passed some insipid tests in junior high school, I became a student in the special education category. I attended elite mathematics and science classes, each with fewer than ten students in the classroom. The high school even invited a professor from National Taiwan University to teach a weekly math class. In senior high school, we had our own lab and a small budget for a scientific experimental project. During the summer, we attended science and technology summer science camp and took classes at the National Taiwan University for free. Despite the advantages, and maybe because I was not talented enough, I quit the special education lab class and transferred to a regular one in my final year of senior high school.

In contrast, my brother was not even allowed to get into a special education class for students at the other end of the normal distribution. I can still remember the tears of my mom after she received the result of my brother's IQ test. My brother was diagnosed as "mentally retarded," because of his CP diagnosis although all of my family members know that my brother does not have intellectual disabilities. There was no proper accommodation to allow him to voice for himself. According to the educational system at that time, his disability was "too severe to be educated." In other words, statistics divide people into different categories. The power and ideology behind the statistics—the ideology of development, promoting science and technology and able-bodyism—decided the distribution of resources and excluded people with disabilities from school.

As far as I know, more than half of my senior high school classmates from the "special education" classes moved to the United States, obtained graduate degrees, and became American citizens. None of them became a scientist working for the Taiwanese people. Many people question, "Why do we waste money on intellectually disabled children?" But nobody has asked, "Why do we waste money educating people who eventually become American citizens?" Is not education a fundamental right in modern society?

I thought that accepting my brother's disability had never been a problem for me. Until junior high school, I did not realize the invisible line I had drawn within myself between him and my social life. I can still remember an occasion during a break from a "voluntary self-study" evening section in junior high school. I was chatting with a close friend and we were complaining about the high expectations from home, school, and society. I mentioned how my sister, who had entered the best senior high school, pressured me to do well in the senior high school entrance examination. He then asked me, "Do you have other siblings?" I was

silent for a while and then told him that I have a brother who has CP. He suddenly laughed at me and said, "You must feel ashamed of your brother. I usually hear you talking a lot about how successful your sister is, but never hear you saying anything about your brother. I didn't even know that you had a brother."

I was suddenly speechless. He was right. I always mentioned my over-achiever sister to my classmates and friends and complained about the pressure I felt in her shadow. I almost never mentioned anything about my brother. I suddenly realized that I also had drawn a line in my heart that separated my brother from my social world.

From 1987 to 1996, my high school and college years, Taiwan experienced a rapid democratic transition. Martial law was lifted and people in Taiwan suddenly had the rights of assembly and freedom of speech to make demands on the state. I can still remember my mom coming back from demonstrations and petitions, one after another. She always showed a mixed feeling of anxiety and excitement because she was not quite sure it was safe to speak up in public, but was thrilled to be expressing herself and voicing her concerns regarding disability rights to the government.

Like many college students at that time, I could not resist the temptation to be part of the burgeoning student movements. With no special commitment to particular issues, I participated in several "studies groups" and protests—Taiwanese sovereignty, labor, environmentalism, feminism, gay rights, and so on. Like many students at that time, I enjoyed the label of "student activist" and relished the idea of "going against the state." The freedom to walk in the middle of the streets was actually a lot of fun. If my memory is correct, I never participated in any disability rights demonstrations in college, even though my mom was there. I guess that, in a way, it was fashionable for college students at that time to obtain the label of "activists

for whatever" except "disability." My mom was usually supportive of my little student activism, while my dad was more uncertain and warned me to keep some distance from politics.

To a large extent, people do not realize that disability is everywhere. I have become more aware of the veil of disability around myself in the process of taking disability studies seminars and doing research on the disability rights movement in Taiwan. I am not quite sure why I ended up choosing to do my dissertation on the disability rights movement, but I am glad to have rediscovered my experiences with disability in the process of writing. My personal experience has constituted my entrance to disability studies and social movements. Writing about it has been an invaluable process of lifting the veil. The problem of the twenty-first century is the problem of how society defines the "normal" and treats the "different."

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Hands of Another

Nathan E. Say

Abstract: I believe that our biggest battles in the Disabled Community are battles we face with our personal care attendants. This poem was experienced and written during an intense three week period in which I fired and then hired a new attendant. "Hands of Another" are his hands, and are symbolic of any personal care attendant.

My body exhausted…

A Class skipped, an exam failed; my body parts washed and re-washed, over and over by my useless, deformed hands that inadequately, minimally do the job. Parts missed and neglected, I'm so sorry—I can't reach you, only the hands of another can.

Dreams vanish, room smells, "A's" disappear, a graduate school erased, a Sunday missed, a homework assignment done late, wrinkled clothes worn—the iron too hot for my hands to touch, Only the hands of another can.

My body exhausted—time rolls by, literally without me for days.

Sacrifice given—blessings received, blessings missed, blessings lost, blessings misinterpreted as curses—body exhausted, smelly rooms, disappearing grades, erased graduate schools, missed Sundays, late homework assignments, worn wrinkled clothes—all for the hands of another;

Those hands that go missed and prayed for, longed for. Where are you, hands of another? My body longs for these hands of another; my dreams need these hands of another, my room cries out for these hands of another; my disappearing grades have to be found by these hands of another; graduate schools impressed by these hands of another; Sundays returned by the hands of another; assignments done on time because of them, wrinkled clothes smoothed out gently because of them, the iron vigorously rubbed by them.

The hands of another gone because of blurred boundaries.

My spirit withdraws during separation, I must find another set of hands, another soul; Away with you--be gone hands of another. My disjointed ugly, deformed hands, wish your hands away from my body, and my room and my clothes—but never your spirit, never your laughter, never your tears, or your joy or your sadness, your desire, your dreams, your hopes, just your hands away from me.

Your soul now hot with anger and confusion—stop this madness, this taunting, this name calling—I never wished for your negativity; just your generosity and just your hands. Your absent hands I wanted here;

Your gentle absent hands were away with your spirit... I LONGED FOR BOTH, I COULD NEVER GET BOTH...

Now, can I get your distant spirit sir? Just your distant spirit? No sir, not your hands, just your spirit. Can I get your spirit?

Hands and spirit gone—I am left with my soul, and my useless hands. Me, please tell me how much more I should have given? Should I have sacrificed my exhausted body? Just my smelly room? Just my grades... Its just temporal education. Just my graduate schools—its just grades on paper never to be looked upon by the people that really need to see them. Should I have sacrificed Spiritual self for a completely temporal experience? How many more homework assignments should have turned in late, how many sloppy clothes wearing days should I have had, for one more day with the hands and the soul of another?

NO. NONE I SAY— I DESERVE A BODY, LATHERED, WASHED AND RINSED

CLEAN… I DESERVE A ROOM THAT SMELLS LIKE A GOOD EXPERIENCE. GRADES THAT I EARNED BECAUSE MY SOUL HAS BEEN TOUCHED BY THE HANDS OF ANOTHER THAT'S WORTHY TO SEE MY SOUL. I DESERVE TO PICK THE GRADUATE SCHOOL I WILL ATTEND, NOT JUST GO TO THE ONLY ONE THAT WILL TAKE ME. I DESERVE A SPIRITUAL EXPERIENCE. I DESERVE TO DO MY HOMEWORK ON TIME, I DESERVED IRONED CLOTHES

Yet, I still long for that soul and those hands of another, one reunited if only but for a brief month, or a year, or two years, or five. Until the sacrifice comes, and the washings stop, the clothes get wrinkled, my room smells.

I need your presence near me, can I just have your presence?

Nathan Say graduated from Brigham Young University-Hawai'i in December, 2006, with a Bachelor's Degree in History, and has Cerebral Palsy and various learning disabilities as a result of a premature birth. An active member of the Disabled Community, Nathan is working on turning his private collection of disability related poetry into a public collection widely accessible to the Disabled Community and beyond.

Steaming, Compressed Air

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Levindale Nursing Home
&
Zosha Stuckey
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Abstract: This essay, composed over a span of eight months, was developed through a collaboration meant to redefine notions of writing that excludes people with disabilities. As post-colonial/collaborative composition theory suggests (Davies, 1992), the author and the writer of the narrative are two distinct people. While the author constructed the words verbally through a series of ongoing dialogues, the writer transcribed, edited, and re-ordered the text. Douglas Biklen's book, Communication Unbound (1993), inspired us to explore these non-traditional ways of "writing" that, while grounded in conversation and collaboration, also disrupt models of efficiency and individualism.

Key Words: Parkinson's, disability, facilitated communication

Introduction

This essay recounts the experience of my disability. In it, I demonstrate how I have lost the ability to know who I am. It shows how my body has lost its balance and how my mind has lost the ability to formulate language easily. I offer the experience of what it is like to live in my body and mind. I was able to write this because I worked collaboratively with someone who pulled language out of me. I have never before thought of myself as an author. I'm still waiting to realize why I deserve a place in a table of contents.

Essay

Steaming compressed air. Fresh air doesn't surround me the way I'd like it to. My body is hot and I have lost the ability to know who I am.

Have you ever gone into the back of a dress shop and looked at yourself in the mirror? You may have looked better than you expected, you may have looked worse. Either way, you still knew who you were. Sometimes I pass a mirror and realize that the person I thought was standing there is not standing at all, they are sitting and they are in a wheelchair. I wonder how the person in the mirror will get from sitting to

standing? It's the indefiniteness of how long will this person persist in trying to stand up?

The first shock came in 1987 when I realized that I could not stand on my own anymore. When things were good I didn't think about how things might get bad. I didn't know I had a problem coming up.

I can't speak right these days. It's very difficult to formulate language. It's hot and cold. I can't grab hold of what I'm trying to say. I start to write a sentence in my head, then it stops and it doesn't flow. The more I turn the light on to see it, the less it penetrates the surface. I can't spell or hurry up and put together a sentence that makes sense.

Life doesn't feel chronological. I never know where I am in time. When I'm there isn't there a now here? I try to figure out how I approach things—I start with zero and then I try again. When is zero, is it yesterday? It takes time to place myself into space and time. I don't want to rush. I try to analyze and maintain control as I go along and in the meantime now is built up. I don't have any view of the future.

I never know where I am in space either. There's no experience at all. The experience doesn't even experience itself. How can you be less than nothing? It seems like everything is moving around me. I can't describe it. The furniture is moving around, then it's standing still. I feel dizzy like everything is moving around and I'm going in the opposite direction. I feel like I'm always walking backwards. The wheelchair—it's like a cage—I feel as if as there is somebody behind me that I can't see. I can't turn around like I want to. I can't always look where I want to. I can't be aware of one direction and the other at the same time.

My mouth is dry and I'm crooked. I lean. I have a dry mouth and a blank expression inside my head. My legs are thick and weak and twisted. The left leg is not grabbing hold of my foot. The foot is not grabbing hold of the floor.

The left leg feels weak. Outside on the edges the legs are uneven around the knee and the buttocks. Thin mushy pasta—I like it with some firmness to it like the Pennsylvania Dutch do it. It has grips and flavor. It feels even. The fact that I can't stick both shoulders up and back. They feel as if they're shaking and trying to grab hold of something. I get the feeling I don't have a good grip. As if I don't understand the process—how you move the skin around the bones and leave it alone. A building at the beginning of its construction. Where does the body begin? Where does it end?

I talk to myself a lot. I ask myself what are we doing here? I keep trying to know where I am or why I am here, but I rarely figure it out. I say to myself you should smile more. There are lots of things to smile about. I just can't recognize them fast enough.

I am sitting across from the nurse's desk. I am trying to read, which is very difficult. The doctor is around and he seems to want me to smile no matter what. I am told to smile all of the time. Without a good reason, without a history, without a build-up of some kind of story. Just smile, be weak. That's when I want to be left alone. He just says smile. I say to him I've been told that before. He probably figures that I have a contrariness, that I don't want to comply. They want you to produce a good result and I just don't have the energy to do that right now.

The remarkable thing here is how the ability to stand up or sit up is so important. Even when I sit up, I'm crooked and uneasy. Then the doctors look at me and say just smile. As soon as you need an appliance to help you stand up you are already in trouble. I never thought I'd be in a place like this. Does it make me feel less of a person? Yes…that seems to be the problem. If I was at home and I had to go to the bathroom, I would just go. But now, because I have lost the ability to stand, I have to go according to a schedule. I am allowed to use the restroom every 2 hours, no more. And they get nasty about it,

harass me about how I just went or snicker at me.

Things aren't bad now, I just feel weak. I just want to be able to relax and not think about how things could get worse. Everybody dies a little bit every day. You have to get used to the idea that there will be less of you left. I am trying to improve my attitude but I know the disease is progressing. I'm trying to put together a positive image of myself. It's like going in circles, after 18 years I still am in shock. But I don't think I'll ever give up. I'm old enough now where I can just sit and ponder.

Devera Gordon has lived with Parkinson's since 1987. She is a resident of a long-term care rehabilitation hospital in Baltimore, Maryland USA. She is 74 years old.

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Building Familial Spaces[1] for Transition and Work: From the Fantastic to the Normal

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Abstract: Transition for persons with disability is a process of negotiating difficult situations and barriers set by others and by systems. My strategies to overcome those barriers in my personal transitions through education systems and employment included the creations of familiar spaces in which group support plays a major role. This paper tracks my process through the familiar spaces and gives examples of encounters with barriers along my transition through hospital treatments to schools and then work.

Key Words: spaces, disabilities, transition

Why Am I Having Difficulty Writing this Paper?

When my friend, Steven Brown, and the rest of the good folks at the University of Hawai'i Center on Disability Studies, asked me to participate in the 2005 Capacity Building Institute, "Enhancing Transition to Postsecondary Education and Employment for Youth with Disabilities through *Culturally Relevant Supports, Services and Education*," I agonized for days before writing. I took awhile to recognize two reasons why I was having such difficulty writing about my experience as a person with disability who has gone through the issues discussed in the Institute. The first reason is because I simply have not had the time to reflect on what I have done, how I (and those around me) did what we had to do to get me through life on a daily basis. The second reason is that the experience I had and continue to have in Chuuk is quite different from what others in the Institute experienced.

Although we may be able to draw some thematic similarities across our experiences, all the experiences have particularities that make them different. Mine is unique to the cultural practices and contemporary problems of my place. For example, while seeing a person in a wheelchair in all aspects of life is considered the norm in Hawai'i, it is still "fantastic" and "fascinating" to see the only visible Chuukese person in a wheelchair going to work. In Chuuk, people like me are considered "sick," and sick people do not work. Furthermore, the job market in Chuuk is so depressed that searching for any job is fiercely competitive. For a person with a visible disability, to work is not "normal." It is fantastic, not commonplace, and even threatening and unfair to able-bodied folks.

I firmly believe that problems of transitions and work for persons with disability have a great deal to do with the wider social and economic issues the community is going through. It is, after all, the community that defines and produces barriers for persons with disability. So I figure my contribution is to describe the wider cultural challenges and problems that exist in my place and then attempt to offer some reflections about my own challenges in transition and work.

First, let me introduce the place where I am from and set the plot for reflections on my personal transitions. I am from Chuuk State, the most populated of the four states in the Federated States of Micronesia (FSM). The FSM, the Republic of Palau (ROP), the Republic of the Marshall Islands (RMI) and the Commonwealth of the Northern Marianas together used to be the Trust Territory of the Pacific Islands, or TTPI, part of the post World War-II United Nations Trusteeship program. In its efforts to promote a democratic government in the islands, the United States introduced social, economic, health, and education programs, and a good number of federal programs aimed at promoting positive social changes. After the island nations voted to go their separate ways into the post-colonial era, each maintained close relationships

with the U.S. The current relationship, which is called the Compact of Free Association, now in its second term[2], provides these island nations (FSM, ROP, and RMI)[3] with U.S. assistance in grants and federal programs.

But, as the tired old cliché goes, things do not always turn out as planned. Even with all the time and resources poured into these small island nations, development, or planned development, comes reluctantly and slowly. The challenges are enormous. When a visiting staff member of the Joint Economic Monitoring Committee Office (JEMCO) came to Chuuk, he was critical about the status of education in Chuuk State. JEMCO cautioned state and national leaders about the poor status of education in Chuuk.[4] Moreover, if we measure the success of transition to post-secondary education and employment for student and youth with disabilities by counting the number of students, we will need only a few fingers on one hand to show its success. Maybe just one finger will be needed.

Personal Stories: Change in My Life

I was injured in June of 1980, a few days after my freshman year in high school. I fell off a rock and broke my neck, leaving me paralyzed from the chest down. I was brought to Honolulu, where I spent a whole year, mostly at the Rehabilitation Hospital of the Pacific, "rehabbing." I would be labeled a C-6 quadriplegic, a label that puts me in an obscured category; I am still unfamiliar with its usefulness. Actually any term that identifies and categorizes my disability seems to be more useful for me outside of my home island, for example in Hawai'i and in academic circles. In Chuuk, where I have spent most of my life during my disability, the terms, even in their local translations, bear little meaning for me.

I returned to Xavier High School (XHS) in Chuuk after a year in Hawai'i. The director of the school at that time, Father Francis Hezel, insisted I try to go back to school in Chuuk.

He met with my parents and asked if I could return to XHS. Although my parents agreed with the priest that I should return to school, they silently disagreed with him. But out of respect for him, they did so quietly. They wanted me to return home, back to my island, and live out the rest of my life, crippled and house-ridden. That was the cultural norm and practice for persons with disability before and, still in many cases, since I arrived in 1982. Persons with disability are considered sick.

Xavier was, and is still, a Jesuit boarding school for boys, but recently started admitting girls as day students. It sits off by itself on a hill on the northern end of the island of Weno. Its isolation suited me well because it kept me out of full view of the public. Except for one summer, I lived almost the whole three years at the school, which was about an hour away from downtown. Once in a while I would spend hours driving around downtown, but I hardly ever got out of the car or spent time with friends and relatives living away from the school. That lack of public exposure helped my parents to accept the priest's request to allow me to return to school.

The compromise I struck with my parents was I would have a relative or two stay with me at the school as my attendants. The school designed a support system for me when I returned to Xavier. The director of the school invited two of my uncles to come and live with me in one of the faculty units. The school also arranged to keep them occupied and employed when I did not need their help. They were given jobs in the Maintenance Department. To assist my uncles, a number of student volunteers helped with my daily routines.

We started with a group of four or five friends, who were mostly my classmates. These guys were willing to handle my personal care needs, such as helping me in the shower and using the toilet, getting dressed, and other hygienic tasks. Other students volunteered to push me around to classes, the cafeteria, study sessions,

and church. There were layers, or levels of help, available to anyone who wanted to take part in my care.

Eventually, I would come to rely more and more on the student volunteers. By my senior year, I depended solely on the support of the student help. At Xavier, graduating classes are small, and students tend to be very close with each other. Lifetime friendships are established in these tight-knit small classes so, for me, the support group we created at the school still exists today.

Four months before the end of my senior year, I visited Guam and the University of Guam (UOG). A number of my friends and relatives were there. So I started making plans to go to UOG. Again I had to deal with my parents. Luckily for me, the same uncles who stayed with me for a while at XHS now attended UOG. Four of my high school friends also were at UOG, so they helped form the core of my support group there. My parents reluctantly allowed me to go to the university in Guam.

The transition to Guam and UOG was more difficult than I expected. The challenge was far greater than I faced at XHS. First, unlike XHS where I was asked to go back to school and some system was set up for me, UOG was not ready for a young kid in a wheelchair from Chuuk who wanted to be a fulltime boarding student.

The university did not have any system set up to deal with a student with disabilities who wanted to live in the dorm. There was no help provided for assistance. The staff and management of the housing department were not at all familiar with my needs, much less the laws that applied to them. As a result, they became not only passively unhelpful, but they actively put barriers in the way of being helpful. For example, they would not allow students who lived off campus to come in at night to help me until I took up the issue with the president of the university.

For the first two years, I received no educational or instructional support services for students with disabilities. It was especially difficult for me because I could afford only a manual wheelchair. Sometimes I would be stuck in places and not make it to class. There was no functional system to offer any support. One professor refused to move his class from the second floor until the Vice President of Instruction intervened two weeks after the semester had begun.

I had to set up my own system, or network, of help. I started training students and non-students to be attendants. Since I could not pay everyone who helped me, I had to rely on a group of volunteers of friends and relatives. I managed to pay for room and board for one live-in attendant and relied heavily on this volunteer group. I approached and recruited friends who were comfortable doing different things for me: pushing me around campus, transferring me in and out of cars, and driving me around. They helped me with my daily routines: showering, dressing, and cooking. They spent the nights as my roommate and turned me in bed to prevent pressure sores.

Interestingly enough, we considered at one point hiring a nurse or an aide, but quickly ruled out the idea. I was not comfortable having strangers handling my care. However, I became close with a nurse friend whom I allowed to help in my daily care. The circle of friend helpers I created in Guam was similar to the one I had at XHS. My friends from XHS with me at UOG continued to help me and helped train others who were willing to help.

During my junior and senior years the Student Support Services opened at UOG. There I got some instructional support, but more importantly, I found a lifetime ally and fellow advocate, the director of the program, Yoichi Rengiil, who would help me land my first professional job as a radio announcer.

Beside Mr. Rengiil, I also won the support of the Special Education department professors who advocated for me. These professors had to remind the UOG officials of the applicable federal laws we knew the university was violating. We also recruited the Dean of Students. Along with Mr. Rengiil's help we were able to bring Jane Jarrows, disability advocate, on campus to meet with university officials. One of the UOG officials we targeted was Dr. Roy Suda, the Vice President of Instruction. To show my challenges of being wheeled around campus, we asked him to push me around one morning. We had to give up the experiment after my first two classes because we were concerned about his health. Then he realized what we had to go through everyday. Not only did that create awareness, it gave us a breakthrough with the officials.

When I left UOG in 1992, only one building had an elevator, and there were hardly any decent ramps. I visited the same school in 1998, and there were three or four new buildings with elevators and ramps in all buildings, with proper regulation design.

Wanting to Work

Besides getting an education, and because of getting an education, I naturally wanted to work. Often, many persons with disability opt to stay out of the work force because of the many challenges they encounter. I believe it important to find work that I not only enjoy doing but find rewarding. Nothing is more demeaning to persons with disability than being forced into a situation where the only type of work available to them does not provide adequately for their needs and yields little to no satisfaction.

First "Job"

I remember the first job I had. I was "hired" by the maintenance department of the high school to help out in the shop. I specifically asked to work in the shop because I loved being around machinery. The shop had an electrical saw workers used to cut wood. That is what I

wanted to do. However, the head of the maintenance department, a Jesuit brother, would not allow me near the machine in fear I might injure myself. So, for a whole summer, I was paid 25 cents an hour to sort old rusty screws and bolts. I was not even sure if anybody actually used those old items, but the maintenance department was supposed to keep me busy and "employed." I hated that job so much I missed enough days in my first month of work that I was eventually "not expected to show up."

My First Paycheck

When I was a Freshman at the University of Guam, I received my first paycheck as a college work-study student. It took a good number of days searching university offices for anyone to employ me under the university work-study program. I managed to convince an old friend in the Education division to hire me as an operator on the university distant-education radio network. One of the most satisfying moments of my life was when I received my first paycheck. I was so happy I sent it home to my grandmother.

Meaningful Work

Working at the radio network was getting less enjoyable over time because the supervisor began to treat me unfairly. She would write me sealed notes complaining about many personal issues, which I felt too uncomfortable to counter. So I grew more and more resentful towards my work and the place. However, during lunch hours I managed to attach myself to a group of fellow communication majors who were trying to revive an old radio station at the university. There I found one of my passions in life, radio announcing. I thoroughly enjoyed being on the air.

However, this situation presented a predicament that often confronts everyone. Many times, because of a lack of choices and options, we find ourselves working in jobs we cannot stand, or doing for free the work we love to do. I spent three years doing volunteer hours on the school radio before I was able to land a paid radio job on one of Guam's radio stations.

I applied with several stations and encountered discrimination that would break my interest for long periods of time. Then I would regroup and search for jobs again with other radio stations. One general manager told me straightforward he would not hire me because he thought I would not be able to use the bathroom facility in the building. Another did not know I was in a wheelchair and was excited after hearing my demo tape. He called the school radio station and asked to see me. However when I showed up in his office, he uncomfortably informed me he had already offered the job to another applicant. The truth was the job was filled two weeks later. Finally, my friend Yoichi Rengiil, who knew one of the general managers, helped me land my first professional job. I was given a slot for a graveyard shift. The General Manager even hired a helper to work with me. I was the happiest Disc Jockey on the radio from midnight to six o'clock in the morning, with a strong following to boot. The General Manager promoted me to other shifts six months later.

Choice of Work and Career

After I realized there was no money in radio, I went back to school. I needed to leave Guam because I wanted to experience a new place. I arrived in Hawai'i in 1992 and enrolled at the University of Hawai'i at Mānoa (UH-M). I have always wanted to be a history teacher, so I picked UH-M because of the excellent mix of Hawai'i's racial histories. I started rebuilding my network of support. I convinced the UH-M housing office to allow a cousin to room with me in the dorms even if he was not a student at the university. Other members of my support group were classmates and friends from school and the community. I found help also at the KOKUA program (UH-M's Disabled Students Services Office), which helps students with special needs. I earned my graduate degrees from the UH-M and went back home in 1997 to teach history and culture studies.

I was hired to teach history at the College of Micronesia-FSM Chuuk Campus. In 2002,

I became director of the Chuuk Campus. I enjoy working at the College's Chuuk Campus. I am doing what I enjoy doing in the place I love, teaching people I genuinely love. They are my people. My family, friends, and students are part of my support group.

Reflections

I want to offer some reflections on the discussions above. First of all, at the beginning of every turn of events and experience for me there is always uncertainty. If there is a concept that dominates my life as a person with disability, it is the series of uncertainties that surrounds every major turn in my life. As a matter of fact, a major part of my "rehabilitation" process, especially the more meaningful ones, has to do with undoing these uncertain blocks by familiarizing myself with their challenges and devising ways to overcome them.

Most of this rehabbing was done after I left the Rehabilitation Hospital. One common issue of all uncertainties is that they are not common; therefore, we have little prior knowledge of how to deal with them. We need to familiarize ourselves with the challenges of disability.[5] To do that, people with disabilities need to be visible. We have to be "out there" in the mix of life stating what our needs are and fighting for them. There is no institutionalized rehab technique for uncertainty; it can only be overcome with persistence and visibility.

Secondly, it is very important to build a support network. Call it a circle of friends, because that is exactly what it entails. Over time, keep casting that network wider and wider. You will need the help of everyone, even those with whom you do not see eye-to-eye on other issues. I have learned the best support systems are the ones that are least regulated and least official. In other words, a system of help that is mostly voluntary. People are effective if they help out at the level and form in which they are comfortable. Disabled persons need the helping hands and healing nature of familiar/familial bodies to help smooth the rough edges of uncertainties in life.

With the first and the second, what you are doing is called advocacy. We need to keep the issues fresh as much as possible. Awareness is achieved and maintained when issues are actively discussed—in other words, maintaining active public discourse.

Like I stated at the beginning, the problems of transition are enormous in a place like Chuuk where general economic and cultural challenges are pervasive. The poor condition of education affects all children. In Chuuk, successful transition (by all students) through all the levels of education, from primary to secondary to post-secondary, is a feat accomplished by only a handful. Since a western education was introduced in Chuuk after World War II in the 1950s, only a handful of Chuukese have earned graduate degrees. Only two have earned Ph.D. degrees.

That poor education system thus presents added challenges to children with special needs. Furthermore, their right to exist and participate in those limited systems is not secured. Culturally, they are labeled as sick, and public education is not considered the appropriate place for them. Until recently, no law protected their rights to full education. But even now that we have that law, it is not well enforced.

So, now you understand what I meant when I said to show the number of students with disability from Chuuk who have managed to transition from high school to college, you would need just one finger.

Studies at UH-Manoa, Chuuk Special Education Division and College of Micronesia—FSM.

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Endnotes

[1] The concept of familial and familiar spaces as healing vessels is a concept borrowed from fellow Micronesian historian Vicente Diaz. This was part of his presentation at the Pacific History Association conference in Hilo, Hawai'i 1996. Subsequent personal communications through many years helped me with this concept. I have also used this concept in another paper, "Chuukese travellers and the idea of horizons."
[2] The U.S. negotiated three separate Compacts with ROP, RMI and FSM. Although these Compacts exist in in perpetuity, U.S. funding assistance expired in the first fifteen years. For RMI and FSM, the funds ended in 2003. Those funding provisions have been renegotiated in what is now called the Amended Compact.
[3] The Northern Marianas elected to become a Commonwealth of the United States in 1975.
[4] Although the report focused primarily on primary and secondary education, those of us who work at the post-secondary level are not without our share of the problem.
[5] I often say it is better to be stared at than be ignored. I would rather people stare at me so they could see me and see what I need rather than ignore me and my needs.

The Squeaky Wheel: An Unauthorized Autobiography

Brian Shaughnessy, MFA, JD

Abstract: What if someone walked into surgery and awoke quadriplegic never having been warned of this risk? What if they not only survived but also endured the horrors of this disability with hope and humor? What if they returned to school, earned a Master's degree in theater and then a law degree and got married? What if they wrote a funny and tearful book about it and created a new business model to market the story? Brian Shaughnessy did. This is an excerpt from his 2005 memoir.

Key Words: memoir, Hawai'i, disability

Rainbows - 1999

Rainbows float in bubbles over the heads of the wedding guests and out over the white streaked turquoise ocean which looks like precious marble. The sea is sky-blue at the next beach -- then indigo with Koko Head volcano beyond. The water at each beach in Hawai'i is a different shade of blue. Past the guests and bubbles sit two regal Asian women with shoulder length hair wearing white muumuus and playing Elvis' *Can't Help Falling in Love* on the harp and flute. The guests are armed with disposable cameras and bubbles. As the guests arrive a Polaroid is taken of them and the picture glued into a book where guests jot down regards for the betrothed. The table at the entrance to the huge backyard is covered in stuffed bunnies.

The preacher beside me wears a polyester pale-blue suit. He is tall, bald and looks like he just stepped out of the Ozarks. He tells those gathered he has been asked to interpret the ceremony using American Sign Language. I see my sister, Shelley, raise her hands and twist them -- American Sign Language for applause. My best-person, my sister Dawn, is beside me. She has prepared a speech. Dawn has Down syndrome.

The smell of the lawn, the ocean and plumerias waft past us. Down the grassy aisle march the five cutest little brown girls ever. Each looks like she was drawn for Hallmark. They wear the cutest pink dresses ever. Each carries a large stuffed bunny. Now my bride Amy exits the house wearing a *haku* lei made by a law school classmate. Amy's long black hair cascades down the front of her bridal gown. I fight tears. She is a gift from God. The guests stand and smile. In lieu of a bouquet of flowers, Amy carries a pink, stuffed bunny. It is the year of the rabbit.

I wear new black cowboy boots. Actually the boots are entirely made from petroleum products, which makes them synthetic-boy boots. These are complemented by black trousers, a white shirt with Superman cufflinks and a black and blue paisley tuxedo vest. My father has just removed my *tres*-cool tortoiseshell sunglasses. My red hair shines from under the Chinese *bob* hat I wear. The hat is a black silk cross between a yarmulke and a Muslim's hat. My momentarily wife has placed a red circle with the Chinese *kanji* for happiness on the center of the hat's band. I'm sure I look like Hop Sing, the Chinese cook from Bonanza, but friends tell me I look like the emperor. The only possible thing that can take away from this idyllic picture is the wheelchair under my ass.

February 2, 1983

"Mr. Shaughnessy?"

"Mr. Shaughnessy."

"Why are you waking me?" I ask. It feels as if it has only been moments since the anesthetic took effect and I drifted to sleep. Ninety-nine, 98,97...

But that was a long time ago in a reality far, far away.

"The surgery is over, Mr. Shaughnessy. Can you tell me your name?" There is a hint in there.

"Brian Shaughnessy."

"Do you know where you are?"

"I'm at the University of Minnesota Hospital," I say as I taste... what is that taste? ... Lysol.

"Okay, very good. Can you tell me the date?"

"Feb. 2nd, 1983. Can I have a blanket?"

I am freezing. I am certain that they performed the surgery in a meat locker and that I was covered only with frost.

The individual asking questions is moving about wearing standard blue hospital scrubs. These are different than the operating room green scrubs. I know this because I once worked at this hospital... in the kitchen. May God forgive me.

He is checking my eyes with the flashlight and then dons his stethoscope. First, he listens to my chest and heart; then, as the stethoscope slides below my nipples, the sensation nearly vanishes. I start to look down but immediately feel pain.

"You're lucky you're inside today; there was a nasty blizzard."

I am not feeling particularly lucky. I am slowly becoming aware of the fact that a group of people cut open the back of my neck, broke off tiny pieces of my spine to access my spinal canal and performed some surgical voodoo in there. Something is terribly wrong.

"Breathe deep," Blue-scrubs commands. He has checked my heart rate, pulse, eyes, etc. Blue-scrubs is around six feet tall and in his mid-twenties, with brown hair, a cropped beard and Buddy Holly glasses.

"Can you squeeze my fingers?"

Oh my God! What the hell did these people do? I squeeze his fingers, becoming aware I have

10 percent of the strength I had before going to sleep. I am definitely beginning to wake up.

"Is that the best you can do?"

What the hell do you think? Wouldn't I break them right now if you gave me the opportunity? "What is going on?" I begin to ask the question.

"Lift your right leg for me."

Okay now, THIS is big. The anesthesia clouding my thinking is hastily pushed out by the nightmare possibilities consuming every speck of gray matter. I make a Herculean effort to raise my right leg. What a simple request and what tremendous effort to accomplish ... nothing. It doesn't move. I hear my leg hit the bed. What the…?

"Very good. Now can you do that with your left leg for me?"

"Do what? It didn't move!" My mind shrieks as I make the effort to lower my head and look at my feet, and I am unpleasantly reminded that knives and other implements have been busy at work for an unknown amount of time. Why can't I feel my leg move? Jesus.

"I didn't feel my right leg move."

"That's okay. Try the left leg for me, please."

Oh, well, if you're going to be polite about it I guess I'll just do as I am asked and not bother you with my silly concerns. I make the effort again. I hear the thump back on the bed, but I am unaware that my leg moved.

"Can you feel my hand on your foot?" he asks with the calmness of a stranger asking my occupation.

"Barely," I respond trying not to lose my mind.

"Which toe am I touching?"

I start to look toward my feet but pain stops me. He continues to check for sensation; it is clear that it stops almost completely exactly at my nipples.

"What's going on? What happened? Can I have another blanket?"

"I'll get somebody to bring you another blanket. The doc will be in soon to answer your other questions. He's talking to your family right now."

What the hell is he telling them? I wonder. 'Hi, I'm the doctor that crippled your son, brother, grandson…? The surgery went just fine. You should be able to roll him out of here in a couple of days." How does he know *what* to tell them? I don't even know what's going on.

"Can I have another blanket?" I ask this question several times and each time they bring another blanket. The pile of blankets is now thicker than my body. A group of doctors come and give the same tests Blue-scrubs gave. This is intermittently followed by nurses doing the same. No one looks me in the eye.

"Your father and your brother want to come in and talk to you. Is that okay?"

What will I tell them? "Yes, send them in."

"They can only have a couple minutes."

Fine, I think, since I have no idea what to tell them and what not to tell them.

My father and brother enter the room. They are smiling. They know nothing.

"Big Red! How are you feeling?" my father asks. My father is a stocky five-foot-eight inches with salt and pepper hair, a gray mustache and the charm of the Irish revealed in his dancing eyes. As is his custom, he wears a suit. My brother has a similar phenotype to mine. He is about five-foot-ten and muscular with red hair and a large neck.

"I'm freezing," I respond. "Have them give me another blanket."

Another blanket is heaped on and I continue to shiver as my dad talks about the blizzard and my brother Dan talks about a basketball game, but none of it makes any sense. I say I'm fine, tired, sore etc. but my mind screams, Tell them these bastards crippled me. Tell them to make the doctor guarantee I will walk out of this hospital. Tell them I should have died on the operating table because my life is over. No one -- especially not me -- can live this way.

But I fight this urge and a nurse ushers them out. They tell me to get better fast; they will return the next day; and everyone's real proud and buzz buzz buzz.

"We're going to move you to the intensive care unit, Mr. Shaughnessy."

"This is going to go away, isn't it?" I ask.

"I don't know," is the three-syllable answer.

"Well, who does know? Where is the doctor?" I ask looking about the room as carefully as one can when he knows that the slightest movement of his neck will result in ice pick stabs of horrific pain. There are two small beds. I am the only one in the room now although others have come and gone. There are many sets of scrubs in this room and they are all occupied by medical personnel.

As We Discussed/Disgust

I see the doctor walk into the room. He is tall with dark hair only beginning to reveal gray. Aside from being taller, he looks like he could be a younger version of my father. He wears glasses like my father wore for many years. He exudes the status of neurosurgeon as he moves. He sits next to the bed and says, "The surgery was more complicated than anticipated because of unrevealed scar tissue in the spinal canal." He says the paralysis is probably just "spinal shock" and should go away in a few days. But "AS WE

DISCUSSED" there is a possibility I will remain paralyzed.

What the hell is he talking about? We never talked about paralysis. He said the surgery might kill me. I'm thinking, somebody better do *that* if the surgery did not because this is just not tolerable. The intense pain and the shock keep me from arguing with Dr. Liar.

Personnel bring a gurney alongside the small bed I am in. It takes some time to remove the blankets before they transfer me. They slide a plastic board underneath me, and as I slip from the bed to the gurney, I see a nearly pencil-wide tube in my dick. I remember one of the people in the operating room telling me he would need to do this for the surgery. I tried to talk him out of it, but he claimed it was needed, and he would do it after I was under. A nasty trick to pull on somebody sleeping. But there it is. I can't feel it. The doctor lies to me; there is a tube in my dick I can't feel... what next?

I am wheeled from the recovery room to the intensive care unit. As they move me from the gurney to the bed a realization hits. "What time is it?" I blurt out.

"11:20 p.m."

Oh my God! This was supposed to be a four-hour surgery, starting at noon, which means my love, Mary, was expecting a call around 4:00 telling her I'm okay. It's seven plus hours later. I asked my father to make that call. I know that as an attorney he has never returned a phone call in his life!

"I need you to make a phone call!"

"Okay."

"Please dial 785-8914 and ask for Mary."

"What do you want me to tell her?"

Well, there is the six million dollar question. What do I want a stranger to tell one of the most important people in my life who is

certain I'm dead? "Tell her... tell her... I'm fine. Let her know that the surgery took longer than they thought, and I'll see her tomorrow." I stare about the room. There are six patients, three on each side of the room. There is a glass enclosure where the nurses remain when not tending to patients. The room is dark; death, pain and profound sadness hang in the air. These blue-scrubbed nurses don't laugh.

The night is endless. A pair of nurses comes around every 15 minutes to check vital signs. I sleep but *only* because I am full of top shelf painkillers. Every slight movement of my neck triggers intense pain despite more narcotics in me than a 747 has passengers.

Periodically I am awakened by the sound of clapping. Someone is cupping his or her hands, which makes the sound hollower... and louder. I look toward the bed next to me where two people are pummeling an obese man in this manner. Why? Why? Why? Aren't I being tortured enough without this? Cut it out! Stop waking me to this! Every pore of my body cries out, but I am silent.

I pray. I tell God I can't take this. It would have been better had I died on the operating table. The pain is too great and limitations too profound for me or anyone to endure. My Catholic upbringing kicks in as I remember scripture, "Take this cup from me." I recall what that line did for Jesus and I cry.

Two nurses check vital signs and have me squeeze their hands. I do it weakly and the sensation is not "normal." One of them commands me to lift my leg. I try but it doesn't move.

"Very good."

"It didn't move!" I insist.

"Yes, it did! They both did! Try the left one again."

I try again. I don't see it moving. "See?"

"You didn't feel that?"

"I didn't feel anything!" I scream, cry. My eyes plead for assurance... a single word of hope. Instead, the two girls giggle... and walk away. I wish I could get up and kill them.

The next nurse lingers.

"Anything I can do for you?"

"This is going to go away, isn't it?"

"I don't know. They told you this might happen, right?"

"Nobody told me anything! I don't even know what 'this' is."

"When the neurosurgeon explained the surgery to you, he didn't talk about the possibility of paralysis as a result of surgery to the spine?" she asks incredulously.

"No!"

"How old are you?"

"Twenty-four."

"You didn't know that surgery in the spinal canal could result in paralysis?"

"I'm sorry; I'm a theater major. We don't know science stuff."

"No, I guess you wouldn't." Heavy sigh from her. "That should have all been explained to you, written down on the consent forms and put in your chart. What *did* the doc tell you?"

"He said I might DIE, but that that was not likely because of my age and health."

"The surgeon should inform you of ALL risks and this is an obvious one to anyone with a medical background. Let me look at your chart, and I'll talk to you on the post-op floor, ok?"

I never see her again.

After a night in the intensive care unit I am moved to the post-operative floor. It is a regular hospital room with two beds. It looks straight

down the hallway to the ward I was on before the surgery. I see the doctors and others from that side who were so friendly to me before the surgery. Now they look in and don't even acknowledge my existence. I wonder what I am going to tell my family. My friends? *My mom?* Mary. She'll be here soon...

I have been unable to move my neck because of the profound pain. I watch TV mindlessly as doctors, nurses and med students enter, examine, and speak to and about me in a detached manner as if I am a frog in the pan of a high school lab experiment.

Mary arrives. I see her lithe, animated step and smiling face as she approaches the room – singing "Make 'em Laugh" from *Singing in the Rain*. Mary loves movie musicals. Singing in the Rain is her favorite. Mary's hair is almost my color. She is fair, freckled and slight of build. More than once we have been asked if we are brother and sister. I have been told the ultimate form of egotism is to copulate with someone who shares your features. She comes bearing outside food and drink, aware of the heinous reputation of hospital food (food I once prepared may God have mercy on my wretched soul). Her eyes meet mine and I turn away. She comes to me, setting the food on the hospital table. She sits next to me on the bed.

"Hi Honey," she says with an innocence and trust for human beings that will soon disappear forever ... maybe in the next sixty seconds. My eyes meet hers -- brown to brown. Immediately, I begin to cry.

"What's wrong?" She tries to put her arms around me and becomes aware of the staples and bandages behind my neck. "Oh, can I hold you?"

"I wish you would," I struggle to say through a cracking voice.

"What's wrong?"

I explain to her that right now I can't stand up, can't go to the bathroom, can't sit up, can't hold the sandwich nor the drink she brought, and although they tell me my legs are moving, I don't know they are. I tell her there is a tube in my dick I can't feel. A single tear appears in her right eye. I tell her I have very little sensation from my nipples down and now her tears flow as quickly as mine. I tell her the doctors say this may be temporary or it may be permanent, but my mind is made up: I will walk out or kill myself. I tell her of the nurse's nastiness. I need an ally and now I have one.

"You know," she begins. Her eyes no longer dance. "By about six o'clock I was pretty sure you were dead. By eight o'clock I was sure. I was sort of mad at your dad for not calling and telling me that but... I mean, you're dead and who the fuck am I? I'm just some chick his son goes out with."

I try to shake my head and feel an immediate stab of pain. I struggle through sobs to speak. She puts her finger to my lips. "So, from eight until almost midnight I was going out of my mind. The phone rang and I figured one of your brothers finally got the idea to tell me. I cannot *tell* you how glad I was to hear the nurse say that you were fine and that you would see me today. These assholes don't know you. I know you're going to walk out of here," she sobs, "and I'm gonna walk out with you and tell that nurse and the rest of them to go fuck themselves. Let's eat!"

We make out. At my encouragement she pulls the curtain and places a breast in my face. I ask for more but she claims the request is absurd. She is feeding me. This is the first time. It won't be the last.

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at the Disability Rights Legal Center at Loyola Marymount School of Law and a writer. Brian has just signed an option contract for the movie rights to the *Squeaky Wheel*, which can be purchased at www.squeakywheelbook.com, Amazon, and other on-line as well as physical edifices that tender books. At Brian's web page you can buy the book, participate in his unique promo-plan (which awards PRIZES!), get other "Squeaky" merchandise and support others with disabilities in their legal and artistic endeavors. Brian considers his most important job to be father to his five-year-old son – Amadeus Yun Chi Shaughnessy.

RESEARCH ARTICLES

Disability and School in France

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Translated from the French by Tammy Berberi.

Abstract: Historically in France, the education of children with disabilities has been characterized by isolation from other schoolchildren, within an adapted framework. Today, policies of integration reject segregation by welcoming "different" children into ordinary classrooms. After describing the major shifts in the education of children with disabilities, this article describes the social implications and stakes of integration.

Key Words: education, integration, France

Editor's Note: This article was reviewed in French and translated by RDS reviewer Tammy Berberi. The French version appears directly following the English translation. RDS is currently accepting a limited number of articles written in French. To learn more please email Megan Conway at mconway@hawaii.edu.

In France, the history of the education of children with disabilities is linked to the development of various institutions which are driven in part by the elaboration of teaching models developed to educate "abnormal" children. Broadly speaking, the evolution of educational paradigms related to disabilities has been fueled by philosophical and scientific debates about the perfectibility of man. Very early on, pedagogical methods were recognized as a way to compensate for developmental delays caused by intellectual, physical, or sensory disabilities. Myriad theories of the education of disabled children span nearly three centuries.

In the 18th century, in *Lettre sur les aveugles à l'usage de ceux qui voient*, (which precedes by two years *Lettre sur les sourds et muets à l'usage de ceux qui entendent*), Diderot defends the notion that, although deprived of sight, blind people are endowed with intelligence and able to perceive the physical world: "If ever a philosopher deaf and blind from birth were to create a man in the manner of Descartes, I daresay, Madame, that he would place his soul in the tips of his fingers, since in them lies one's capacity for perception and the sum of one's knowledge. And who would deign tell this man that his head is the seat of thought? And if our heads are exhausted by the work of the imagination, it is because the effort we exert to imagine is similar to that which we make in order to perceive objects that are very near to us or very small. But that is not the case for a man blind and deaf from birth; the perceptions he will have developed through touch will be, so to speak, the mold for all of his ideas; and I would not be surprised if after a long meditation, his fingers were as tired as our heads."[1] In this spirit, Abbé de l'Epée created the first school for the deaf and mute in 1760. Likewise, Abbé Haüy created the first institute for blind children to teach them his method of recognizing numbers and letters by touch.

In the 19th century, the experiments undertaken by Dr Itard on Victor, the "wild child" found in the Aveyron, led the doctor to consider

the child's "idiocy" a result of a lack of stimulation in his environment. The method developed by Itard challenges those psychiatrists who reduce the objective of child psychology to congenital pathology, thereby undermining the role of educational and therapeutic methods of treatment. This is undoubtedly the reason why the last lines of the study published by Itard in 1801 and 1806 call for a change in the way science considers "different" people, inviting men in power and scientists to show more concern for them. Later, between 1881 and 1884, laws mandating free and obligatory schooling establish educational norms that allow us to distinguish "normal" from "abnormal" children. This distinction leads to the first major law mandating a specialized education that provides for the creation of classes for children unable to succeed in a "normal" classroom but able to succeed in an environment adapted to their abilities.

For about three centuries, the question of the educational capacity of "abnormal" children led to the elaboration of a variety of teaching methods and techniques adapted to a particular disability, all in reference to an educational paradigm in which the child's individual progress is of the utmost importance. So much so that a very broad consensus exists around the possibility of granting disabled children access to the school environment. On the other hand, the issue that today has political stakes is the context in which this access should be provided. The separate, specialized education heretofore provided to disabled children must make way for integration in a "normal" educational setting, as indicated by the most recent law in favor of equal rights and opportunities, the participation and the citizenship of disabled persons, ratified in France on February 11, 2005. In addition to recalling the principles related to the education of "children and adolescents with disabilities or health-related impairments" of June 30, 1975, article 19 grants to disabled children the same right accorded to all children: the right to attend the school closest to their home. Why does the law of 2005 revisit principles promulgated thirty years earlier? What

obstacles hinder the implementation of the law? Answering these two questions requires retracing the history of special education in France. A historical approach to the matter allows a broader perspective than would a discussion of current debates.[2] As a result, this article is divided into two sections: the first will present the major phases of the education of disabled children in France, and the second will discuss the stakes and the implications of a shift in favor of integration, beginning with the new political issue raised in the most recent law for equal rights and opportunities, the participation and citizenship of disabled persons, ratified on February 11, 2005.

A Century of Special Education in France

As the introduction to this article suggests, a salient characteristic of special education in France is the fact that it developed independently of public education. The autonomy of the field of special education, alternately shaped by internal debates and techniques developed by professionals in a variety of fields, resulted in a specialized network that is distinct from the school system. Only over time has such a separate system revealed itself to be harmful to disabled children in the sense that segregation may have hindered their social integration and participation in the rights of citizenship.

At first, the project of developing a vast educational program in the interests of equality was quite laudable. Begun by Jules Ferry at the end of the 19th century, the program focused its efforts on schools. For Ferry, education represents a means to defend justice and to struggle against social inequality by permitting each person to find a place in an industrial society that suits his abilities. Likewise, to similar ends special education had to provide "abnormal" students with schooling. This explains the creation of special classes to accommodate students whose abilities were below average among their peers. In 1904, a special commission was created to consider:

The conditions in which one might provide a specialized education to 'abnormal' children. The charge of the commission was complicated: it had to determine the indices of various forms of abnormality and their degree of severity; to establish by means of a survey the approximate number of "abnormal" children; to determine the types of specialized schools that had to be created; to adopt basic pedagogical techniques; and to study the training required of a new personnel.[3]

Once the parameters of the project were determined, what remained to be seen is which children would benefit from specialized classes. From this point on, two concepts would be at odds, which would give rise to two competing notions of child abnormality.[4] On the one hand, Dr. Bourneville, a psychiatrist already well-known for having created classes at the Bicêtre asylum, defended the theory that "idiot" children could be educated by means of an adapted education. On the other, the psychologist Binet, whose work led to the invention of a metric scale for measuring intelligence, defends the position that only those children unable to perform in an ordinary classroom should have access to special classes. Binet's theory was adopted, which led to the creation of specialized courses in schools. Inevitably, however, the law reinforced a distinction between "abnormal" children in the schools and "abnormal" children in the asylum. The former, whose development was slightly delayed, distinguished themselves from their peers only by weaker performance in school; in contrast, the latter were easily identified by the extent of their disabilities. This distinction established two opposing perspectives—the medical and the pedagogical approaches—which are still at odds today.

A period of relative calm follows these embittered ideological battles of the early 20th century. Few adapted classes were created and asylum schools disappeared, the result of the fact that few doctors were interested in the field of child abnormalities. The period of the Front Populaire (1936-38) is marked by plans to provide a com-plete public system ranging from mental health care to adapted classes. These plans are never realized. In 1943, under the Vichy government, that the notion of a "maladjusted" child facilitates the convergence of state, judicial, and medical-sociological claims and the advent of child psychiatry.

At the end of World War II, the idea of a democratic educational system that provides all children the same opportunities begins taking shape. The emergence of such a system is hindered by the existence of a small number of "maladjusted" children. In order to function, this democratic system would have to identify these students, separate them from "normal" students, and offer them an adapted education. In 1948, the Director of the National Center for the Training of Special Education Teachers stated clearly: "Retarded children must complete their schooling in specialized classes for which the curriculum, in content as well as intention, is tailored to their socialization." At the same time, the post-war period is marked by the creation of specialized establishments and the rise of special education. Unable to enroll their children in specialized classes and refusing to accept what the psychiatric sector had to offer, parents worked together to open centers for the care and specialized education of their children—centers that still function today.

The 1970s, A Turning Point

The law 75-534 of June 30, 1975 for people with disabilities once again takes up the question of integration in schools by confirming the fundamental principle that, "The prevention and diagnosis of disabilities, the care, education, professional training and job placement, the guarantee of basic resources, social integration and access to sports and leisure for young people and adults with physical, sensory, and mental handicaps is a national obligation." This law remains a point of reference in discussions of the integration of people with disabilities because it emphasizes the many resources society can dedicate to protecting them from exclusion. Logically, school will play

a part in this integration as the relationship between schools and the array of specialized services developed for children with disabilities evolves. It is increasingly obvious that the attitudes favoring segregation which characterized the institution of special education must give way to a spirit of openness. The integration in normal classes and institutional structures from which children with disabilities had been previously excluded becomes the standard. The first article of the law of July 10, 1989 insists upon this: "The acquisition of general knowledge and recognized skills is guaranteed all young people, regardless of one's social, cultural, or geographical background." The integration of young people with disabilities is thenceforth an issue of major political importance, and a wide spectrum of agencies and services must contribute to that goal.

The question becomes whether, since that time, institutional changes and the evolution of political perspectives have had a notable impact on the situation of disabled children at school. Quantitatively, the results of different studies converge to suggest that the numbers of integrated students has increased, but not rapidly. As a result, volunteer efforts advocating integration were redoubled, and Handiscol was launched in 1999.[6] Handiscol has several objectives, notably the identification of the range of initiatives and systems in place to enable the integration of children and adolescents with disabilities into the regular school system (primary and secondary school); communicating with parents who have enrolled or hope to enroll their disabled child in the regular curriculum; and communicating useful information and tools to teachers with disabled children in their classrooms. French legislation increasingly conforms to European norms, including those regarding inclusive education. This in itself reveals the will to change educational model. It is no longer a matter of integrating children with specific needs into an environment wherein the conditions of integration are set by those representing a "normal" paradigm. Rather, an inclusive educational model transforms its physical environment, organization, and proce-

dures to recognize specific needs as intrinsic to every child's education.[7]

One observation remains: the caution with which policies of integration were adopted, its slow evolution over the last twenty years, and the difficulties that the parents of these children must resolve reveal that the many obstacles produced by the history of special education weigh heavily upon current efforts. In order to achieve full inclusion, several obstacles must be overcome. The first obstacle lies in the antagonism surrounding the creation of the special education sector and directed towards schools. This opposition nourished the professional identities of special educators, who emphasize the ways in which they differ from ordinary teachers. The image of an impersonal school that is unable to recognize a child's individuality seemed to justify their commitment as well as the use of more responsive strategies to help "different" children. Opening the doors of the regular school to these children defies a fundamental historical distinction between providing care and teaching. The second obstacle is linked to the economic implications of full inclusion. One might think of the integration of disabled children in schools as a way to reduce health-care costs, which can be significant, depending on the level of responsibility assumed by the state. Although a worthy enterprise, integration may begin to seem suspicious if it is a means for the government to save money rather than to achieve an educational objective (integration into a regular school is far less expensive than education in a specialized setting). In the context of limited public resources, the project of integration might serve pragmatic purposes, one option among many which are defined by purely economic rationale. School personnel and teachers, in particular, whose response to transformation is shaped by cynicism, will not expend the energy required to implement integration. Game theory, which reveals the strategies of various players and their differing capacities for anticipation, demonstrates that in certain situations, rational subjects do not maximize their gains. For example, they may decide to play if

they do not trust their partner. The third obstacle that must be overcome is the minimal amount of specialized training enjoyed by regular teachers. The portion of teacher training devoted to disabilities and adapted pedagogical methods is relatively small, and this lack of knowledge hinders the integration of children with disabilities into ordinary classes.

It is precisely these obstacles that the law of February 11, 2005, in favor of the equal rights and opportunities, participation, and citizenship of people with disabilities, ought to be able to remedy. By reiterating the fact that a handicapped child has the right to attend the school closest to home, this law should facilitate procedures for the parents when the question of the state's obligation to provide an education arises (in France, children ages 6 to 16 are required to attend school). Nonetheless, these difficulties remain, and it is not certain whether the law is enough to resolve them, in the sense that a considerable distance often separates principles from reality. First, in the realm of information, parents are often obliged to ally themselves with an association in order to know their rights and try to defend them; second, in the realm of teacher training and education, since many teachers declare themselves to be unable to adapt their pedagogical methods in order to effectively teach a student with a disability for lack of appropriate training or adequate information; third, in the realm of resources, since auxiliary personnel, such as an aid whose job is to assist the teacher and to accompany the disabled student in the school environment, is clearly insufficient. Moreover, renovating existing structures to make them more accessible to students with disabilities is difficult to imagine, given the lack of available resources. Furthermore, maintaining specialized personnel in schools is not very common; more often, a student is sent to locations outside the school for auxiliary services. This is surely the reason why integration typically occurs on a part-time rather than a full-time basis.

For now, it is too soon to know whether this law will be effective in improving integration. We must ensure its gradual implementation by taking lessons from past transformations as well as those currently underway. The law is indissociable from improved funding and from a shift in perceptions surrounding disability. Certainly, the state must provide an answer to the question of how to fund such changes. There is also a question of human resources: how to facilitate frequent encounters and meaningful exchanges, and how to foster clarity about the modalities of collaboration between everyone implicated in the process of integration. This will give rise to an effective partnership, since collaboration must not be limited to a simple exchange of information. The process of determining a set of shared educational norms, the result of the observation of students, experience, and the knowledge and abilities of all partners is as integral to the process as the recognition of each partner by the institution. Finally, the circulation of innovative systems may be a source of inspiration for improving the process of integration in French schools as well as in other countries, as long as the uniqueness of each educational system is taken into account.

Taking stock of the various players and discrepancies involved in implementing integration in French schools clarifies integration as an individual as well as a collective effort. Individual because it is a gradual and evolving process, the aim of which is to guide the student on the path of cognitive and social development; collective because it should be the result of shared efforts, a concrete and concerted elaboration of steps intended to advance partners in education. In order to promote integration in schools, we must revisit procedural and pedagogical frameworks, and examine images of the disabled as well as our understanding of teaching as a profession. In other words, the stakes are high because integration will have an impact on the very structure of French society, forcing various players to confront their own fears and reluctance to participate, and institutions to remedy barriers and areas of dysfunction. Yet [we know that practice

modifies perception, and not the inverse. Change will come from teachers, from special educators, from parents…or, perhaps better stated, from those players in the story of integration who have good reasons to believe in it. It is not enough to facilitate the access of children with disabilities to regular schools; we also have to create a rich and stimulating environment. We must harness learning, relational, and material conditions favorable accepting and enabling the development of the child in school. Only then will we be ready to begin talking about a truly inclusive education.

That education is a trampoline for social integration is irrefutable; but it may also play a decisive role in abetting the long-term exclusion of people with disabilities. Integration or inclusion: the terms are well chosen if we are ready to consider the full import of their educational and social implications.

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Endnotes

[1] Diderot, D. (1749). Lettre sur les aveugles à l'usage de ceux qui voient. Suivie de Additions à la lettre sur les aveugles. Paris: Éditions Garnier et Frères, 1961, pp. 73-164. Édition originale publiée à Londres.
[2] See two articles which appeared in Le Monde, "La scolarisation des enfants handicapés se met doucement en place," October 6, 2005 and "Un millier de nouvelles classes d'ici 2010" October 6, 2005 (page 12).
[3] Bourgeois L. 1907, Lettre Préface à Alfred Binet et Théodore Simon, Les enfants anormaux. Guide pour l'admission des enfants anormauz dans les classes de perfectionnement, Paris, Arman Colin, p. 8.
[4] Mazereau, P., 2003, Les institutions scolaires et medico-éducatives en France; histoire et actualité du jeu croisé des categorizations de l'enfant deficient intellectuel, Colloque International de l'Afec, Lyon.
[5] Mezeix P., 1948, Les enfants inadaptés et l'école primaire, Paris, Bourrelier, p. 44.
[6] See the following link: accessed 2/28/06, http://www.education.gouv.fr/handiscol/default.htm
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Handicap et école. Le cas français.

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Abstract: En France, l'histoire de l'éducation scolaire des enfants handicapés est marquée par une mise à l'écart à l'intérieur de structures adaptées. Aujourd'hui, la politique d'intégration scolaire veut aller à rebours de cette logique ségrégative en favorisant l'accueil des élèves « différents » à l'école ordinaire. Après avoir présenté les grandes étapes de l'éducation des enfants « déficients », cet article cerne les enjeux et les implications sociales du mouvement en faveur de l'intégration scolaire.

Key Words: éducation, intégration scolaire, France

En France, l'histoire de l'éducation des handicapés est en lien avec le développement d'institutions diverses dont l'impulsion est due en partie à l'élaboration de modèles pédagogiques s'organisant autour de l'éducabilité des « a-normaux ». Plus largement, l'évolution des paradigmes éducatifs appliqués à la déficience s'est nourrie des débats scientifiques et philosophiques sur la nature de l'homme et sa perfectibilité. Très tôt, l'action pédagogique s'est imposée comme le moyen de combler les retards de l'enfant dus à une incapacité intellectuelle, physique ou sensorielle. Les références théoriques sont nombreuses et s'échelonnent sur trois siècles environ.

Au 18e siècle, la *Lettre sur les aveugles à l'usage de ceux qui voient* (qui précède de deux années la *Lettre sur les sourds et muets à l'usage de ceux qui entendent et qui voient*) permet à Diderot de défendre l'idée selon laquelle les aveugles, bien que privés de la vue, ne sont pas dépourvus de sensibilité et surtout d'intelligence : « si jamais un philosophe aveugle et sourd de naissance fait un homme à l'imitation de celui de Descartes,

j'ose vous assurer, madame, qu'il placera l'âme au bout des doigts ; car c'est de là que lui viennent ses principales sensations, et toutes ses connaissances. Et qui l'avertirait que sa tête est le siège de ses pensées ? Si les travaux de l'imagination épuisent la nôtre, c'est que l'effort que nous faisons pour imaginer est assez semblable à celui que nous faisons pour apercevoir des objets très proches ou très petits. Mais il n'en sera pas de même de l'aveugle et sourd de naissance ; les sensations qu'il aura prises par le toucher seront, pour ainsi dire, le moule de toutes ses idées ; et je ne serais pas surpris qu'après une profonde méditation, il eût les doigts aussi fatigués que nous avons la tête »[1] . C'est dans cet esprit qu'est créée en 1760 la première école de sourds et muets par l'Abbé de l'Epée, et que suivra en 1786 la création de l'institut des enfants aveugles dirigé par l'Abbé Haüy afin qu'il éduque les enfants accueillis selon sa méthode de reconnaissance des chiffres et des lettres par le toucher.

Au début du 19e siècle, les travaux menés par Itard auprès de Victor, l'enfant sauvage trouvé dans l'Aveyron, conduisent le médecin à expliquer « l'idiotie » de l'enfant par l'insuffisance de stimulations du milieu. La méthode proposée par Itard va ainsi à l'encontre des idées développées par les aliénistes qui réduisent en définitive l'objet de la psychiatrie infantile à une pathologie congénitale, avortant par la même occasion toute tentative de traitement éducatif et thérapeutique. C'est sans doute la raison pour laquelle les dernières lignes du rapport que publie Jean Itard en 1801 et 1806 sont un appel à un changement de regard à porter sur les êtres différents et une invite adressée aux hommes de pouvoir et de science à plus de sollicitude. Plus tard les lois sur la gratuité et l'obligation scolaires votées entre 1881 et 1884 font de l'éducation une norme permettant de distinguer les enfants « anormaux » des enfants « normaux ». Cette distinction aboutit à la promulgation en 1909 de la première grande loi sur l'éducation spécialisée qui prévoit la création des classes de perfectionnement afin d'accueillir les élèves incapables de suivre un enseignement « normal »

mais pouvant suivre un enseignement adapté dans la mesure de leurs compétences.

Depuis trois siècles environ, la question de l'éducabilité des enfants « anormaux » a permis d'élaborer des méthodes pédagogiques adaptées au type de handicap, cela en référence à un paradigme éducatif où la notion de progrès de l'enfant est centrale. Si bien qu'un très large consensus existe autour de la possibilité de faire accéder les enfants handicapés à la culture scolaire. En revanche, ce qui aujourd'hui en France est élevé au rang d'enjeu politique est le contexte dans lequel cet accès doit se faire. L'orientation des élèves handicapés vers des structures spécialisées doit désormais céder la place à l'accueil des ces élèves à l'école ordinaire. C'est bien ce que préconise avec force la dernière loi pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées votée en France le 11 février 2005. Outre le rappel des principes liés à la scolarisation des « enfants et adolescents handicapés ou présentant un trouble invalidant de la santé » déjà contenus dans la loi d'orientation en faveur des personnes handicapées du 30 juin 1975, l'article 19 accorde à tout enfant ou adolescent « handicapé » le droit d'être inscrit, comme tout enfant ou adolescent, dans l'établissement d'enseignement qui est le plus proche de son domicile. Pourquoi, en 2005, la loi revient-elle sur des principes déjà promulgués trente années plus tôt ? Quels sont les obstacles qui entraveraient la mise en œuvre de la loi ? Répondre à ces deux questions suppose au préalable de retracer l'histoire de l'éducation spéciale en France. Un regard rétrospectif posé sur l'éducation spécialisée des enfants « handicapés » permet de situer le débat sur l'ouverture des portes de l'école ordinaire à ces enfants dans une perspective temporelle plus large que celle qui se contenterait d'une analyse conjoncturelle[2]. En conséquence cet article est divisé en deux parties : une première partie présentera les grandes étapes de l'éducation des enfants « handicapés », une deuxième partie tentera de situer les enjeux et les implications immédiates du mouvement en faveur de l'intégration scolaire à partir de la

nouvelle problématique politique figurant dans le dernier texte de loi pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées votée le 11 février 2005.

Un Siècle d'Education Spéciale en France

Comme le laisse entendre l'introduction de cet article, l'une des caractéristiques de l'éducation spéciale en France est de s'être constituée indépendamment des modèles éducatifs « ordinaires ». L'autonomisation du champ de l'éducation spécialisée relayée par des débats internes et des pratiques émanant de professionnels spécialisés a conduit à la constitution d'un réseau spécialisé distinct de l'école ordinaire. Ce n'est que progressivement que l'institutionnalisation de l'éducation spécialisée est apparue comme dommageable aux handicapés dans la mesure où la séparation entre la voie ordinaire et la voie spécialisée pouvait être une entrave à l'intégration sociale et à l'exercice de la citoyenneté.

À l'origine, la démarche était louable puisqu'il s'agissait de développer un vaste programme d'éducation où la notion d'égalité est centrale. Ce programme, initié par Jules Ferry à la fin du 19e siècle, concentre ses efforts sur l'école. L'institution scolaire représente en effet le moyen de défendre la valeur de justice et de lutter contre les inégalités en permettant à chacun de trouver sa place dans la société industrielle en fonction de ses compétences. Elle doit assurer par conséquent aux enfants « anormaux » un enseignement scolaire, au même titre qu'un élève « normal » Ceci explique la création de classes spéciales afin d'accueillir les élèves dont le niveau de compétences est inférieur à celui de la moyenne des élèves. En 1904 une commission spéciale est créée pour envisager « *l'étude des conditions dans lesquelles il devait être pourvu à l'éducation des enfants anormaux. La tâche était complexe : il s'agissait de déterminer les caractères auxquels se reconnaissent les diverses formes et les divers degrés de l'anomalie - d'établir par enquête le nombre approximatif des enfants anormaux*

- de fixer les types d'écoles spéciales dont la création s'imposait - de dégager, au moins dans leurs grandes lignes, les procédés pédagogiques à employer - d'étudier la formation d'un personnel nouveau »[3]. Le principe étant énoncé, la question était de savoir quels étaient les enfants susceptibles de bénéficier de classes spécialisées. Deux conceptions vont alors s'opposer, ce qui donnera lieu à deux visions antagoniques du problème de l'anormalité infantile[4]. D'un côté, le médecin aliéniste Bourneville (déjà connu pour avoir créer les classes d'asile de Bicêtre) défend la thèse de l'éducabilité des enfants « idiots » dès lors qu'ils reçoivent un enseignement adapté ; de l'autre, le psychologue Binet dont les travaux le conduisent à la construction de l'échelle métrique de l'intelligence défend l'idée qu'il faut réserver cette possibilité aux seuls enfants qui ne peuvent pas suivre l'enseignement ordinaire. C'est le point de vue de Binet qui sera finalement retenu. Ce qui aboutit à la création en 1909 des classes de perfectionnement au sein de l'école « normale ». Inévitablement, la loi instaure une distinction entre les « anormaux d'école » et les « anormaux d'asile ». Les premiers, arriérés légers, ne se distinguent des autres élèves que par la faiblesse de leurs acquisitions scolaires ; les seconds restent essentiellement identifiable à travers la pathologie perturbatrice qui les accable. Au final, une opposition se met en place entre une vision médicale et une vision pédagogique dont on trouve aujourd'hui encore les marques.

Aux oppositions parfois virulentes du début du XXe succède une période de relative accalmie dans la mesure où très peu de classes de perfectionnement furent créées, et que les écoles d'asile disparurent par manque de médecins intéressés par le champ de l'anormalité infantile. Par ailleurs, la période du gouvernement politique du Front Populaire (1936-1938) sera marquée par l'élaboration d'un vaste plan prévoyant un dispositif public complet depuis le dispensaire d'hygiène mentale jusqu'aux classes de perfectionnement. Celui-ci restera lettre morte. C'est en 1943, sous le régime de Vichy, que l'adoption de la notion d'enfance inadaptée facilitera à la

fois la convergence de la demande étatique, judiciaire et médico-sociale et l'apparition de la psychiatrie infantile.

Au sortir de la seconde guerre mondiale, l'idée d'une école démocratique qui donnerait à tous les mêmes chances se précise. Cette idée bute pourtant sur l'existence d'une minorité d'élèves « inadaptés ». Pour fonctionner, l'école démocratique doit d'abord repérer ces élèves, puis les séparer des élèves « normaux », pour enfin leur proposer une scolarisation adaptée. En 1948, le directeur du centre national de formation des instituteurs spécialisés l'indiquait clairement : « précisons que les débiles doivent terminer leur scolarité dans la classe de perfectionnement dont le programme, dans son contenu comme dans son esprit, est adapté à leur destination sociale »[5]. Dans le même temps, cette période d'après-guerre est marquée par la création d'établissements spécialisés et le début de la montée en puissance du secteur de l'éducation spécialisée. Faute de pouvoir faire admettre leurs enfants dans les classes de perfectionnement et refusant la relégation vers le secteur psychiatrique, des parents se regroupent en association. Ils ouvrent ainsi des établissements de soins et d'éducations spécialisées encore très bien implantés aujourd'hui.

Le Tournant des Années 70

En 1975, la loi d'orientation n° 75-534 du 30 juin en faveur des personnes handicapées reprend la question de l'intégration scolaire en posant comme principe de base que « la prévention et le dépistage des handicaps, les soins, l'éducation, la formation et l'orientation professionnelle, l'emploi, la garantie d'un minimum de ressources, l'intégration sociale et l'accès aux sports et aux loisirs du mineur et de l'adulte handicapés physiques, sensoriels ou mentaux constituent une obligation nationale ». Cette loi reste un texte de référence en matière d'intégration des personnes handicapées dans la mesure où elle insiste sur les moyens dont se dote la société pour protéger contre l'exclusion

les personnes « handicapées ». C'est logiquement que l'école sera mise à contribution sur la base d'une évolution des rapports entre l'école et les établissements spécialisés vers lesquels sont orientés les élèves « handicapés ». Il devient évident à présent que l'attitude ségrégative qui caractérisait les structures de l'éducation spécialisée doit céder la place à une attitude d'ouverture. L'intégration scolaire dans des structures ordinaires de l'école de tous les enfants naguère exclus devient le mot d'ordre. L'article premier de la loi d'orientation du 10 juillet 1989 insiste sur ce point : l'acquisition d'une culture générale et d'une qualification reconnue est assurée à tous les jeunes, quelle que soit leur origine sociale, culturelle ou géographique. L'intégration scolaire des jeunes « handicapés » fait désormais partie des préoccupations politiques majeures, et les établissements et services de soins doivent apporter leur contribution.

La question qui se pose alors est de savoir si les changements institutionnels et l'évolution des orientations politiques ont eu un effet notable sur la situation des handicapés à l'école. D'un point de vue quantitatif, les résultats des différentes enquêtes sont convergents : les intégrations individuelles et collectives ont augmenté, mais de manière lente. En conséquence, une relance volontariste en faveur de l'intégration scolaire des élèves « handicapés » est faite à partir de 1999 à travers le plan Handiscol'[6]. Celui-ci poursuit plusieurs objectifs, notamment l'identification de l'ensemble des mesures ou dispositifs mis en place pour favoriser la scolarisation des enfants et adolescents « handicapés » en milieu scolaire ordinaire (école primaire, collège, lycée) ainsi que la communication aux parents qui scolarisent ou souhaitent scolariser leur enfant handicapé en milieu ordinaire ou aux enseignants qui accueillent des élèves handicapés des informations ou aides utiles. On constate aussi une mise en conformité progressive aux normes européennes de la législation française comme c'est le cas avec la notion d'éducation inclusive. Celle-ci traduit bien la volonté de changer de paradigme puisqu'il s'agit désormais

de passer d'une intégration scolaire où ce sont les « normaux » qui fixent les conditions d'entrée des enfants à besoins spécifiques, à une éducation incluant dans son organisation matérielle et ses démarches la notion même de besoins spécifiques[7].

Un constat demeure : la prudence avec laquelle s'est initiée la politique d'intégration, la lenteur de son rythme d'évolution au cours des vingt dernières années, les difficultés que les parents doivent résoudre montrent qu'à l'évidence les obstacles produits par l'histoire du champ de l'éducation des enfants handicapés pèsent aujourd'hui de tout leur poids. La mise en œuvre véritable d'une politique d'inclusion suppose alors de dépasser ces différents obstacles qui relèvent de plusieurs ordres. Le premier obstacle réside dans la prégnance de l'antagonisme qui a présidé à la construction du secteur spécialisé. Celui-ci s'est érigé contre l'école. Cette opposition a nourri les identités professionnelles des éducateurs spécialisés, lesquels pointent leurs différences avec les enseignants de l'école ordinaire. L'image d'une école dépersonnalisante, incapable de prendre en compte la spécificité de l'enfant a permis de justifier l'engagement et les méthodes « réparatrices » des professionnels en faveur des enfants différents. L'ouverture des portes de l'école ordinaire aux enfants différents contrevient aux conceptions éducatives fondées sur la séparation entre le soin et l'enseignement. Le second obstacle est en lien avec la dimension économique de cet élan inclusif. On peut penser en effet que l'intégration scolaire est une façon de réduire les coûts des dépenses de santé qui peuvent être importants selon le type de prise en charge. La démarche, quoique louable, peut devenir suspicieuse lorsque l'éducation des handicapés apparaît comme le moyen pour l'État de faire des économies (une intégration scolaire en milieu ordinaire coûte beaucoup moins chère qu'une scolarisation dans un établissement spécialisé) avant d'être une finalité éducative. Dans un contexte économique de limite des dépenses publiques, l'intégration scolaire peut être perçue dans sa dimension instrumentale, en l'occurrence

une simple option parmi d'autres au service d'une rationalité économique. De ce fait, les efforts qui sont demandés lors d'une intégration scolaire au personnel de l'école ordinaire, en particulier aux enseignants, peuvent ne pas être déployés par des acteurs qui voient dans cette rationalité économique un certain cynisme. La théorie des jeux qui met au jour les stratégies des acteurs et leurs capacités d'anticipation montre que des sujets rationnels, dans certaines situations, ne maximisent pas leurs gains. Ils peuvent par exemple choisir de ne pas jouer le jeu s'ils ne sont pas sûrs de leur partenaire, c'est-à-dire s'ils ne leur font pas confiance. Le troisième obstacle est le niveau de formation minimale des enseignants de l'école ordinaire en matière de handicap et d'éducation spécialisée. La part consacrée à l'étude des handicaps et des méthodes pédagogiques adaptées est relativement réduite, ce qui constitue une entrave à l'accueil de l'enfant « handicapé » dans une classe ordinaire.

Ce sont ces obstacles que la dernière loi du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées devrait pouvoir lever. En rappelant que l'inscription d'un enfant « handicapé » dans une école ordinaire proche du domicile est un droit, cette loi doit faciliter la démarche des parents d'enfant handicapé lorsque se pose la question de l'obligation scolaire (en France, tous les enfants âgés entre 6 et 16 ans doivent obligatoirement suivre une scolarité). Or, des difficultés demeurent et il n'est pas certain que la loi suffise à les résoudre dans la mesure où, comme on vient de le voir, il peut y avoir une distance entre les principes et la réalité. Dans le domaine de l'information tout d'abord puisque les parents sont parfois obligés de s'organiser au sein d'une association pour connaître leurs droits et tenter de les défendre. Dans le champ de la formation ensuite car nombreux sont les enseignants qui déclarent être incapables sur un plan pédagogique à accueillir un élèves handicapé, faute de formation ou plus simplement d'informations. Dans le domaine des moyens enfin car le personnel supplétif (c'est-à-dire

les auxiliaires de vie scolaire) chargé d'aider l'enseignant dans sa classe et d'accompagner l'enfant handicapé dans l'école ordinaire est nettement insuffisant. De plus, l'aménagement des locaux afin de les rendre plus accessibles est difficilement envisageable sur un plan financier. Par ailleurs, l'accueil d'un personnel spécialisé dans la journée sur place afin d'intervenir auprès de l'enfant handicapé n'est pas une option très courante, et l'on demande plutôt à l'élève de se rendre dans des locaux extérieurs à l'école ordinaire. C'est sûrement la raison pour laquelle l'intégration scolaire en France se déroule plus souvent à temps partiel qu'à plein temps.

À ce jour, il est prématuré de juger de l'efficacité de cette loi. Il conviendrait cependant d'être attentif à ce que sa mise en œuvre progressive se fasse en ayant tiré les enseignements du passé et du présent. La loi est indissociable d'un renforcement des moyens et d'un changement dans les représentations. Il y a, certes, la question des moyens financiers à laquelle devra répondre l'Etat. Il y a aussi la question des moyens humains qui supposent notamment une fréquence des rencontres, une qualité des échanges, une clarté des modalités de collaboration entre tous les acteurs impliqués dans un travail d'intégration. Cela afin d'élaborer un partenariat efficace car les collaborations ne peuvent pas se limiter à un simple échange d'informations. La démarche de construction commune de normes éducatives, prenant appui sur l'observation des enfants, sur l'expérience ainsi que sur les connaissances et compétences respectives des partenaires est nécessaire, au même titre qu'une reconnaissance institutionnelle de chacun. Enfin, la diffusion de dispositifs innovants peut être une source d'inspiration pour améliorer les conditions de l'intégration en France comme dans les différents pays, à condition évidemment que soit prise en compte la singularité des systèmes éducatifs.

L'inventaire à la fois des partenaires et des décalages présents lors de la mise en place d'une intégration scolaire incline à concevoir celle-ci comme un acte individuel et collectif. Indivi-duel puisqu'il s'agit d'un processus évolutif dont la finalité est de conduire l'enfant sur la voie du progrès cognitif et social ; collectif car il doit être l'émanation d'une production commune, une élaboration concrète et concertée d'un choix d'actions à mener par l'ensemble des partenaires éducatifs. Promouvoir une intégration scolaire suppose aussi de revoir les cadres règlementaires et pédagogiques, les images du handicap ainsi que les conceptions du métier. C'est dire si l'enjeu important puisque cela concerne les cadres sociaux de la vie collective, les peurs et les résistances des différents acteurs eux-mêmes, les cloisonnements et les dysfonctionnements institutionnels. Or, nous savons que ce sont les pratiques qui modifient les représentations et non l'inverse. Le changement viendra des enseignants, des éducateurs spécialisés, des parents, … ou si l'on préfère des acteurs de l'intégration scolaire qui auront de bonnes raisons de croire en elle. Il ne suffit pas de faciliter l'accès des enfants handicapés à l'école ordinaire ; il faut aussi mettre en place un environnement riche et stimulant. Il faut de plus que soient réunies toutes les conditions relationnelles, éducatives et matérielles favorables à l'accueil de l'enfant et à son développement. C'est à cette condition que l'on pourra par la suite parler non plus d'intégration scolaire mais d'éducation inclusive.

Il est incontestable que l'école ordinaire constitue un tremplin à l'intégration sociale ; mais elle peut jouer aussi un rôle important dans le processus de mise à l'index du handicap. Intégration ou inclusion, les termes sont bien choisis si l'on veut bien en penser toutes les implications scolaires et sociales.

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Endnotes

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164. Édition originale publiée à Londres.

[2] On peut se reporter à cet égard aux deux articles parus dans le quotidien *Le Monde* le 6 octobre 2005 intitulés « La scolarisation des élèves handicapés se met doucement en place », et « Un millier de nouvelles classes d'ici 2010 » (page 12).

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Students' Perceptions about Successfully Transitioning to Postsecondary Institutions

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Abstract: Through the auspices of federal legislation, students with disabilities are gaining access to higher education. Still for many students with disabilities, the paramount barriers facing them in their transition to postsecondary education are overwhelming. This paper reports the findings of a qualitative study of 59 postsecondary students with disabilities on factors students perceived to inhibit or contribute to their successful transition into college. The study examines support services and access to reasonable accommodations available to students with disabilities. Students reported the major barriers to accessing college and succeeding in college were societal attitudes, lack of preparation, and financial constraints. The students also identified self-determination and families as necessary supports that propelled their transition into postsecondary education. Recommendations and suggestions for teachers, students, and families are presented by the study's participants to support students' with disabilities access and retention in postsecondary institutions.

Key Words: transition, postsecondary education, supports

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Access to postsecondary education for students with disabilities is supported through Section 504 of the Rehabilitation Act of 1973 Subpart E (34 C.F.R.) and the Americans with Disabilities Act (PL 101-336, July 1990). Harvey (2001) credits the Rehabilitation Act of 1973, Section 504, as providing support, services, and inclusion opportunities for individuals with disabilities over the past several years. As a requirement of this mandate, secondary and postsecondary institutions had to make reasonable accommodations for students with disabilities (Sitlington, Clark, & Kolstoe, 2000).

The Americans with Disabilities Act of 1990 further protects civil liberties for individuals with disabilities across education, employment, public services, public accommodations, transportation, and telecommunications. The Act mandates that employers and educational institutions make reasonable accommodations for individuals with disabilities to existing facilities. This law extends Section 504 of the Rehabilitation Act of 1973 to the private sector by requiring access to reasonable accommodations in employment, schools, and community facilities (Sitlington, et al, 2000). Under the Act, educational institutions, including postsecondary institutions, are "required by law to provide any reasonable accommodation necessary for those persons with disabilities to have equal access to educational opportunities and services available

to non-disabled peers, if requested" (Pierangelo & Crane, 1997, p. 156).

Although the emphasis on legislation has significantly impacted students' with disabilities transition to work and postsecondary institutions, outcomes for these students remain challenging. The National Council on Disability (NCD) (2000) concludes post-school outcomes for many youths with disabilities remain poor. These students are faced with many problems that contribute to: "(a) poor graduation rates from high school; (b) low employment rates after high school; (c) low postsecondary education participation; and (d) an increasing number of youths receiving Social Security benefits and not leaving the benefit rolls" (p.3).

Many concerns and issues exist that inhibit the success of these students (Cavin, Alper, Sinclair, & Sitlington, 2001; Horn & Berktold, 1999). For example, many students arrive at college unprepared to advocate for the services they need. They are unaware of the new responsibilities they have relating to self-disclosure about their disability, providing the institution with appropriate documentation, and being able to articulate their needs for assistance (Lehmann, Davies, & Laurin, 2000).

Sitlington and her colleagues (2000) found factors such as students' successful completion of high school academic courses, appropriateness of social skills, and engagement in transition planning to be predictive of students' interest in gaining a postsecondary education. Postsecondary survival seems to be related to students' ability to exert control over their lives by becoming aware of their strengths and weaknesses, to make decisions based upon this knowledge, and to communicate their understanding to others (Field, Martin, Miller, Ward, & Wehmeyer, 1998; Stodden, 2001).

Teachers are prominent players in raising students' expectations for college and preparing them for it. According to Reiff, Gerber, and Ginsberg (1997), "The influence teachers exert can have either profound negative or positive impacts" on students with disabilities (p.159). In other words, teachers are instrumental in motivating students to either excel or to surrender. Teachers who set high expectations for students and provide necessary academic grounding prepare students for postsecondary environments, particularly college (Hart, Zaft, & Zimbrich, 2001). Additionally, students transitioning into postsecondary education need parental support (Brotherson, Berdine, & Sartini, 1993; Benz & Halpern, 1987). Parents' efforts to support their children and their expectations for their children's futures are central to charting the course towards productive citizenry (Tobin, 2003). Their involvement in their child's high school education facilitates a successful transition from school to adult life (NCD, 1989).

Postsecondary institutions may also inhibit students' entrance to college by inadvertently conveying the message that students with disabilities are not welcome. As noted by Stodden and Whelley (2004), these institutions may not have an opportunity to evaluate the need for systemic change "created by lack of coordination of educational and related services" (p.13). As a result, instructors may demonstrate a lack of understanding about issues related to students with disabilities (Lehmann, et. al., 2000). Furthermore, various rules and regulations may have unintended consequences of prohibiting students from attending postsecondary schooling, particularly in the areas of financial assistance (Burgstahler, Crawford, & Acosta, 2001).

For many students with disabilities, the barriers facing them in their transition to postsecondary education can be overwhelming. Advocating the appropriate supports to overcome these barriers is daunting at best, but more likely to be completely baffling. Consequently, the purpose of this research study was to determine what factors postsecondary students with disabilities perceived as inhibiting and contributing to their successful transition into higher education institutions.

Method

This qualitative research is part of a larger mixed-methods study conducted by Garrison-Wade (2004) through the Exceeding Expectations Model Demonstration Project (EEP) (CFDA 84.32M). The EEP was funded through the Office of Special Education and Rehabilitative Services (OSERS) to address problems facing students with disabilities during their transition to adulthood. The project implemented a demonstration model for increasing access to and retention of students with disabilities at postsecondary institutions in five states: Colorado, Idaho, Iowa, South Dakota, and Wyoming (Lehmann & Davies, 2001). The philosophical foundation of the EEP was

(a) providing multiple opportunities for collaboration between diverse groups, (b) promoting change via the self-determination of all participants through training and by allowing participants to choose how to best implement the model based upon their site needs, and (c) recognizing the societal and community values of successfully including persons with disabilities in postsecondary education (Lehmann & Davies, 2001, p. 14).

The major goals of the project were to assure individual sites create processes that welcome and facilitate student success, provide essential information to students, parents and educators to prepare for postsecondary education, and to foster service providers' understanding of their responsibilities for serving students with disabilities. The project implemented its goals through various modes: summer institutions, utility of products, and dissemination of resources. The EEP's main purpose was to "validate a transition model to increase student access and retention in postsecondary education" (Lehmann & Davies, 2001, p. 1). The EEP was unique in that it built upon the experiences of its consumers by listening to them and developing collaborative partnerships (Lehmann & Davies, 2001).

Participants and Sites

Participants were sought from three public state universities and five junior colleges/ community colleges in one of five states taking part in the EEP (i.e., Colorado, Idaho, Wyoming, South Dakota, and Iowa). Seven of the eight universities/colleges participated in this study. Coordinators in the disability resources services offices identified potential participants and invited them to participate in focus groups. Fifty-nine postsecondary participants with various types of self-identified disabilities (learning disability, physical disability, speech and language impairment, traumatic brain injury, emotional disturbance, and multiple disabilities) between the ages of 18 to 56 agreed to participate. The participants were almost evenly divided between males (n = 29) and females (n = 30). All study participants were enrolled in postsecondary education and received services from their institution's disability resources services office. Although no additional demographic information was sought, the researcher noted during visits that focus group participants were a fair representation of the institution's larger student body. Therefore, the majority of participants were Caucasian and from middle class socioeconomic backgrounds.

Focus Groups

Over the course of nine months (i.e., July 2003 to April 2004), nine focus group discussions were conducted at seven postsecondary sites. Participants who volunteered for the study completed consent forms outlining the scope of the project and their rights as participants. Group size ranged from three to eleven participants. Each participant was limited to participation in only one focus group. The first author facilitated all the focus groups using a semi-structured format. The discussions took place at the participants' postsecondary sites. All the focus groups were audiotaped.

Students were asked to respond to questions about their transition from high school to post-

Table 1
Focus Group Questions

Questions	Detail Probes or Expanders
1. Who helped you decide to apply for college?	• Did your family or friends encourage you?
2. What barriers did you encounter in applying for college?	• What made it difficult for you?
3. What high school experiences, and or resources prepared you for college?	• Any special programs or resource teachers?
4. How could your high school have helped you to better prepare for college?	• Study Skills assistance, tutoring…
5. What skills and training do you think students need prior to entering college to be successful in college?	• Please be specific. • How about your reading, math, and study skills?
6. What do you know about the services on your campus which provide accommodations to students with disabilities?	• Tell me more about these services. • What types of accommodations are provided?
7. Discuss your level of satisfaction with these services.	• On a scale of 1 to 5, with 1 indicating low satisfaction and 5 indicating the highest satisfaction. Explain your rating.
8. What has been the most important help you have received thus far in college?	• For example, academic, counselor, special accommodations, financial assistance, tutoring, encouragement, etc.
9. Which support and/or resources have been the most helpful?	• Describe your level of satisfaction with these support services/resources.
10. What barriers have you encountered in completing your postsecondary (college) program?	• Academic, social, family, etc…
11. Tell me about specific experiences, positive and/or negative, you have had regarding disability-related access issues with faculty and staff in high school and/or college.	• How did these experiences make you feel?
12. Share any information you think could be helpful to faculty and staff, students, and Exceeding Expectations project to better provide services and activities to assist students with disabilities.	• Anything you can tell us will help others. • How does that affect other students?

Table 2
Students' Perceptions about Barriers

Theme	Elements
Attitudes	• Secondary and Postsecondary Teachers' lack of understanding • Secondary and Postsecondary Teachers' lack of knowledge • Secondary and Postsecondary Teachers lowered expectations • Peer teasing
Student Preparedness	• Lack of participation in advanced math and English classes
Financial Constraints	• Cost of college • Disability-related financial obligations • Limited financial assistance options • Complicated financial regulations

secondary institutions. Twelve major questions aligned with the EEP goals were asked, followed by probing questions to obtain a more in-depth description and response from participants. More specifically, students were asked to discuss factors and/or individuals that influenced them to pursue postsecondary opportunities, including (a) services/accommodations received prior to coming to college, (b) barriers to their success, and (c) support services/assistance needed for their success. Additionally, students were encouraged to talk about services and/or individuals helpful in their successful transition to postsecondary institutions. Guidelines were provided to help the interview process flow more freely. Table 1 presents the focus group questions.

Data Analysis

Data analysis involved coding transcriptions line-by-line using constant comparative analysis (Strauss & Corbin, 1998). The constant comparative analysis process included "opening coding," "axial coding," and "selective coding" units of examination (Strauss & Corbin, 1998). This approach was inductive in that no prior codes were assigned, but "induced" from the data. The

researcher thoroughly read the data several times to get a sense of the information, in order to put together segments of information that were alike across focus groups. The focus group questions provided the organizational framework for initial or open coding. Various Microsoft Word tools (highlighting, comment bar, theme format) were used to manage and analyze the data. Open codes were grouped into themes. Further, an inductive approach was used to identify codes for remarks made that did not fit into initial categories. Axial coding involved linking various codes by placing them into conceptual categories. In the final step, selective coding, the researcher explicated themes and used them to form stories from the data. From the themes, the researcher selected key quotes to present the participants' stories.

Throughout the data collection and analysis process, the researcher employed several steps to increase the study's trustworthiness and transparency. Specifically, the researcher reviewed transcripts to assure their accuracy and maintained a journal with notes about the data collection process, thoughts and insights about student data, and observations about all aspects of the individual sites.

Findings

Barriers

Students painted a dour picture about their transition from high school to postsecondary education. This feeling was epitomized by the

comment of one student, "There was nothing to help me transition into college and I had to kind of feel myself around blindly, trying to figure it out." Students identified a myriad of barriers that presented themselves during their transition. Three themes emerged: 1) attitudes; 2) student preparedness, and 3) financial constraints. These factors inhibit students' interest in postsecondary educational opportunities and decrease their ability to succeed.

Attitudes

Beliefs of educators and peers created doubt or fear within students about the possibility of attaining a postsecondary education. The attitudes that seemed to be the most difficult for students to overcome were secondary educators' low expectations for them, and the treatment students received from peers in high school. The attitudes described appeared to have the effect of diminishing students' confidence about their ability to succeed in new environments.

For example, teachers did not perceive that students could succeed. According to one student:

"My teachers let me slide through classes. I had some teachers who wanted me to succeed, go on and make it through college and they were more than willing to give me oral exams or give me extra time on tests. But I also had teachers who would say not to worry about the test. Then there were others who said not to bother because I wasn't going to make it."

Other people often have unrealistic notions about what it means to have a disability; that a disability is temporary:

"Whenever I tell people my disability, brain injury, they always immediately assume it's like a broken leg where you can just work around it. You can work around it, but it's always going to be there."

Further, implications that the disability was a liability precluded any possible success:

"All of my teachers told me in high school, college is a lot of reading. And that was one of the fears that I had, but it wasn't enough to stop me from coming."

Educators' lack of knowledge or understanding about the realities of having a disability led them to have lowered expectations for students and may have contributed to not addressing the attitudes of other students. Students openly discussed teasing they received from high school peers. One student said:

"My peers were mean and called me retarded. High school was really hard. I didn't want to go and I hated it, but during my junior year, I didn't care. I knew they didn't know what they were talking about. It took a while to get over it. They were really mean to me. My parents told me not to listen to them but it was hard not to."

These taunts left students feeling unsure about entering into new settings such as college, fueling their fears and self doubts as evidenced by this student's response, "The biggest problem was that I was afraid I couldn't achieve." This fear was acknowledged by most of the students as shown in this quote: "To me, there was definitely a fear of having to drop out for health reasons or falling behind in classes because of some sort of cognitive problem."

As students deliberated about applying for college they expressed insecurities about all aspects of college: "To start, I was intimidated by postsecondary education." Poor high school experiences translated into concerns about being able to acquire friends: "I had some fears of making new friends. It was kind of nerve racking…" Their concerns regarding their academic preparation also became more realistic as they started college coursework.

Student Preparedness

Students reported they were not prepared for the rigors of college classes. Said one student, "I wasn't prepared. I expected to fail. In fact, I'm

very surprised I haven't." When asked to rank their level of skills, many students indicated they were not adequately skilled in mathematics or English prior to coming to college. The major concern they raised was that by being placed in lower level high school math and English courses, they were at a disadvantage for having a successful college experience. Specifically, math classes were described as:

"Dumb, dumb math is for people who choose after three years of high school math that they don't want to take pre-calculus or trigonometry or algebra II. So a lot of people would take consumer math, which is dividend, interest, and compound interest, simple stuff you should have learned back in algebra I or geometry. It's very easy and an easy A."

The consequences of not taking college-bound math courses in high school were that students had to take additional prerequisite courses to develop basic mathematical skills. For example, one student had to take the entry-level math course four times before passing it. According to another student, "... When I came here, I needed the basic levels."

Math was not the only problem, as highlighted in one student's comments. English classes also did not prepare students for the rigors of college. According to one student, "During my junior and senior years in high school, my English classes were pretty much jokes. There weren't any writing classes." Ultimately, the need for additional courses increased students' time at the postsecondary institution and limited their eligibility for financial support.

Table 3
Students' Perceptions of Support

Theme	Elements
Student Self determination	• Be persistent • Rely on self
Family Support	• Build confidence • Provide guidance

Financial Constraints

Students identified obtaining financial assistance as a major obstacle for attending college. As noted by one focus group respondent, "Money is a barrier because I think I'll be here more than four years. It's expensive." The difficulties of funding college are compounded by financial obligations related to health insurance.

"It's not tuition only. If I want insurance, it's $800 plus for this year. That doesn't cover any prescriptions. There is a $1500 deductible before they cover a lot of things. There's not necessarily help for that. If I were a TA, they'd cover a certain amount."

But, there were not many opportunities for students to receive teaching assistant (TA) positions. Students lagging behind their classmates in terms of academic preparations found themselves needing more time to study and having less time for work. One student lucky enough to be offered a campus job reported that glitches within the financial system limited the amount of funds they could earn: "I found out that whatever I would get paid there would automatically come off my financial aid, so I would have to have another job to support having that job."

As noted by another student, the complexity of the financial assistance situation was magnified by the number of other support systems in which students were engaged:

"I needed a lot of help to try to figure out supplemental security income, supplemental disability income, vocational rehab, Medicare, Medicaid and what each one pays for. The paperwork you have to fill out is like an essay. I wish it could be more centralized in that capacity."

Supports

Students did not dwell on barriers. They also talked about qualities within themselves that propelled them forward dur-

ing their transition into postsecondary education and about individuals who influenced their decision to enter college. As shown in Table 3, themes emerged in two categories: The internalized strengths that drove them to tackle seemingly negative events, and the role of their families in helping them to pursue goals. Specifically, the two most overarching themes were the need for students to be self-determined and the importance of parental support.

Self-Determination

Participants described their own fortitude and persistence as being driving forces in their quest to enter into postsecondary education. Self-confidence and self-reliance were seen as inner strengths that propelled them forward and helped them to ignore perceived obstacles to attending college. Several students mentioned that their reaction to others' lowered expectations for them was to approach life as a series of challenges. A common refrain relating to their persistence is illustrated by this student's comment:

"When someone tells me I can't do it, that motivates me even more to prove to them that I can do it and I not only can but I will succeed. No matter what they say, I will do it. It might take longer than most but I will do it."

Students' tenacity was evident in one student's reflection on what it took for them to achieve their educational goals: "I just think over the years I've always had to struggle but I've always made it. If I put my mind to something, I know I can do it." Students' persistence carried them through their initial considerations about attending college:

"I'm stubborn and I refuse to let the chronic fatigue dictate what I do. I've had a lot of problems but I've decided that's what I want to do [sic college] and I'm going to find a way to do it."

Persistence also facilitated their entrance into a system for which most had not been prepared and stood as a reminder of their dreary high school social experiences:

"I sat down and I thought, well, is this (college) going to work for me? Am I going to be able to get through this? Am I going to be able to get all of this work done? I got down on myself the other day thinking about it, and I thought to myself that I don't know if I'm ever going to be able to do this. I then looked at myself and said, you know what, you can do it."

Students also reported that self-reliance, counting on yourself to figure out how to overcome potential obstacles, was another useful tool in their quest to be included in postsecondary education. For example, "I've learned that you have to rely on yourself before you learn to rely on others. You learn how to do things by yourself first…" The mantra of these students was similar to the one articulated by this student who said:

"I've known for most of my life that when I have to do things by myself, I have to believe in myself and actually do what I want to do… Just follow your dreams."

Students' belief in themselves even helped them to cope with the teasing they experienced:

"I've gotten a lot better over time, other people's perceptions of me used to bother me a lot but now I've learned not to care because it's not their life, it's mine. If they don't understand me, it's their loss, not mine."

Families

Students attributed their self-confidence and persistence to their families' positive influence. Families conveyed their confidence in their children. One student said, "I grew up believing I could do anything. My parents said that I could do anything I want to do." Parents offered more specific guidance helping students to realize that college was a viable option:

"…My parents were the first to support me. They were the first to say, it's really important for you to go to college. They explained to me what might happen if I didn't go to college opposed to what might happen if I did go to college."

Parents taught their children to be self-reliant, for instance, "They (my parents) didn't want me to rely on others; they never gave me any other option." In addition, parents promoted confidence. According to one student, "My father really helped me a lot. He taught me that the only way to know how to do something is to believe that you can do it."

Student Recommendations

Students offered recommendations and suggestions about how to support access to and retention in postsecondary institutions. Students' quotes illustrate how their personal reflections upon situations occurring as they applied for and entered into postsecondary education helped them to reframe their experiences into the context of lessons learned that could be beneficial to others like themselves. These recommendations are intended for other students, high school teachers, and families.

Students recommend:

- Recognize that students with disabilities are "just as smart as anybody else."

- Don't characterize and generalize students' needs because their needs may vary.

- Don't discourage students.

- Establish high expectations for students and collaborate with parents to support students' successful transition to college: "Try to treat us as you treat any other student."

- Provide intensive transitional guidance to students pursing postsecondary education, during and after the time they enter a postsecondary setting.

- Prior to starting college, show students the services that are available at the college and assign a contact person before they arrive on campus.

- High School counselors should help students transition by assisting with the paperwork, filling out scholarship forms, providing contact information on college and university services and accommodations, and arranging a trip to tour the college campus prior to leaving high school.

- Students should learn to write better and take more college prep English and Math classes.

- Students should be patient, realizing that they have a problem and that there are accommodations to help them.

- Parents shouldn't be afraid to be over aggressive in making sure that their "kids" get what they need: "Be willing to stand up for your kids but at the same time, make sure they can handle things on their own."

- Teach your child to be independent while in high school, it will help them learn responsibilities before they get to college: "Be extra supportive."

These suggestions mirror students' concerns in all areas except the area of financial constraints. The majority of the quotes are about helping students to better prepare for postsecondary education. More specifically, students asked that high school teachers encourage them to establish and achieve high expectations. They wanted to be acknowledged: "Basically, if I ask for something, listen." They wanted the bar to be set high, because, "when you have people pushing you, and telling you to do things, you tend to do it better." Participants repeatedly requested that they be held to the same standards as their non-disabled peers, that expectations need to be the same.

Students offered details about useful strategies for helping them to gain entrance into higher education. They recommended that familiarity with services and campuses be encouraged through tours of colleges and meetings with relevant college officials. They noted that

students are "…really in need of intense transitional guidance, before they enter the postsecondary setting, during the process of entering it, and after they enter…" Ideas related to encouraging students to consider college as an option included having current college students with disabilities speak to high school classes to spark interest in the notion of going to college and to discuss how to best bridge the gap between high school and higher education.

Respondents also counseled high school students to take responsibility and accept the challenge of attending college. They suggested learning how to advocate for yourself: "You have to look for help and you have to ask for help." They also identified strategies to better prepare students for rigorous postsecondary academic requirements: "Learn to write. Take more English and Math courses."

The complicated nature of families' roles is evident in students' reflective statements. Students were grateful for their families' perseverance on their behalf, saying, "Thankfully, over the years my mom has learned to not let go of the problem until it is solved." Conversely, students were aware that their parents needed to foster student emancipation: "Let your child be independent when they are in high school and help them to learn responsibilities…" Students clearly wanted to learn how to take control of their lives:

"Another personal area with me, the one I feel very strongly about, is to try to make sure we're empowering students and not enabling them. That's kind of a fine line, but we should always try to work on empowerment."

Discussion

The findings in this study were consistent with those of previous research. Many students with disabilities are not expected to attend college. Many parents and educators view college as a difficult transition for students with disabilities. Ultimately, they may not encourage students with disabilities to pursue college as an option. Inadvertently, they may limit students' potential for going to college by not challenging them to learn how to write, or to enroll in advanced math courses. Consequently, as students in this study illuminated, students with disabilities lag behind their non-disabled peers in terms of postsecondary academic preparedness (NCD, 2003).

There are many reasons for the lack of preparedness enumerated in this study and confirmed in the existing research knowledge base. As students in our study implied and Henderson (1999) concludes, students with disabilities do not receive the same kinds of preparation for postsecondary education as their non-disabled peers. For example, as noted by Rattin (2001), "… Students with learning disabilities have entered college unprepared to handle the academic expectations of their college instructors" (p.30). Therefore, these students have extreme difficulties reading college textbooks (Hart, et al, 2001). Furthermore, college requirements for them are particularly problematic given their poor study skills, negative self-concept, dependency on others, and various negative behaviors and feelings (Rattin, 2001). One solution recommended by Johnson, et al. (2002) is to establish high expectations for students with disabilities.

This study extends the existing body of knowledge by offering rich insights into students' perceptions regarding the supports necessary for successful access, retention, and completion of postsecondary degrees. Students are aware that they are not being prepared adequately to meet the demands of college, and they feel cheated. They want secondary teachers to treat them like other students. They demand respect and want to be heard.

Students highlighted the problems associated with paying for a college education. The prospect of having a large tuition debt compounded by limited availability of financial support is disheartening. Many students reported not hav-

ing the time to work because they had no free time. Their time was devoted to studying, just to keep up with classmates. Furthermore, students confirmed that taking fewer than the required amount of classes or having to take preparatory classes made them ineligible for many loans. It would seem there are policy issues surrounding institutional financial aid programs that need to be addressed if students with disabilities are to be recruited into postsecondary education.

Our research also uncovered some interesting dilemmas related to preparing students for postsecondary education. Clearly, the attitudes of teachers and peers jeopardize the confidence of students to apply for and enter into postsecondary education. Although students did not distinguish whether or not they were referring to special education or general education teachers, it is safe to assume that reflection with respect to serving students needs to occur in both groups.

High school special education teachers are usually responsible for advising students with disabilities about the courses they need to take. Judgments are made on the basis of several factors, including willingness of teachers to work with students with disabilities and the potential for success that the course offers the student. As a result, teachers may avoid recommending courses reserved for college-bound students. In another scenario, it is conceivable that general education teachers having little training about serving non-typical learners, who are focused on improving students' scores on high stakes tests, are more willing to send students with learning or behavior difficulties to resource teachers. Resource teachers are generally trained to be pedagogy experts and may not have advanced content knowledge in areas such as calculus or 19th Century English literature. Teachers with the best of intentions and under systemically-induced duress make choices for students with disabilities that inhibit students' ability to move forward into postsecondary education. The dilemma is twofold: How can teachers en-

roll students who, by virtue of their label may have problems that interfere with learning, into advanced pre-college classes? Also, is the use of a resource setting the most efficient way to address students' remedial problems in secondary education?

The teasing reported by students cannot be overlooked. Teasing is mean–spirited. Students are looking towards engaging in future environments in which offending peers may well be present. Students tormented in high school may anticipate the same treatment in college and therefore decide not to apply. Somehow, the high school ethos or culture must reinforce respectful behaviors and promote dignity for all of its community members.

This research clarifies another aspect of the transition puzzle. Collaboration is needed to support students' progress towards college. Teachers, families, and students all have a responsibility to contribute to the postsecondary educational success of students. Students are in need of self-determination skills so they can communicate their needs and learn about effective study strategies. Families can help by reminding students that the "sky is the limit." Teachers, both special educators and general educators, pave the way by maintaining high expectations for all students. This study provides insight into a direction for conducting future research. More information is needed about the students' high school course schedules and the extent to which courses taken are associated with postsecondary educational success.

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Supporting Families of Children with Disabilities: What's Missing?

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Abstract: This article presents findings from a web-based survey in which advocates and primary caregivers of children with disabilities were asked to indicate their level of satisfaction with various services and service providers, and their perceptions about how closely these services centered on family needs. A total of 68 valid responses to this pilot survey were obtained from subscribers of electronic mailing groups. The survey included questions about accessibility and affordability of services, satisfaction with services, degree of family involvement allowed by service providers, and information relating to the family-centered principles of treating and educating children with different types of disabilities. Eighty percent (80%) of respondents described a frustrating and invalidating process for acquiring services. However, once families were in the health care, educational, and social services systems, they reported finding the services received helpful. Implications for disability and health care policy derived from this research are offered.

Key Words: children with disabilities, family-centered, disability policy

According to the U.S. Department of Health and Human Services (2002a; 2002c), more than 50 million Americans or almost 20% of the total population have some type of developmental, physical, or mental disability that hinders their independence or prevents them from making a full contribution to work, education, family, or community life. In addition, an estimated $300 billion is spent annually on care for Americans with disabilities (U.S. Dept. of Health and Human Services, 2002b).

The economic effects of living with a disability are substantial, and especially difficult for families who often do not have the financial resources to meet these costs. The literature estimates that 68% of U.S. households with children with disabilities have annual incomes of less than $25,000, indicating a substantial economic hardship (National Council on Disability, 2000). Health care policies that limit insurance coverage for certain conditions and establish income ceilings for accessing coverage exacerbate the financial burdens for families of children with disabilities. Some studies report as few as 11% of children with disabilities are insured, 6% are without a usual source of medical care, and 18% report being dissatisfied with their source of care (Newacheck et al., 1998).

Besides the financial strain, parents living with a child with a disability may experience wide-ranging physical demands and may be at-risk for increased health problems themselves (Ritchie et al., 2000.) The effects of disabilities are far reaching, and if inadequately addressed, they result in increased physical, social, and financial suffering for children with disabilities and their families (Selber, Rondero-Hernandez, & Tijerina, 2005).

This article examines the development and piloting of a web-based survey to capture the experiences and perspectives of family caregivers and advocates of children with disabilities about services they acquired for their children. A basic assumption of this study was that families of children with disabilities often perceive service needs differently than service providers. As a result, families' perceptions of what works and does not work are important to an understanding of how services may be improved. The article also provides information about the study results and implications for practice and policy in the field of disabilities.

Background of the Project

A four-year federal grant was awarded to the state level health authority in Texas, located in the southwestern region of the U.S., to build statewide capacity for serving children with disabilities and their families. The grant formed part of the U.S. Centers for Disease Control and Prevention's (CDC) nationwide effort to help states better understand, prevent, and serve children and adults with disabilities and their families. Midcourse through the grant, the state health authority negotiated a contract with a local school of social work at a state-supported university in Texas to provide technical assistance for moving the state towards a family-centered model of care. There were multiple methodologies employed during the overall project and throughout the course of the two-year partnership, including secondary analysis of data, focus groups, stakeholder surveys, key informant interviews, and content analysis of strategic plans. The focus of this article includes one aspect of the project's scope of activities--the piloting of a survey to learn more about families' perceptions of the family-centered nature of the service system in order to assess its potential as a strategy for enhancing services among children with disabilities.

The Family-Centered Strategy

Family-centered care represents a consumer-oriented model of care that treats an individual with disabilities and their family with respect and dignity (Johnson, 1999). The concept appears in the literature of family-centered planning (FCP) and supports the development of service delivery systems that are responsive to family needs, linking this to enhanced quality of life (Patterson, Garwick, Bennett, & Blum, 1997). According to this model, families are viewed as the experts and are expected to participate equally with care providers regarding their children's needs and treatment (D'Antuono, 1998; Simeonsson, 1994; Simeonsson, Bailey, Huntington, & Brandon, 1991). One of the

core values of this model is the importance of respecting the family's values, environment, culture, resources, needs, and strengths and viewing such characteristics as assets for the design of patient care and treatment (Allen & Petr, 1998; D'Antuono, 1998; Trivette, Dunst, & Hamby, 1996). In addition, family-centered models view the family as the primary context for promoting health, and place the family at the center of service design and delivery activities (Dunst, Trivette, & Hamby, 1996).

Hostler (1994) found the two key elements of a family-centered planning model included meaningful participation by families in decision-making processes and an institutional culture flexible enough to respond to the ongoing collaboration between families and health care providers. Thus, adopting a family-centered planning model requires a substantial cultural change for many health, educational, and social service providers (Bailey, Buysse, Edmonson, & Smith, 1992; Johnson, 1999). The model also requires that family members be highly active in service settings when making decisions that concern their children. Leaders in education, health, and human service organizations who are committed to FCP principles must also find ways to involve children with special needs and their families in such program and policy issues as planning new facilities, revising care policies, educating and evaluating staff members, and evaluating service systems (Johnson, 1999).

Although there are dissenting opinions about the value and implementation of family-centered care (Dunst, Johanson, Trivette, & Hamby, 1991; Powell, 1996), research on family-centered models has gained momentum in a variety of areas over the last decade, including work with families of children with chronic illness, developmental disabilities, early childhood intervention programs, rehabilitation programs, and mental health systems of care (Bailey et al., 1998; Patterson et al., 1997). Discussion about family-centered care is also linked with discussions about improving the quality of life for peo-

ple with disabilities such as enhancing a sense of personal control over life decisions, heightened consumer satisfaction with services, and a sense of client well-being (Bailey et al., 1998; Gibson, 1995; King, Rosenbaum, & King, 1997; Selber et al., 2005; Trivette, Dunst, Boyd & Hamby, 1996). This theoretical framework was used to guide the overall project's research efforts to enhance the promotion of statewide services for families of children with disabilities.

Method

The Family-Centered Services (FCS) pilot survey was developed for two purposes. First, it was envisioned as a way to "triangulate" or bring in a third perspective to the ongoing research project's examination of state services for families of children with disabilities. Triangulation is a qualitative research strategy that seeks to pursue other sources of knowledge to confirm, disaffirm, and co-validate findings discovered through other methodologies about the same subject matter (Denzin & Lincoln, 1998). In this case, the survey complemented and informed content analysis and focus group methodologies that were being used by the authors to build knowledge about family-centered care for families of children with disabilities. They also examined if family-centered principles were evident in diverse service agency structures. The pilot survey, therefore, was developed to augment the research activities of the overall project, as well as to explore and extend current knowledge reported in the literature about accessibility and affordability of services, degree of involvement allowed by service providers, and consumer satisfaction with services for children with different types of disabilities. Although literature indicates that other factors are of importance in providing support to these families, such as informal support systems, this study examines only families' perceptions of formal systems of care (Streeter & Franklin, 1992).

Data from two statewide focus groups completed with families and providers revealed perceptions of existing state service systems in Texas, desired improvements for the system, and illuminated understanding about the prevalence and experience of secondary conditions. The domains selected in the pilot survey were designed to further test and develop these initial observations and findings as well as examine areas highlighted in the literature as important to families (Trivette, Dunst, & Hamby, 1996; Bailey et al., 1992). The survey captured data on the utilization, structure, and family-centered nature of services, training of staff in those services, financial impact of their child's illness, and their communities' readiness to serve their children's needs. The survey sought to address several questions including:

1. What do families experience when seeking services?

2. How much do families participate in the on-going treatment of their child?

3. Do families believe they have a voice in agency policies and procedures?

4. Are families accepted and understood in their communities?[1]

A web-based methodology was used to help ensure that the instrument was accessible, easy to use, understandable, and visually appealing (Bailey, 2000; Gaddis, 1998; Leaver, 2000; Murphy, Lee, Turbiville, Turnbull, & Summers, 1991; Murphy, Lee, Turnbull and Turbiville, 1995; Schonlau, Fricker, & Elliott, 2001). Use of on-line surveys is currently considered an innovative strategy for conducting survey research and is gaining popularity in the social science research community (Grahn & Swenson, 1998). Time and budget constraints also led researchers to conclude that distributing the survey via the internet would be an efficient way of accessing a pool of individuals knowledgeable about disabilities in a relatively short period of time with minimal cost. This conclusion was supported by the literature that has portrayed web-based surveys as the ideal "universal medium" for col-

Table 1
Demographics of Respondents

	Respondents	
	n	%
Relationship to child:		
Mother	56	82
Father	5	7
Other (grandparent, foster, adopted)	7	11
Age of Respondent:		
29 and under	5	7
30 – 49	48	71
50 and above	15	23
Education:		
High School	7	11
Some College, Vocational, Technical	23	34
Bachelors Degree	24	35
Masters, Ph.D., M.D.	14	20
Race or Ethnicity:		
Native American	1	1
Asian	3	4
Black	5	8
Hispanic	6	9
White	50	74
Other	1	1
Declined to answer	2	3
Marital Status:		
Domestic Partnership	2	3
Married	54	79
Separated/Divorced	8	12
Single	4	6
Widowed	0	0

Snowball and convenience sampling strategies were utilized to recruit potential participants for the study. The first set of participants was identified by membership on listservs devoted to developmental disabilities, special health care needs of children, and advocacy for people with disabilities. Among the listserv members were primary caregivers of one or more children with developmental disabilities, professionals, and family members interested in issues related to developmental disabilities. Also included were policy-makers and community advocates for people with developmental disabilities in the state.

The websites and listservs were chosen through several strategies. First, service providers, advocates, and family members who had completed the focus groups in the larger research project were contacted to see if they would agree to participate as respondents and to forward to the research team names of other people who might be interested in participating in the study. Next, websites in Texas were identified for associations and agencies that served families of children with disabilities in order to reach a wide sample of service providers and families as potential respondents. The websites provided staff names and email addresses for public access and the listservs provided permission to distribute materials noteworthy for their audiences. The research staff accessed these sites for distribution

lecting and disseminating mass amounts of information quickly and inexpensively through various operating system platforms and across geographic distances (Flowers, Bray, & Algozzine, 1999).

Table 2
Primary Diagnoses of Children of Respondents

	Responses
Anxiety	2
ADHD/ADD	6
Bi-polar Disorder	8
Depression/Cyclothymia	1
Obsessive Compulsive Disorder	3
Oppositionally Defiant/Conduct Disorder	3
Post Traumatic Stress Disorder	1
Asperger Syndrome	4
Autism	15
Blind	2
Cancer	1
Cerebral Palsy	8
Deaf	1
Down Syndrome/Mental Retardation	8
Epilepsy/Seizure Disorder	4
Fetal Alcohol Effects/Syndrome	7
Pervasive Developmental Disorder	9
Traumatic Brain Injury	3
Other	8
Diagnosis Unknown	2

of the invitation to respond to the pilot survey. Examples of websites and listservs that were utilized for selecting potential respondents included: American Medical Association specialty groups in the Texas area; Texas State Social Work Licensure listserv; Texas Department of Health internal listserv; Texas Office for Prevention of Developmental Disabilities; the Texas Mental Health and Mental Retardation Authority; Advisory Board members of local and state level agencies and projects that serve families of children with disabilities, and Texas State University Schools of Education and Social Work. In addition, staff from non-profit advocacy groups such as Advocacy Inc. and the Texas Council on

Developmental Disabilities were also used to promote the survey.

Permission from the University's Institutional Review Board for protection of human subjects included assurances that the research team would protect confidentiality by not requesting the respondents provide personal identifying information. In addition, no "cookies" were dropped on the respondent's computer to ensure anonymity. All data collected were kept on a separate computer that was password protected in the project's office.

Notice of the survey was announced in a general electronic email invitation sent to the identified participants and announced on listservs. The electronic email invitation explained the purpose of the survey and provided the link to access the survey if the potential respondent decided to voluntarily participate. Another means of accessing the survey was through a link posted on the research team's University website which included the same information as in the email invitations. The website announcement reviewed the purpose of the pilot survey and the request to participate including the link which carried the respondent to the on-line survey. The invitation reached approximately 430 potential participants and could be accessed on-line for 17 days. It carried a special request that service providers pass the survey along to their consumers, increasing the potential number of families who received the pilot survey instrument.

An email address listed on the invitation allowed respondents or potential respondents to

contact the researchers for questions. The project staff received several positive inquiries about the survey from both family members and service providers. One service provider wrote to request hard copies of the instrument so that she could use it with her families to evaluate her agency's services.

The university's web page posted an electronic invitation throughout the survey period. In addition to explaining the purpose of the survey, the invitation stated that participation was voluntary, and that anonymity was guaranteed. A link to the survey was located at the end of the invitation to attract people who found the site using search engines.

Results

The FCS pilot survey consisted of 24 closed and open-ended questions intended to measure the perceptions and demographics of family members of children with special health care needs. Sixty-eight (68) individuals completed the pilot survey, which represented a 15% return rate. The response rates of internet-based, convenience sample surveys typically vary from 6-75 % (Bauman & Airey, 2000; Schonlau et al., 2001). Although the 15% response rate in the existing study limits the generalizability of the findings, there are some preliminary insights that are worthy of examination.

Participants were predominantly college-educated, white, non-Hispanic, mothers of children with disabilities who were married and between the ages of 30 to 50 years.

The majority of children with disabilities (48%, N=32) referred to by the caregivers in the survey were between 5 and 11 years of age. The primary disabilities reported by respondents were Asperger/autism (28%), Down syndrome/ mental retardation (14.7%), and cerebral palsy (11.7%). A portion of respondents also reported emotional disorders (23.5%). Forty respondents (58%, N=40) reported that their child (or children) had multiple diagnoses, while two respon-

dents reported they had not received a conclusive diagnosis at the time of the survey. Specific secondary diagnoses included: diabetes, Attention Deficit Hyperactivity Disorder (ADHD), bipolar disorder, major depression cardiovascular, respiratory and intestinal disorders; and sensory disorders such as hearing impairment and loss of vision.

A Likert scale allowed respondents to rank their responses on certain questions according to five levels of agreement: strongly agree, agree, neutral, disagree, or strongly disagree. Discussion is limited to the most outstanding topics related to family-centered care. These topics include service acquisition and costs, family participation in planning, family influence in agency policies and procedures, community acceptance and understanding, and a general commentary about the survey instrument and experiences of families who care for a child with a disability.

Service Acquisition and Costs

The three services that were most used by the caregivers included educational services (76.5%, N= 52), medical services (69.1%, N=47), supportive services (48.5%, N= 33), and mental health services (42.6%, N= 29). Almost two-thirds (63.3%, N= 43) of the respondents disagreed with the proposition that acquiring services and resources was an easy task to accomplish, whereas one-fifth of the respondents agreed with this proposition, and the remaining were neutral (17.6%, N= 12).

Also, 80.9% (N= 55) stated that information about services was not readily available to them. However, when they did get information, respondents answered that it most often came from other parents (77.9%, N= 53), advocacy groups (75%, N=51), physicians (57.4%, N=39) and program staff (48.8% N= 33).

The majority of responses (55.2%, N=37) indicated that families had difficulties getting health insurance to cover their children's medical conditions, whereas only about a quarter of the

respondents (25.3%, N=17) disagreed with this statement. The majority of responses (65.0%, N=47) indicated that caregivers generally had difficulties finding affordable services for their child, while about 11.8% (N=8) reported having trouble finding services they could afford. On the subject of out-of-pocket costs for treatment, approximately 46% (N=31) of respondents perceived these costs as extremely high, while about 54% of respondents found out-of-pocket costs of treatment either manageable or not a problem to pay. When asked what types of out-of-pocket expenses they had to pay, respondents described them to be either co-payments (65.6%, N=40) or costs associated with the purchase of medications (57.4%, N=35).

Family Participation in Planning

Respondents' perceptions were mixed when it came to their role in contributing to the assessment, intervention, and treatment of their child. Of the 68 respondents, 42.6% (N= 29) agreed they were perceived by professionals as contributing partners in the treatment processes, while 26.4% (N= 18) disagreed with this statement, and almost one-third of respondents (30.9%, N=21) took a neutral stance on this issue. In addition, 60.3%, (N=41) agreed their families were considered part of the team when it came to the development of individual education plans (IEP), individual family service plans (IFSP), or admission, review and discharge meetings (ARDs). However, 33.9% (N=23) of respondents did not perceive they were treated as team members or were neutral on this statement.

Family Influence in Agency Policies and Procedures

Of the respondents completing the survey, 70.1% (N=47) disagreed or were neutral when asked if they perceived that agencies typically try to involve their families in evaluating and modifying agency policies and procedures. A little more than one-quarter (28.4%) agreed with this statement.

Community Acceptance and Understanding

When surveyed about how readily their communities accepted or understood their children's condition, 66.2% (N=45) disagreed that such a situation existed in their communities. Responses were more neutral (19.1%, N-13) in relationship to this statement, than in agreement (14.7%, N=10). Almost all respondents (98.5%, N=67) agreed that their communities could benefit from more training for staff who work with children with special needs.

General Commentary

An open-ended question was presented to participants soliciting suggestions or comments concerning the content of the survey. Thirty-five (35) of the 68 participants completed the item. Approximately one-third (31.4%) offered specific suggestions related to the survey. But 60% of the respondents wrote specifically about their personal experiences in accessing the help they needed, turning this section of the survey into a forum of discussion about the challenges, frustrations, or sorrow they have confronted in their lives as parents and caregivers of children with disabilities.

These qualitative responses were analyzed and organized into four specific content areas: 1) barriers to services; 2) barriers to education; 3) economic and/or insurance resource barriers, and 4) general comments. The three most commonly reported barriers experienced by families who completed the pilot survey were barriers related to acquiring services (48.5 %), economic and/or insurance resource barriers (31.4%), and barriers related to the education of their child (28.5%). Some of the responses were particularly descriptive of the depths of struggle that parents experience when they confront these barriers. When describing barriers to accessing services, one parent painted a gloomy picture of daily life: "Need help. In constant crisis. Can't find a meds doctor… Can't get a referral for a neurologist recommended by medical doctor, need long-term care—can't afford it—health maintenance

organization won't help…" Discussions related to economic and/or insurance resources elicited this response: "…The only way I have been able to ensure my child's health care needs are met, is to go on public assistance (which I hate!)." In addition one respondent said, "We have Supplemental Security Income (SSI) and live poor to get the medical care he needs." When grappling to describe barriers in the educational arena, one parent contributed, "We've had some outrageous things happen and don't feel that due process is an option as we are in a very small school district and fear that our children will suffer if we proceed with a complaint." A general comment about the experience of caring for a child with great service needs was summed up in this statement: "This has cost me my career, my marriage of 28 years, the patience and understanding of family and friends, and my child's entire social and emotional well-being."

This snapshot of the comments offered in this portion of the survey lend an intimate insight into what it is like when one's needs and the needs of one's child or family go unaddressed. Although some respondents expressed appreciation for what help they did receive, it was acknowledged that it came at a great cost—for some financial ruin and for others the destruction of the family unit. Based on the comments of survey participants, it appears that the demands of caring for a child with a disability are compounded by social and economic hardships and exacerbated much more when services are not configured to surround and support the needs of the family unit.

Discussion

The FCS on-line pilot survey was a beginning attempt to describe perceptions and experiences of family members of children with disabilities regarding the quality and family-centered nature of services. Although the response rate (15%) was limited, it fell within the range of 6 to 75 percent response rates reported for electronic surveys (Bauman & Airey, 2000;

Schonlau et. al, 2001). Generalizability to other populations of families with children with disabilities is not possible. Although the study generated a small sample size (N=68) it proved useful in exploring some of the main ideas and findings produced by the overall research project to date. The information reported cannot be considered representative of all families with children with disabilities, but the perceptions and experiences conveyed by respondents do serve to inform readers about parents' understandings and experiences of acquiring services for their children, and the extent to which some families struggle to get the services they need. The responses also serve to inform professionals about consumer perceptions of the quality of treatment that families sometimes receive from them and the communities in which they live.

Affordability of services was a formidable barrier to service. The majority of respondents had difficulties finding affordable services for their children with disabilities. In addition, the majority of respondents indicated they had trouble finding health insurance and paying for medication costs. Families also reported out-of-pocket expenses as a contributing factor to difficulty in acquiring needed health care services. While services may be affordable for some, a large number of responses indicated that out-of-pocket costs act as a barrier to care. The literature reports that across the nation parents of children with disabilities identify insurance and its costs as one of the most difficult issues facing them in their attempts to care for their children with disabilities (National Council on Disabilities, 2000). Also, Fujiura, Roccoforte, and Braddock (1994) described an inverse relationship between the amount of out-of-pocket expenses and annual income for families supporting an adult member with mental retardation. These findings heighten the need for further study about how to help alleviate families from some of the economic burden they bear when caring for children with disabilities, even if they qualify for health insurance or public programs. Such policy changes might also influence the families'

decisions to care for their children in the community and help families stay together instead of disintegrating, an event that often brings further pain and financial difficulties. Since family-centered principles advocate accessibility as an important element of service delivery, it is to be expected that the issue of affordability will be an important aspect of services from a family's perception of quality.

Responses also demonstrated that some families did not know how to qualify for services or programs. This may imply a need for increased communication between providers and consumers about existing health, social, and educational services and resources. In addition, since respondents indicated that they received the most helpful information from other families, policies that support mentoring programs and other forms of support between families of the newly diagnosed and those already familiar with service systems should be encouraged.

The majority of survey participants indicated that they encountered difficulties in acquiring services they needed. As one respondent conveyed, "We fought long and hard for proper diagnosis and services …After literally abandoning him on the steps of a hospital, they finally [admitted] him." Another respondent added, "When I was seeking the services I now receive, I felt as though I was alone and no one cared if we stayed together as a family." These statements suggest that service systems should be more responsive to the needs of families, and less contentious when brokering services. The literature demonstrates that if services are not made accessible in a timely manner and are not individualized for the needs of clients, both characteristics of family-centered services, children and families may be placed at-risk for developing secondary conditions and an overall worsening of the child's condition (Streissguth, 1997a; 1997b; Streissguth, Barr, H., Kogan, J., & Bookstein, 1996). Secondary conditions such as depression, social isolation, relationship difficulties, and behavioral conduct disorders seriously af-

fect children and their family members, further complicating the primary condition. These secondary conditions also increase the need for additional services, bringing added obstacles, and new rounds of emotional and financial burdens (Frey, Szalda-Petree, Traci, & Seekins 2001; McCarthy & Stough, 1999; Rondero, 2001; Selber, 2001; Streisguth, 1997a). Research indicates that additional factors such as assistance from informal networks of support like other family members and friends are added resources that often can help families mitigate such difficulties with the formal provision of services (Streeter & Franklin, 1992). However, this topic was not explored in the present study but should be a future topic of research to understand exactly how informal networks might help alleviate the obstacles that formal systems of care often manifest for these families.

Although most respondents thought they were perceived as "part of the team" when it came to developing educational and service plans for their children, there was mixed agreement about whether professionals perceived families as important and contributing partners in assessment and intervention activities. Special education law may have institutionalized the role of parents in developing educational plans, but the notion of viewing parents as "experts" about their children still seems to fall short of the ideal proposed by researchers in family-centered care (Arango, 1999; D'Antuono, 1998; Simeonsson, et al., 1991). A sense of being "left out" was also detected in survey responses related to family participation and planning. More than half of the survey respondents reported they had no influence in shaping agency policies and procedures. McCarthy and Stough (1999) found that quality of life is highly dependent on self-determination and is only achievable when families of individuals with severe, chronic disabilities have access and input into essential services. Thus, family input, an essential element of family-centered care seemed lacking according to these respondent families.

Conclusions

Data from numerous studies, and special initiatives cited in this article suggest that for many children, having a disability infers social and economic hardship for themselves and their families. In addition, the demands of the child's chronic condition often overwhelm a family (Selber, et al., 2005). There are numerous challenges that face these families beyond access to formal service provision, which was the focus of this pilot study. Such issues as emotional and relationship difficulties and community isolation are equally important topics for further research. However, there was little deviation in the commentary of recommendations and needs stated by respondents in this study, regardless of the child's disability or condition. Their voices tell us that their circumstances are worsened much more when services do not reflect family-centered characteristics such as being supportive, accessible, flexible, comprehensive and centered around the needs of families. Although this study was only focused on formal service provision and not informal supports that can be of vital help for these families, future studies on the role of family members, friends, and community members might add to the understanding of their lives and how other informal supports might mitigate inadequacies in formal systems of care.

In general, professionals in health, educational, and social service systems utilize a disease and deficiency perspective, as opposed to a family-centered one. The former perspective clashes with a child-centered and family-centered perspective, especially when parents view their children's condition in a more positive and optimistic light. The devaluing of these types of parental perspectives was exquisitely described during focus group research facilitated by the same authors (Rondero, 2001). Comments voiced by parents and advocates during these sessions also described their perceptions of the inadequate treatment children and their families receive from medical, educational, social service

agencies, and the community at large. In general, this treatment was ascribed to several factors:

- Systematic use of a disease and deficiency perspective for treating persons with developmental disabilities and their families, emphasizing deficits more than assets;

- Inadequate professional preparation of medical, educational and social service personnel to address the psychosocial needs of individuals with developmental disabilities and their families;

- The absence of a continuum of services that is comprehensive, and supports the development and lifelong needs of children with special health care needs and their families, and

- Inadequate governmental support at federal, state, and local levels that enforce accountability in the provision of services to children with special health care needs and their families (Rondero, 2001; Selber, 2001).

These factors also speak to commentary gathered by the FCS pilot survey. Although the survey has limited generalizability, the study contributes to the discussion on the perceptions of families about the importance of characteristics of family-centered services for children with disabilities and their families. Such issues as access, quality of input into service decisions, timeliness of services, and the priority of service affordability and ease of access are some of the factors that speak to the family-centered nature of services and the quality of services that this study highlights. The study also serves to inform the profession about the daily challenges confronted by these families that go beyond the family-centered nature of services and reflect additional dimensions of quality of service provision. Hopefully, these results and their discussion will advance development

of intervention strategies designed to reduce the abundance of burden these families carry on behalf of their children. The voices of families of children with disabilities continue to tell us of the importance of being family-centered in all of the community's service systems.

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Endnote

[1] A copy of the survey instrument used in this study can be obtained from the first author of the study.

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Family Focused Learning: A Model for Learning from Children with Disabilities and Their Families via Technologies for Voice

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Abstract: In this paper, we describe a collaborative multidisciplinary model for faculty and students learning about culture and children with disabilities and their families in Pacific Island contexts. The model, Family Focused Learning, incorporates aspects of case-based and problem-based learning within the context of "consumer" and "professional" partnerships (Ratliffe, Stodden, & Robinson, 2000; Robinson, 1999).

Children with disabilities and their families share the daily challenges and successes of their lives with graduate students and faculty at the University of Hawai'i, *via video letters, video mapping, cultural brokering and satellite video-conferencing.* To illustrate this process, we present the story of "Tomasi," a child with cerebral palsy in American Samoa, a US territory. Tomasi and his family are "given voice" and act as teachers for an interdisciplinary team of faculty and students from public health, social work, physical therapy, speech pathology, nursing, special education, nutrition, medicine, political science and law.

Key Words: Video Conferencing, family focus, learning communities

*Editor's Note: This article was anonymously peer reviewed.

Introduction

The Center on Disability Studies at the University of Hawai'i has a demonstrated commitment to "giving voice" to persons with disabilities and their families. This commitment to self-determination includes technology and media applications that support dialogue, partnerships and synergy among "professionals" and "consumers." This article describes an innovative project entitled "Family Focused Learning" that employed video letters, video mapping, cultural brokering and teleconferencing to promote cross-cultural communication and consumer empowerment between UH faculty and students, and an economically disadvantaged family in American Samoa who have a child with severe cerebral palsy.

In this semester-long project, 15 graduate students and 12 faculty (representing diverse fields in health, education and social services) entered into a distance relationship with Tomasi, Malia and their 3 children, communicating across the challenges of place and time, culture and language, and perceived imbalances in role and status. It is our hope that the story that fol-

lows will motivate others to build learning communities across distances

Family Focused Learning (FFL)

The UH Center on Disability Studies (CDS) through its MCH LEND program (Health Resources and Services Administration, Maternal and Child Health Bureau) sponsors interdisciplinary courses that use a mentorship model in which a learning community of students across disciplines (including public health, social work, physical therapy, speech pathology, nursing, special education, nutrition, medicine, political science and law) are mentored by their respective faculty to study issues of culture and disability. The MCH LEND Program is a leadership development program designed to respond to national maternal and child health (MCH) and local initiatives to meet the essential intervention and health care services required for children with special health care needs and their families.

A core value of this MCH LEND learning community is to build partnerships between "helping professionals" and families of children with disabilities to promote problem-solving, creativity, and mutual respect. This has not been an easy challenge, as there is a long history of distance and imbalance between professionals and consumers, including the "expert" and "medical" models of service provision, in which professionals are expected to know the answers, and consumers are expected to listen and comply. It is our commitment to replace these worn-out paradigms with models of partnership, family-centered supports, and joint ownership of the problem-solving process (Rocco, Metzger, Zangerle, & Skouge, 2002).

Additionally, the MCH LEND model incorporates aspects of problem-based learning or case-based learning (Albanese & Mitchell, 1993; Barell, 1998; Bruner, 1987; Gardner, 1983; Ratliffe et al., 2000; Robinson, 1999). Both are approaches that have successful histories in medical schools, and in many other educational contexts including university-level special education courses. For example, problem-based learning in medical schools typically consists of a sequence of tutorials in which a vignette is presented to a group of students who "develop hypotheses, discuss underlying mechanisms, and prepare learning issues for clarification and discussion at the next session" (Katsikitis, Hay, Barrett, & Wade, 2002, p. 279). Case-based learning is similar, although a series of vignettes may be presented in a single session (Katsikitis et al., 2002). (For a comprehensive review of research of problem-based learning in medicine, see Albanese & Mitchell, 1993).

Realistic or authentic cases can provide veridical context-laden situations with all of the unique richness and complexities of individual lives, particularly when students and professionals engage with people in real settings, not just paper-based vignettes. A central tenet of Family Focused Learning (FFL) is the co-engagement of professionals and families learning together.

Furthermore, in learning about disability, students and professionals can no longer study without engaging real people within cultural contexts. These notions also have their roots in Vygotsky's sociocultural perspective (Vygotsky, 1978), in which learning and development can only be understood within the cultural settings in which they are situated.

In the Pacific region, disability studies are complicated by professionals from many different fields needing to learn about the cultural contexts and backgrounds of children, a task that is daunting, considering that the Pacific Ocean, perhaps the largest geographic feature on the planet, is covered by thousands of islands. These islands and island groups are peopled by many different and distinct cultural and linguistic groups. Encountering a child sent to Hawai'i to be treated for a disability or a medical condition offers little or no understanding of cultural context.

Well-intentioned professionals from developed countries, comparatively wealthy in ma-

terial resources, may fail to comprehend the implications of educational and socioeconomic differences in developing regions, and the socioeconomic challenges that many island families face. Additionally, Western professionals may not be aware of the often unexpected strengths and positive aspects of extensive cultural resources that support children and families in their home island communities and villages. Unawareness of these challenges and opportunities may lead to frustration when medical or educational recommendations are not followed through.

In 1996, the University of Hawai'i's MCH LEND Project began exploring video technology to document "family voices" and family experiences, which in turn could be incorporated into an inquiry based training curriculum (Ratliffe et al., 2000; Skouge, 1997, 2004b). Faculty mentors and select students began meeting with families in their homes to map the key elements of the family's experiences in raising a child with a disability (Falvey, Forest, Pearpoint, & Rosenberg, 1993; Vandercook, York, & Forest, 1989). These elements include (a) the beauty of their family, (b) daily routines, (c) hopes and dreams for their child with a disability, (d) fears and nightmares, (e) needs, concerns and barriers, (f) strategies to thrive and overcome, (g) positive and negative examples of professional services, and (h) how professionals can be helpful to families. We asked families to tell us stories, believing that story-telling is a natural and comfortable communication form for self determination and consumer empowerment (Dowrick & Skouge, 2001; Dowrick, Skouge, & Galbavy, 1999; Skouge, 2004a, 2004b; Skouge & Boisvert, 2004; J. Skouge, M. Kelly, & K. Thomas, 2003; J. R. Skouge, M. L. Kelly, & K. Thomas, 2003).

Usually, by the second or third home visit, a bond would be established between the university representatives and the family, the "map" was complete and the stories had been identified and rehearsed. At that point, a camera, tripod and microphone were brought into the living room and the stories were recorded in an easy interview style. Every effort was made to simulate a "home video," with the now-trusted faculty handling the camera and guiding the discussion. In addition to videotaping the interviews, "roll over" footage was shot of daily routines (e.g., feeding and bathing) and community activities (e.g., swimming, taking the bus, bowling). The video was then edited at the university into a 30-45 minute "video letter," containing thematic "chapters" of the family stories (Skouge, 1997, 2004a, 2004b; Skouge, et al., 2003; J. R. Skouge, et al., 2003). Over the course of some weeks, these family stories were shared with our students as the focus for in-class discussion, research, writing, and a culminating face-to-face dialogue with the family.

Tomasi and His Family: Adapting the FFL to Telecommunications

In the fall of 1998, the MCH-LEND faculty decided to extend the FFL model to include a Samoan family living in American Samoa. The plan was to follow the protocol described above, utilizing telecommunications as one vehicle for face-to-face dialogue. (For a description of technology issues in American Samoa, see Iding & Skouge, in press). Several of our faculty were making regular visits to Tutuila (American Samoa's main island) and Tomasi and his family were already known to us through prior consultation services. By that time our confidence in the FFL model was high (at least with families living in Hawai'i), so it was not difficult to persuade our 12 graduate faculty to commit the time and energy to a distance learning experiment.

Tomasi Jr. was an intelligent and healthy 6-year old with severe cerebral palsy, unable to speak, walk or otherwise function independently. Tomasi Jr. was born in American Samoa, giving him the rights to access American social services. His parents, Tomasi Sr. and Malia, however, came from economically depressed cir-

cumstances in Western Samoa (now called simply Samoa). They had little formal education and were landless in American Samoa, living in a tiny wooden homestead, a mile or so from the paved road in "the bush." Tomasi Sr. worked the night shift, 6 or 7 days a week at one of the tuna canneries. Malia stayed home to care for Tomasi Jr., his younger brother, Junior, and his sister Rachel. The land and homestead were owned by a matai (chief). Malia spoke only limited English. Tomasi Jr. spoke none at all.

The story that follows represents the greatest cross-cultural, distance education challenge that we had yet faced. Here was an immigrant family, largely disenfranchised in its own homeland, inexperienced with Western ways of health and education, entering into an uncharted relationship with graduate faculty and students at the University of Hawai'i:

"This writer had a long-standing relationship with Special Education in American Samoa, spending as much as 3 months a year working on the main island. I first met Tomasi Jr. at the Special Education Center. He was loved by his teachers and widely acknowledged as a bright boy stuck in a terrible, disabling situation. Instead of a wheelchair, he sat in a folding stroller with a blue canvas sling seat that seemed to swallow-up his tiny body. We would typically see him slumped forward, staring at his lap, with the biggest smile, the greatest laugh and one hand that could ever so slowly reach and grasp. Often he'd be holding a tiny plastic car or animal that he could move across his line of vision. With his imagination going wild, he'd make sounds and hum tunes of joy. He was a smart kid, we all knew, but it seemed like he was going nowhere.

One day I asked the teacher, Taufou, if she would go with me to visit Tomasi's family, explaining to her that we hoped Tomasi and his family might agree to join us in teaching our graduate students about serving children with disabilities and their families, including produc-

ing a video and a teleconference. Taufou enthusiastically agreed and suggested that we follow his school bus home, as she did not know the way. A note was slipped into Tomasi's backpack informing his parents that we would like to make a home visit the following day. "Would that be all right?" we asked. The next morning, Tomasi the courier, returned with their following response: Please come, you will be welcome.

We arrived at 2:00 p.m. on the following day. The road was rough. The foliage of the jungle was hanging listlessly in the afternoon heat. Not even the insects were buzzing. Malia was standing in the clearing, in front of a tiny wooden house, side-by-side with three others, each on stilts, with a much larger house built of block nearby. Children peered from the screenless windows. Their eyes were open wide, and they were whispering and watching.

The van driver unbuckled Tomasi from the front passenger seat and lifted him into his mother's arms. Malia smiled and laughed and hugged him as she greeted us and led the way up the three steps into the tiny cottage. Taufou and I followed, removing our shoes at the door and carrying them inside, aware that the dogs in the yard were eyeing them with anticipation. The living room contained two rough hewn wooden chairs, woven mats on the floor, a tiny television set on a crate in the corner, and an alter with crucifix and framed picture of Jesus. Tomasi was laid on the mats and immediately greeted by his younger brother and sister. We too sat on the mats at Malia's invitation, and before many minutes, Tomasi Sr.(her husband), appeared through a back entrance with a tray of red juice and store bought cookies. Smiling shyly he set the tray on the mats before us, and then sat down himself beside Malia. They loved Tomasi Jr. very much, they explained, and would do anything to help him.

I enlightened them the best I could about how I represented the Center on Disability Studies at the University of Hawai'i, and that we

were interested in forming a partnership with a family such as theirs, in order for our students to learn about Samoan families and what it is like to raise a child with a disability. I particularly wanted them to understand that we were not a service organization, nor were we in any position to promise supports and services; that, instead, we were professors and students trying to learn from families how it is to raise a child with a disability and what professionals should know in order to be culturally responsive. To this day I do not know if Malia and Tomasi understood the intent of my communication, but in good faith, they agreed to participate."

Producing a Video Letter and Video "Map"

Our first challenge was to produce a video letter to be taken back to Hawai'i. One of our colleagues, Martha Guinan, flew to American Samoa to assist with the video production. Martha is the mother of a child with Down syndrome as well as an accomplished "family facilitator" and videographer. The video camera, rather than being intrusive, proved to be a tremendous facilitator of communication and "story telling." After reviewing with Malia and Tomasi Sr. the elements of "mapping," we started with asking Malia to tell the story of Tomasi Jr.'s life from the time of his birth to the present. Next, we filmed Tomasi Jr.'s daily routine, which also provided an easy framework for story telling: getting washed and dressed; eating breakfast; riding the bus; engaging in school routines (morning circle, story time, computer, lunch, art, music, and community recreation); coming home from school; life in the living room (games and books); playing in the yard; going to church; eating supper, and going to bed.

What we found as we produced the video was that both Tomasi Jr.'s family and his teachers became invested in its outcome. Tomasi shared his garden. Malia showed us how she prepared foods and fed Tomasi mashed bananas. Tomasi taught us his hand-signs for communication.

His teachers showed us how books could be adapted so he could turn the pages, and how Tomasi could communicate with picture boards, work the computer, and even run an electric train using adapted switches. The process of making the video seemed to create awareness, in which everyone wanted Tomasi to shine. Everyone learned from one another. Expectations for Tomasi were heightened. It took nearly a week to get all the shots and interviews, but finally the "map" was complete – we had given voice to the family to express its hopes and dreams. Malia chose to be interviewed in English. Tomasi was interviewed in Samoan.

Employing the Video as "Inquiry Based Learning"

The video was edited back in Hawai'i, and shown during a 3 hour Friday afternoon session in our graduate forum. The video was divided into four thematic chapters, which were viewed and critiqued by students and faculty organized into teams. Samoan informants from UH were invited to participate on each team to answer questions and explain cultural ambiguities. The mission of the teams was to critically reflect on each of the chapters in terms of: (a) What are we hearing from Tomasi and his family? (b) What other information do we want or need? and, (c) What might be a learning issue to research that would help this family?

By the end of that first Friday session, a tremendous outpouring of student dialogue and questioning had been generated: "How do Samoans perceive disabilities, in terms of causes and expectations?" "What kinds of adaptations could be built for their home so that Tomasi could be more active and independent?" "How do Samoans balance traditional medicine with the 'palagi' or 'western ways'?" "Are there assistive technologies that could help Tomasi to learn and communicate (augmentative communication and computer software)?" "What is the Samoan diet?" "Where does a Samoan child fit into the family and community?" "What servic-

es and supports are available in American Samoa for children with disabilities?"

Each team prioritized a research topic, interviewed informants, conducted literature reviews, and then wrote reports in "family friendly" language for Tomasi's parents – sharing the information they had learned, along with questions they would like to ask the family during the upcoming teleconference. The tone of the reports was not to be expert or academic. The reports were more like letters to the family, with open invitations for dialogue and values sharing – respecting Malia and Tomasi as cultural informants and teachers. Several weeks were allowed for the writing of the reports. In order to share the reports with the family, they were presented in class and videotaped, with each team member introducing themselves, and sharing something personal with Tomasi's family, in addition to the report.

The Teleconference

We then returned to American Samoa in preparation for the teleconference. Taking a VCR and television to Malia and Tomasi's home, the team presentations were viewed in the family living room, along with the written reports. Tomasi's teacher, Taufou (the same person who had assisted in the production of the video), accompanied us for the family meeting. Each team presentation was viewed and discussed in Samoan language. Tomasi and Malia rehearsed what they would like to say in response to each of the reports. A written outline was created, which included both things to say and things to show (including various foods, traditional medicines, and positioning devices for Tomasi, including a stroller and a corner chair). Malia chose to write a letter in English to each of the teams, thanking them for their research and answering select questions. These letters were subsequently read aloud during the teleconference.

The teleconference was scheduled for a 3 hour block on a Friday afternoon, utilizing the Peace Satellite link between the University of Hawai'i and the LBJ Hospital on Tutuila. We were scheduled to pick up the family at 11:00 a.m., in order to make it to the LBJ Hospital by noon. Malia, her mother, Tomasi Sr., Rachel, Junior, and Tomasi Jr. were waiting with great anticipation in the clearing when we arrived. They were all wearing new clothes, which Malia had sewn by hand. She looked at us with a half-hearted smile, whispering that they were all very nervous. It was perhaps then that we first realized the seriousness of this experiment. Here was a family, without economic means, struggling on the very margins of Samoan society, raising a child with severe cerebral palsy, engaged in a relationship with professors and their students from a world far, far away – connected by video from a humble shelter in American Samoa to an air conditioned classroom on O'ahu. They were probably thinking, "And now what? A teleconference?" It is doubtful that Tomasi Jr. and Malia could imagine what this event would be. It was an act of faith to climb into the truck and embark on the road to town.

We arrived at the hospital. The teleconference facility was ready. Tomasi's teachers and other special education invitees were waiting. Tomasi and his family were positioned in the front of what was becoming a throng. A technician turned on a large television set. And there, flickering to life, came the faces of the 30 or so "friends" across the water – professors, graduate students and Samoan cultural brokers. There was Martha's face, familiar and comforting, greeting us from Hawai'i. Everyone took their turn to say, "Hello." The process was orchestrated with Martha facilitating one end, and Taufou and one author facilitating the other.

The papers were discussed one at a time, with care taken that Malia and Tomasi spoke first to each of the papers, with prompts and supports from the facilitators. Malia read her letters. Tomasi Jr. spoke in Samoan, with Taufou translating. Malia demonstrated Samoan massage. Students in Hawai'i showed pictures of an adapted swing that could hang from the

tree in the clearing. The 3 hours flew by, amid tears and laughter. All too soon, it was 3:00 and time to say good-bye. The television was turned off and we bundled ourselves back into the truck.

We negotiated the traffic and returned to the clearing, carrying Tomasi into the tiny room that was the center of family life. We sat on the mats, as we had so many times before, to debrief and try to figure out what we had just experienced. Malia told us she could not express the gratitude she and her family felt for all that had happened. They did not feel invisible anymore. It was acceptable to have dreams for themselves and for their son. She had never felt shame for having a child with a disability, but she had never before been empowered to say it. She expressed these sentiments by saying, "And to be with people, educated and knowledgeable and powerful who could listen!"

In Hawai'i, too, the faculty and students expressed a need to debrief. Here was a family they had come to know so well, a discussion that had been so intimate and revealing, between people seemingly far away…but not.

In the months that followed Malia, Tomasi and their family moved to Hawai'i, in order for Tomasi to benefit from Western medical and educational supports. Their saga in Hawai'i has been filled with a mixture of joy and pain, but that is for another story at another time. For our purposes here, let us say that many of our MCH LEND students and faculty rallied in support of this beautiful family to assist them with finding housing, social welfare services, and special education. The bonds of friendship had been forged.

Conclusion

In this article, we illustrate Family Focused Learning by sharing the story of Tomasi, because we believe it to be one of the most effective ways to convey the process of learning about and with a child who has a disability and his family in his own unique cultural context.

Central to the effectiveness of this collaborative "learning community" model are the notions of respect and the willingness of a disparate group of people from different backgrounds to work together. A unique feature of this model involves the child with a disability and his family acting as teachers for an interdisciplinary group of faculty and students from diverse disciplines.

Central also is the use of video and telecommunications technology to create links between families, medical/educational professionals and students that would otherwise be separated by thousands of miles of ocean and vast cultural and socioeconomic divides. It is our hope that this can serve as a useful model for other cultural contexts, as professionals learn to work effectively and respectfully with children with disabilities and their families, and to learn from them as well.

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Encountering Physical Difference: Models of Experience and Dialogue

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Abstract: This paper utilizes Hans-Georg Gadamer's classic philosophical study of the art of interpretation, *Truth and Method (Wahrheit und Methode)* (1960), to examine literary critic Leslie Fiedler's 1996 collection of essays on bioethics and disability, *Tyranny of the Normal*. Because Fiedler's primary analytical model centers around the experience of engaging an abjected Other and subsequently revising one's self-conception based on this experience, it is useful to examine Fiedler's arguments with respect to Gadamer's theories of the hermeneutic circle, the historicity of experience, and the dialectical nature of understanding. Viewing these writings through a Gadamerian lens allows us to devise critical readings of the crucial social moment when the nondisabled "normal" individual and the person with a disability meet. Conversely, Gadamer's text allows us to develop important criticisms of Fiedler's work centered on the ahistorical and non-dialectical character of Fiedler's interpretation of nondisabled individuals' encounters with disability. Juxtaposing these two thinkers allows us to develop philosophical, psychological, and ethical warrants for disability rights activists' assertions that the lives, medical treatments, media representations, and political destinies of people with disabilities must not be determined by the non-disabled alone.

Key Words: hermeneutics, communication, experience

Since the 1990s, Disability Studies as an academic discipline has demonstrated a profound capacity for generating insights and interconnections with disciplines in the Humanities. It is also evident that engaging in academic inquiry from the perspective of Disability Studies can inspire productive study of texts that make no overt mention of disability, leading us to explore new and creative applications of "traditional" or "canonical" texts to the study of theories of disability. Indeed, on March 7, 2004 the Modern Language Association Conference on Disability Issues in the Profession officially recommended that universities, "Incorporate a disability studies perspective into courses across the curriculum" (p. 1).[1] Both projects handily refute critics of Disability Studies who deny it academic legitimacy on the grounds that it "push[es] parochial ideologies…lack[s] intellectual credibility, and…contribut[es] to the balkanization of learning" (Longmore, 2003, p. 5).

The present paper engages in the second mode of study: Engaging in academic inquiry from the perspective of Disability Studies to inspire productive study of texts that make no overt mention of disability. I utilize Hans-Georg Gadamer's classic philosophical study of the art

of interpretation, *Truth and Method (Wahrheit und Methode)* (1960), to examine literary critic Leslie Fiedler's 1996 collection of essays on bioethics and disability, *Tyranny of the Normal*. Because Fiedler's primary analytical model centers around the experience of engaging an Other and subsequently revising one's self-conception based on this experience, it is useful to examine Fiedler's arguments with respect to Gadamer. Though Fiedler does not cite, much less discuss Gadamer's work, the latter's theories of interpretation, the historicity of experience, and the dialectical nature of understanding, prove strikingly applicable to Fiedler's writings. Viewing these writings through a Gadamerian lens allows us to devise critically productive readings of Fiedler's model of human normality and abnormality and his discussion of the crucial social moment when the nondisabled individual and the person with a disability meet. Conversely, Gadamer's text allows us to develop important criticisms of Fiedler's work centered on the ahistorical and non-dialectical character of Fiedler's interpretation of nondisabled individuals' encounters with disability. Furthermore, juxtaposing these two thinkers allows us to develop some philosophical, psychological, and even ethical warrants for disability rights activists' assertions that the lives, medical treatments, media representations, and political destinies of people with disabilities must not be determined by the nondisabled alone.

Leslie Fiedler's Model of Encountering Human Differences

The short title essay of Fiedler's 1996 collection continues the work of his 1978 *Freaks: Myths and Images of the Secret Self*, in which he offers "freakishness" as an analytical category of disability.[2] This concept allows Fiedler to construct an explanation of society's continual fascination with disability while exposing and challenging pervasive assumptions of "normality." Fiedler's project uses his reading of experiences between "normals" and "Freaks" to contest, and ultimately refute, the dominant culture's belief

in "the Normal" as a definitive, naturalized category of social differentiation. In both texts, Fiedler's arguments explicitly emerge from his conception of a core experience, the direct viewing of the "Freak" (a direct experience that, as we shall see, nonetheless demands interpretation). In *Freaks* Fiedler observes that this "confrontation in the flesh…is, in fact, a chief occasion for this book" (p. 16). While textual and cinematic presentations offer startling images of disability, Fiedler believes such presentations are much less powerful removed from the direct experience of viewing an "abnormal" person. In Fiedler's theoretical dynamic, only an immediate encounter with the abnormal Other provides the "sense of quasi-religious awe" with which all societies have confronted disability, and it is thus only through this experience that the viewer truly confronts his or her own "Secret Self." Thus, in Fiedler's psychological explanation for the "moral model" of disability, physical abnormality has captivated societal interests throughout history because by "experiencing" it, so-called nondisabled individuals rediscover their own deeply buried, primal perceptions of themselves as freakish.

Fiedler's model of the experience of a meeting between nondisabled and abnormal individuals is essentially a four-stage process: assumption, recognition, surprise, and revised recognition. Fiedler considers a person freakish if the individual's physical condition makes him or her appear, in comparison with societal generalities, radically and disturbingly other than "normal." At the moment of confrontation with a freakish individual, a nondisabled viewer perceives one of "those wretched caricatures of our idealized body image, which at first appear to represent what is most absolutely 'Other'" (Fiedler, 1996, p. 152). The viewer approaches the Freak with preconceived, socially and psychologically constituted assumptions about what a "typical" human body is, and the initial impression that the Freak is "absolutely 'Other'" initially supports such prejudices, "Thus reassuring us who come to gape that we are 'normal'" (p. 152). However, the ambiguous appearance of the Freak soon

makes the viewer perceive him or her not only as radically different but also as possessing definitively human characteristics, a point of common ground for our perception and intellectual processing of the experience. When such a recognition is made, a moment of shock occurs. This recognition of commonality with the Freak throws the viewer back upon his prejudices regarding Otherness, resulting in a revelation of what Fiedler terms "the Secret Self," his term for a psychic construct of deep-seated personal shame, guilt, or anxiety. If the Freak is like the viewer, the viewer is also like the Freak. A subsequent psychological revision of this revelation makes the viewer aware that all "normal" people feel, at times, out of place or "freakish" when confronted by societal dictates of what is physically "normal." (At some point in our lives all of us have looked in a mirror and worried, "I look so strange because I weigh too much/too little," "I have too much/too little hair," and so forth). Because there is always a fantasy image already underlying it, even the seemingly objective experience of perception is a thoroughly complicated one.

Although his basic pattern for the experience is the same, Fiedler also offers an alternative reading of the psychological dynamics of the confrontation between nondisabled viewer and Freak. Depending on the Freak's physical difference, the viewer's initial assumptions can also be fractured and recognized as false with respect to unique aspects of the human physiological condition. For example, most people approach other individuals with prejudices about human "scale," thus, when one sees a person of short stature, these prejudices are thrust into the forefront of one's consciousness and called into question. Prejudice of scale is revealed as a preconception rather than a universally applicable truth of nature. In two primary ways, therefore, the experience of viewing the Freak causes the viewer to reconsider the prejudices he holds, either about himself or about humanity as a general intellectual category.[3] If Fiedler's model is correct on this score, this imperilment of beliefs

and understandings, imagined as foundational to common existence, constitutes one explanation for the fear disability often elicits from the nondisabled population.[4]

Hans-Georg Gadamer's Understanding of Experience

In one sense, Fiedler's calling the viewing of the Freak an "experience" may indeed be an accurate description. According to the German philosopher Hans-Georg Gadamer (1900-2002), "experience is always initially [an] experience of negation: something is not what we supposed it to be…Every experience worthy of the name thwarts an expectation" (1960, pp. 354, 356). Gadamer's work is one of the twentieth-century's most important treatments of "hermeneutics," or the study of interpretation. As described in *Truth and Method*, Gadamer's conception of the hermeneutic circle (the process by which individuals interpret aspects of their world) seems quite similar to the conceptual processes illustrated by Fiedler. Deriving his ideas partly from Heidegger, Gadamer (1960) writes, using textual explication as an example, "A person trying to understand a text is always projecting…The initial meaning emerges only because he is reading the text with particular expectations in regard to a certain meaning…Working out this fore-projection…is understanding what is there" (p. 267). When does "understanding" occur? For Gadamer, it begins when aspects of experience of an Other conflict with prejudices about that Other, when one is "pulled up short" by the object of experience (be it a text, a person, or an event). One always makes unconscious assumptions when approaching objects of experience; indeed, for Gadamer these would not be objects for experiencing if one did not have these preconceptions. All understanding is thus motivated by a moment of misunderstanding. When these assumptions are not called into question or brought into conflict with a particular experience, one's approach to the Other involves assimilation rather than genuine "understanding." In genuine "understanding," however, the pro-

cess of experience makes us conscious or aware of our own prejudices. All understanding must contain a moment of self-reflection.

According to Gadamer (1960), "Hermeneutic work is based on a polarity of familiarity and strangeness" (p. 295). The "familiarity" allows prejudices to be applied in an initial reading of experience, enabling us to engage the Other on some common ground, while the "strangeness" throws us back upon ourselves and keeps the hermeneutic circle moving forward productively. Fiedler's model does seem, therefore, to describe a hermeneutic circle. The "understanding" of the Freak as a revelation of the "Secret Self," or as a challenge to our preconceptions of the human condition, occurs through an experience in which we are "pulled up short" by the simultaneous "familiarity and strangeness" of an abnormal person. According to Gadamer (1960), the hermeneutic circle results in "Insight" when our experiences have made us realize the falsity and inadequacies of our assumptions, when we are made aware of "the limitations of humanity" because "experience is the experience of human finitude" (p. 357). Similarly, in Fiedler's formulation, in the experience of viewing the Freak one realizes that one's own body deviates from an "ideal" physiology, that there are, in effect, limits to how "normal" anyone's body can be. Or, we realize that our conceptual categories for humanity, such as those regarding scale, do not hold universal currency.

In many ways Fiedler's ideas may be reconciled with Gadamer's assertion that to appreciate the true value of experience one must accept human finitude, in a double sense, as an essential element of the human condition: Experience relies on finitude to produce it and finitude is the self-reflexive object of experience. According to Fiedler (1996), a manifestation of the societal anxiety of physical abnormality is the "Cult of Eternal Youth" that has "driven a population growing ever older and fatter to… popping amphetamines—or removing with the aid of plastic surgery those stigmata of time

and experience once considered worthy of reverence" (p. 156). This so-called "experience," in terms of participation in events over time, marks the body (whether through scars, which speak to an event that touched the body physically, wrinkles, which might be due to stress or an emotional touching of the body, or the alteration that occurs when organic matter ages). Such marks of temporality indicate the truth of the body's past existence, but the obsession with youthful appearances deliberately strives to erase those traces. The "Cult of Eternal Youth" interprets, Fiedler would say mistakenly, aging or aged bodies as unattractive, thus medical technology must elide the evidence of humanity's "finitude." We might say the Cult's proponents presume to be non-human, to set themselves apart from what Heidegger imagined as the essential human beingness in time. From a Gadamerian perspective as well, this effort is strikingly misguided as it represents an attempt to deny the truth of humanity's historicity. Only through the hermeneutic experience, in which understanding occurs, can one realize the fallacy of the illusion that "everything can be reversed, that there is always time for everything" (Gadamer, 1960, p. 357).

In terms of the historicity of human existence, the "Cult of Eternal Youth" demarcates the limit of Fiedler's connection to Gadamer. The Freudian foundations of Fiedler's model of understanding led him to construct theories of experience that differ markedly from Gadamer's sophisticated conception of history and tradition. In attempting to trace the origin of a fascination with human physical differences to determine which came first, living human abnormalities or the imaginative constructions of potential abnormalities in art, Fiedler (1978) explains that we should seek "that psychic need… in depth psychology, which deals with our basic uncertainty about the limits of…our egos…in childhood such uncertainty is strongest" (p. 27). Arising from our "primordial fears," people with physical abnormalities basically represent the return of the repressed, the hidden distressful

feelings of monstrosity that initially arise in the childhood experience of "each sex's early perception of the other's genitalia in adult form," which causes all children to feel freakish either in terms of excess (for males) or deficiency (for females) (p. 32). Fiedler's reading of the experience of viewing the Freak is, therefore, essentialist and universalist. Anyone viewing the Freak at any time, in any cultural context, will necessarily have an experience equivalent to anyone else; after all, the need to view the Freak is "a hunger in all of us" created from primal psychic disturbance (1996, p. 150).

Considering encounters with a Freak from the perspective of a common human experience of freakishness or perceived freakishness allows Fiedler to accomplish two goals. It lends support to his efforts at questioning the very idea of normality as a monolithic category, and it allows him to position himself as an "authority" on disability. If all of us carry a feeling of freakishness buried deep in our psyches, then we must eventually "realize that *there are no normals*" (1996, p. 153). In addition, the notion that freakishness is a common human experience enables Fiedler to speak definitively on the subjects of bioethics and disability, subjects with respect to which, as a literary man, his authority might be questioned. Granted, Fiedler (1996) begins his essay with the disclaimer that he is not a "doctor or a nurse or a social worker...only a poet, novelist, critic," in an ironic nod to the authorities celebrated by those who subscribe to the medical model of disability. If all humanity is in the same psychic condition, the thrust of the essay as a whole argues against a disclaimer that soon appears meaningless (p. 153). Because Fiedler, like all of us, experiences the common human condition of freakishness, he is just as qualified to speak on the subject as anyone else—abled or disabled. Indeed, in his essay, Fiedler frequently incorporates personal anecdotes of his own experiences with "abnormal" people.

A Gadamerian Critique of Fiedler's Model

While Fiedler's arguments about universal human feelings of freakishness, feelings realized with disturbing clarity when one directly encounter the Freak, make the admirable argument for broader egalitarian views of human physicality, they are nonetheless problematic because they fail to take into account the impact of history and tradition on experience. As Gadamer (1960) tells us, experiences and experiencing subjects are always embedded in history, and it is this very embeddedness which allows understanding to occur, for, "To be situated within a tradition does not limit the freedom of knowledge but makes it possible" (p. 361). It is a necessary fact of human existence that "traditions" predetermine how one understands oneself as a subject who can have an experience. Traditions also construct the way in which a text, work of art, or other person is presented as an object for experience, determining the context within which the object will be, at least initially, perceived. Because "we are always situated within traditions," we must realize that our historical foundations "always have a predeterminate influence on any experience," including these that are seemingly subjective. Our "History does not belong to us," Gadamer (1960) stresses, "We belong to it" (pp. 282, 276). Consequently, we also cannot assume that experiences in different historical periods have similar meanings for various participants. To do so would be to assume that "subject" and "experience" are essential categories that remain unchanged by history because they are not constructed by and through history. As historian Joan Scott (1993) argues, experience is not "confined to a fixed order of meaning" but is a "process" the context of which changes significantly over time (p. 409).

Ignoring the fact that history is constitutive of experience, Fiedler grounds his reading of the experience of viewing the Freak in a fundamental and universal egoistic aversion to human difference. As a condition of her or his humanity, ev-

ery human being has encountered him or herself as freakish in childhood and repressed the terrific anxiety of this realization. Such a perspective assumes the preconceptions that one applies to the experience of viewing abnormality are common to all historical periods and contexts. While they may reinforce or reflect general society views of normality, they are not themselves constructed by history. Historical changes only impact ones ability to gain access to the freak or the medium through which one gains this access (side-shows have virtually disappeared from American culture, for instance, but motion pictures are now a dominant visual medium). These historical changes do not, however, influence the core experience itself. An example of Fiedler's extreme ahistoricism may be seen in the governing "iconic" model of abnormality he adopts in *Freaks: Myths and Images of the Secret Self*. In this text he gleans a three-term system of categorizing "monsters" from a Babylonian tablet dated 2800 B.C.E.—a tablet widely believed to be the earliest known written reference to disability—and then uses this system to analyze views of Freaks in fourteenth-century medico-religious interpretations of monsters, the side-show, Victorian fiction, Freudian stages of development, Depression-era cinema, and finally, contemporary medical practices.

The shortcomings of Fiedler's model reveal the advantages of Gadamer's ideas for historical scholarship on disability. While Fiedler's theories about the experience of viewing the Freak, if true, may tell us something about the human psyche, they provide no information about the unique social contexts in which this psyche operates. An example from literary studies demonstrates that the history within which the experiencing subject is embedded is crucial to an understanding of how abnormality gets conceptualized by the nondisabled viewer. Felicity Nussbaum (1997), a scholar of eighteenth-century Anglo women's literature, has discovered that various popular tracts of the period consider "deformities" or "defects of nature" as inclusive of such simple facial features as freckles,

moles, and squinty eyes as well as impairments that today might be labeled more severe congenital conditions. Oddly enough, even virgins were considered "deformed" by some by virtue of the period's attitude towards femininity. As Gadamer (1960), who completely avoided utilizing the most powerful hermeneutic model of his day, psychoanalysis, tells us, the meaning of an object of understanding is always "co-determined also by the historical situation of the interpreter" (p. 296). Does not such a broad conception of abnormality in the eighteenth century indicate not simply a different use of the term "deformity," but an entirely different "situation" or horizon of understanding disability when compared to the present day? Can we say that a person living in eighteenth-century Britain would have even a remotely equivalent "experience" viewing the Fiedlerian Freak as the twenty-first century viewer of a motion picture monster or an individual in a wheelchair on a weekly television drama?

Imagining a more historical hermeneutical consciousness than Fiedler, Gadamer (1960) writes that, "Understanding is to be thought of less as a subjective act," (we might say, merely the return of the repressed for each individual viewer of the Freak), "Than as participating in an event of tradition" (p. 290). Human existence is characterized by its embeddedness in "the continuity of custom and tradition." Thus, the "event of tradition" is an ontological occurrence in the life of the individual (Gadamer, 1960, p. 297). True understanding is not the self-contained operations of a mind discrete from other minds. Rather, true understanding occurs in the larger context of an experience constituted by elements of the human past that have been preserved socially and personally and render present experiences meaningful. Gadamer calls this process the "hermeneutical productivity" of tradition. Consequently, he is also concerned with the way in which our understanding, though conditioned by our traditions, in turn creates new traditions and new horizons of understanding for the future, what he terms the "texture of re-

ciprocal effects" that characterize human experience (Gadamer, 1960, p. 282).

This discussion of the mutually effective relationship of present understanding and traditions, presented in Part Two of *Truth and Method*, represents a further consideration of the purposes expressed in the introduction to the text. Gadamer (1960) writes that his book is meant as a description, a narrative of how the historical "unity of the world in which we live" consists of "the way we experience one another, the way we experience historical traditions, the way we experience the natural givenness of our existence" (p. xxiv). The "way" does not refer to a particular method that produces a monolithic, "correct" interpretation of the world. Rather, Gadamer suggests the "unity of the world," or the primary standpoint from which our understanding occurs at a given moment, is constructed out of the traditions of prior understanding and culturally specific world views of which individuals are the recipients and repositories. This received "unity of the world" is subsequently reformulated by the operation of our processes of understanding, "the way we experience," in the present.

In Fiedler's formulation, the "unity of the world" is constructed by the "desperately" maintained distinction between self and other. We have pre-existent notions of the "normal," and the use of these notions is a means of dealing with the facts of our freakishness and the presence of people who are simply born radically different than others. Though these elements construct the foundations for knowledge of our "normal" world, Fiedler does not present the "unity" itself as historical in the Gadamerian sense. As a result, he fails to admit that this unity, and therefore any understanding of disability, will change over time due to the "texture of reciprocal effects" between tradition and understanding. For example, after Fiedler discusses cosmetic or so-called corrective surgery as a modern medical response to human freakishness, he concludes that eventually only the economically poor will be freaks because they will

be the only ones unable to pay for de-freakment procedures. Yet Fiedler's conclusion really only addresses demographic realities, identifying how the category of "Freak" might undergo a shift in the population. He does not, however, consider the potential for alteration in the understanding of freakishness itself, due to a mutually effective relationship between traditional notions of human difference *and* poverty, and present experiences with medical technology.

A future in which "correction" of all deformities is possible would of necessity disrupt "the way we experience the natural givenness of our experience" and therefore alter profoundly our understanding of abnormality itself. As a result, the other elements that compose the unity of our world would also change, particularly "the way we experience one another." In Fiedler's model, our traditions cast deformity in a pejorative light because it is a primal source of personal anxiety and fear. Furthermore, our new experiences with technology in the modern era have encouraged us to believe deformity does not have to be part of the "natural givenness of our existence." Even assuming Fiedler's model to be accurate in these assessments, abnormality would still necessarily be experienced in relation to a different horizon of understanding. In Gadamer's (1960) terms, each person will have "acquired a new horizon within which something can become and experience for him" (p. 354). In this hypothetical future world, might we not in fact come to read a disabled person whom we encounter as either exhibiting the "vices" of the poor ("she is too indolent to earn the money to correct her deformity"), morally weak ("she has not made the effort to improve herself"), or irrational ("technology has enabled her to change herself if she chooses, so how could she possibly wish to do otherwise")? Failure to correct a deformity could even come to be coded socially as indicative of a psychological disorder, reflecting depression, low self-esteem, or anti-sociality. In such a ghastly future the unity of the world would undergo an alteration. The potential for enforcing the distinction between

normality and abnormality can be imagined as increasing via socio-political and technological mechanisms of control. To borrow a phrase from Harlan Hahn (1987), "The contours of [one's] perceptual range [would] narrow" as the concept of "normalcy" would become ever more solidified. Indeed, Hahn has argued persuasively that contemporary mass media and advertising have already produced this social and psychological effect.

While Fiedler ignores the dynamic interaction between tradition and understanding, Gadamer (1960) both theorizes and discusses its revolutionary potential. In the words of the latter, "Tradition is not simply a permanent precondition; rather, we produce it ourselves inasmuch as we understand, participate in the evolution of tradition, and hence further determine it ourselves" (p. 293). Just as we cannot assume the individual's understanding of physical abnormality is the same across different historical periods, we cannot assume the traditional structure within which "the Freak" gets understood is fundamentally unchanging. Though ones encounter with human physical difference at the present time is conditioned by tradition, it may also in turn contribute to the construction of the conceptual structures and societal conditions that determine how such difference will be encountered and, on a more basic level, considered "freakish" in the future. Certainly, then, age-old conceptions of monstrosity could affect us today. In Gadamer's conception of the relationship between tradition and experience, each encounter with disability also offers the opportunity for revising not only the present encounter but the "horizon" of understanding carried into and shaping future experiences. From this perspective, there is great potential and hope for realizing the alteration of social constructions and perceptions. Even dominant, politically powerful, and seemingly unassailable perceptions of human physical difference can be changed.

As Gadamer (1960) observes, even at the individual, subjective level, "one's experience changes ones whole knowledge…we cannot have the same experience twice" (p. 353). The hermeneutic circle is, as its name suggests, a figure of continual motion. Because the understanding of the interpreter is continually being re-shaped through experiencing an object, her "discovery of the true meaning" of an event "is never finished" (Gadamer, 1960, p. 298). These unending operations of understanding constitute "truth." Like Joan Scott, Gadamer (1960) argues that "experience is a process…It cannot be described simply as the unbroken generation of typical universals," largely because "universal" is itself a fore-conception or prejudice and fore-conceptions are necessarily questioned, altered, reconfigured and/or rejected in the course of the hermeneutic experience (p. 353). We might argue, therefore, that one of Fiedler's primary conceptual errors lies in his assumption that the Freak "means" the repressed Secret Self. His model of the experience of viewing the Freak describes the discovery of what has remained buried, and once this meaning has been recovered, the experience is complete and terminated. Without the recovery of the repressed truth of common human freakishness—a recovery that serves to elide rather than recognize, accept, and understand difference—there is no experience. Thus, each experience of the Freak essentially conveys the same information. Yet, as Gadamer (1960) teaches us, "truth" lies not in a definitive and recoverable meaning but in the process of understanding itself. An experience has "its proper fulfillment not in definitive knowledge" but in openness to the ways in which ones understanding can be changed after encountering the claims made by the Other (p. 355). Understanding is not something a person "has" or something that can be recognized as the property or province of a single individual but is continually unfolding. In reality, after experiencing the realization of our own freakishness, our next experience of the Freak should be fundamentally different. It is through this continually chang-

ing interaction that we truly understands our-selves and the "abnormal" Other as well as the dynamic relationship between the two.

"Openness": Gadamer's Vision of Interpersonal Encounters

For Gadamer, such dynamic relationships are significant because he believes all experience has a dialectical element, a quality of dialogue and exchange. Understanding occurs through a process where we develop, in Gadamer's words, "The truth that becomes visible to me only through the Thou, and only by my letting myself be told something by it" (Gadamer, 1960, p. xxxv). In some ways, Gadamer's descriptions of experience as dialectical are restatements of his basic arguments about understanding. We approach an object with our own preconceptions and horizon of understanding (the first term of the dialectic) and engage the ways in which the object of experience contests or confirms these preconceptions (the second term of the dialectic). This view of experience is, for Gadamer, profoundly ethical. It prompts the call made in the forward to his text for human understanding based on "dialogue" rather than Platonic logic. This approach demands "openness" on the part of the interpreter of any experience. If experience is dialectical, it follows that "we cannot stick blindly to our own fore-meaning about the thing if we want to understand the meaning of another" (p. 268). To do so is to reject the possibilities for the object of experience to influence and change our preconceptions. Instead, "All that is asked is that we remain open to the meaning of the other person or text. But this openness always includes our situating the other meaning in relation to the whole of our own meanings" (p. 268). Given our embeddedness in history, we can never stand completely outside of our own situation and view the Other on its own terms. But if we did not remain within our subject position, we would have no stand-point from which to understand the Other at all. This recognition constitutes Gadamer's critique of historicism. To maintain the integrity

of the dialectic for both participants, one must also recognize and accept the fact that the Other always occupies a position of radical difference from oneself; that is to say, in the case of an experience with another person, one must always allow the Other his or her unique subjectivity.

In *Truth and Method*, these ideas about the dialectical element of experience are often advanced as part of discussions about interpreting texts or works of art. As a result, Gadamer's ideas about hermeneutic understanding have been criticized for being overly academic. Some critics contend Gadamer's theories of dialectical experience fail to account adequately for the dynamic relationship between two human agents. Consequently, Gadamer is taken to task for supposed failure to consider the operations of power and authority in the practice of hermeneutics. However, when Gadamer's considerations of human interaction are compared with Fiedler's—the latter of which seem preeminently concerned with humanity, human response, and the authority and power of norms—it is apparent that Gadamer develops an astute and humane vision of the interpersonal, dialogical aspects of hermeneutics. In Gadamer's view, human finitude continually provides a check upon the ego by reminding us that we can never fully elude our limitations. Furthermore, his discussions of interpersonal experiences are closely related to considerations of the exercise of power and subjection. Fiedler, on the other hand, continually and uncritically figures the Freak as an object for speculation rather than as an individual participating in experience.

Gadamer realizes fully that hermeneutics takes on a unique character when it involves two minds because both are simultaneously the interpreter and the object of interpretation.[5] Unlike an encounter with a text or work of art, "This kind of experience is a moral phenomenon—as is the knowledge acquired through experience, the understanding of the other person" (p. 358). For Gadamer, it should be stressed, "the moral" is not Kantian or Protestant (that is, dependent

fundamentally on the private, internal conscience) but emerges out of mutuality, out of interpersonal relations. If experience is dialectical, each participant in the dialogue must affect, and be affected by, the other's claims to truth or no genuine and useful understanding or experience occurs. Each person who encounters and interprets another must learn something not only about himself but about the other person on the other's own terms. This means accepting the other person as a unique individual embedded in her own context and traditions. When the participants of an interpersonal encounter do not carry on a dialogue of historically transmitted and determined communication, they do not engage in a productive experience. Instead, a single pole of the interaction, or each pole separately, establish the rigid but fallacious categorization of himself as sole interpreter. The other person is an object for, but not of, interpretation. In such a case the interpreter, as Gadamer contends, "himself cannot be reached" (1960). The interpreter's sole objective is to gather information while making his "own standpoint safely unattainable" (p. 303). When an individual refuses to remain open to the "otherness" of the other person and refuses to allow that his own preconceptions might change as a result of learning from the other, the interpersonal encounter fails to produce any "understanding."

The Problems of Interpersonal Encounters with Disability

Interpersonal encounters may also be prevented from being truly dialectical, according to Gadamer (1960), when "the Thou is acknowledged as a person, but despite this acknowledgement the understanding of the Thou is still a form of self-relatedness" on the part of the viewer-interpreter (p. 359). Such an approach can generate a situation in which, "One claims to know the other's claim from his point of view…In this way the Thou loses the immediacy with which it makes its claim… it is co-opted and preempted reflectively from the standpoint of the other person" (, p. 359). Understanding is displaced in favor of appropriation. The "immediacy," (or in this statement, the lack thereof), refers to the uniqueness of a true experience where one sees the other person as an individual distinct from, and unassimilable to, oneself. When Gadamer writes that in a "one-sided conversation" the other's immediate claim is "co-opted and preempted reflectively," he advances two significant arguments. First, because the individual viewing himself as the experiencing subject assumes the other merely tells him about himself (as in Fiedler's model of the nondisabled viewer's encounter with disability), the other functions solely as an object, a mirror. As Gadamer later writes, "A person who reflects himself out of the mutuality of such a relation…destroys its moral bond." This is true because he does not accept the deeply human "mutuality" of two individuals existing in the same position of subjecthood but only grants such subjecthood to himself (p. 360). Second, the experiencing subject comes to assume he can see through the other's eyes and thus anticipate the other's claims, even before any such claims are made. The other can only speak by serving as a mouthpiece for the interpreter. Moreover, "The claim to understand the other person in advance functions to keep the other person's claim at a distance" (p. 360). The "standpoint" of the interpreter, perceived to be a position of intellectual power and authority, remains "safely unattainable" while the other and his or her claims remain essentially in subjection to the interpreter's conceptual horizon. Not only is this colonization of the other's subjectivity typically a problem for academics studying minority cultures, it also lies at the heart of humanitarian socio-political efforts to "help" people with disabilities while excluding these people's participation in such efforts.[6]

When, after reading Gadamer on the dialectical elements of experience, we reconsider Fiedler's depiction of the experience of viewing the Freak, this description appears non-dialectical and therefore extremely problematic. Fiedler's model is rigidly self-reflective. The viewer engages the abnormal individual, is confronted

with his own fore-conceptions about normality and his own buried and anxious deviations from it, and finally comes to see the Freak as a representative of his own repressed "Secret Self." While this model resembles a hermeneutic circle, the viewer in fact learns nothing about the Other on the Other's own terms. In a way that would make Gadamer shudder, Fiedler's hermeneutic circle only makes one pseudo-revolution. The experience collapses into narcissism, and Fiedler's model recognizes no "claim to truth" the Freak can make that is not predetermined in the interpreter's psyche. The Other is either "like me" or "unlike me" while the "me" itself is never really challenged or dislodged. The one-sidedness of this encounter, in which the Freak serves only as the catalyst for the self-education of the non-disabled viewer, parallels the subject of contemporary criticisms of the "individualistic" and "moral" modes of disability. The non-disabled majority often places the responsibility for bringing the world closer to the "essential truths" of humanity squarely on the shoulders of people with disabilities. The mentally retarded must reveal "true innocence" and the paraplegic the potential for triumph over adversity. This is necessary to attain some, albeit a limited, measure of social validation. The unique identity and historical traditions of the person with a disability are elided by the "larger meaning" relevant to all members of society that he or she is assumed to represent.

For Fiedler, particular differences in a viewer's experiences of Freaks are attributable simply to general categorical differences. Hermaphrodites call attention to our anxieties about sex but not scale, while Dwarfs and Giants call attention to our anxieties about scale but not sex. As previously noted, in Fiedler's text the essence of the experience of viewing the Freak is first an act of discovery—the recognition of the return of the repressed—and then an act of colonialism—taking over the Other and making it serve the self. It is decidedly not, however, a singular dialectic formed at a unique historical moment in which two people engage one another in a pro-

cess of mutual understanding. In Gadamerian terms, an encounter of this sort is not a true experience because, with only one recognized hermeneutical consciousness present, there can be no dialogue. The viewer Fiedler describes does not have to struggle to situate himself "in relation to" the other's claims to truth (as Gadamer would say) in the course of having an interpersonal experience. Conversely, the Freak's understanding does not undergo any complementary process, as Fiedler does not see the Freak *interacting* in the experience as an individual whose traditions, claims and identity may be distinctly different from those of the viewer. In fact, the viewer never needs to speak to, question, or even simply listen to the physically abnormal Other to have a meaningful experience and achieve self-understanding.[7]

Fiedler's theoretical model denies the Freak a dialogical role. At the most fundamental level, the model assumes the experience occurs when one of the participants is considered "normal." The spectator who encounters a Freak is able to have an experience of understanding because the feelings of freakishness buried "in the depths of our unconscious" are brought to light (Fiedler, 1996, p. 152). For these feelings to be repressed in the first place, however, the spectator must have developed a sense of self based upon an assumption of "normality." Fiedler thus fails to address the crucial question: how would a spectator with a disability, who already knows he or she is considered freakish, experience an encounter with another physically abnormal individual? Presumably nothing would happen, no shock and no recognition, nothing about which to theorize. Thus, freakishness is only significant when, or because, it comes into contact with the "normal," and the fundamental experience theorized in *Freaks* and *The Tyranny of the Normal* necessarily assumes a non-disabled spectator and a disabled object. Ironically, then, Fiedler's model of the experience of viewing the Freak can be disrupted by the introduction of physical difference.[8] The unaccounted-for body in his model is the abnormal body situated as

something other than an object of perception. I would suggest at this point that it is precisely this disruption of models of normalcy through the process of "coming into subjecthood" as a person with a disability that characterizes some of the best creative writing on physical difference, such as Christy Brown's *My Left Foot* (1954) and Jean Stewart's *The Body's Memory* (1989).

It is somewhat surprising that Fiedler neglects to consider the experience of viewing the Freak could be dialectical. He makes a point of stressing that the loss of the circus sideshow in American popular culture and the rise of mass media representations of physical difference represent a loss of experiential contexts in "which full-grown oddities have looked down out of living eyes to meet the living eyes of the audience." A "loss of the old confrontation in the flesh" Fiedler (1978) views, nostalgically, as also producing the less subversive encounters with physical abnormality in the image-dominated late-twentieth and early twenty-first centuries (pp. 18, 16). Unfortunately, Fiedler fails to address his ideas to the abnormal individual behind the "living eyes." How do the dynamics of experience change when the Freak understands him or herself as being seen and subsequently communicates this recognition to the nondisabled viewer? When we do not direct our inquiry and communication towards the abnormal Other in any encounter—theoretical or otherwise—such powerful, significant, and provocative questions are not pursued.

I would suggest the primary reason for this absence, in Fiedler as in other academic inquiries into disability, lies in a failure to preserve the otherness of the physically different individual. According to Gadamer, understanding cannot truly occur unless a hermeneutic consciousness is put in dialogue with an Other whose integrity as other is maintained. This consciousness "must be, from the start, sensitive to…alterity" so the Other "can present itself in all its otherness and thus assert its own truth"; otherwise, there is no dialectic (Gadamer, 1960, p. 261).[9]

For Fiedler, the notion of "otherness" is only important because of its role in the interpreter's repression. Unless one initially sees the Freak as radically abnormal, one does not attempt to reconcile this fore-conception with the contradictory element of the Freak's humanity. It is in the course of this mental struggle that one realizes the Freak reflects the co-existent humanity and freakishness of ones Secret Self. Fiedler thus ultimately desires a realization that the viewer and the Freak share a common human condition, "that *there are no normals*," that, at heart, everyone is the same (Fiedler, 1996, p. 159). In the final analysis, Fiedler's arguments serve to reject the otherness that could serve as a basis for Gadamerian dialogue. While Gadamer calls for us to accept and understand that some differences between ourselves and others cannot be breached entirely, Fiedler attempts to disabuse us of our "illusion" that people with disabilities are different from "normals." In *The Tyranny of the Normal*, experience involves piercing through the façade of an otherness that operates as a psychic shield (like Freud's Dream Work, as described in *The Interpretation of Dreams*), preventing us from realizing the truth that would liberate humanity. In the Fiedlerian universe, the preservation of otherness is profoundly bigoted and immoral.

The Promises of Interpersonal Encounters with Disability

Truth and Method reminds us, however, that we should be wary of collapsing distinctions of identity, of asserting that there really are no "abnormal others." As Gadamer demonstrates, when we do not appreciate an otherness that is "*against me*," we do not really allow the other's claim to "say something," because we have "always already smoothed [them] out beforehand" (p. 361). Put another way, the varying claims to truth made by people with disabilities are not interchangeable, and each disabled person's statements cannot be enlisted solely in the service of developing nondisabled people's self-con-

sciousness and confirming their predetermined assumptions.

As British sociologist and disability rights advocate Michael Oliver observes (in a book published the same year as Fiedler's *Tyranny of the Normal*), on a quotidian level people with disabilities are consistently oppressed by a mainstream society that refuses to considers its traditional assumptions and disability as engaged in a dialogue. As part of a devastating critique of the "medical model" of disability, Oliver (1996) points out that physicians continue to be socialized to believe they are disability "experts" and subsequently "impose" medical treatments on disabled people who were never consulted about their physical needs. When disabled people choose to actively "criticize or reject this imposed treatment," these medical professionals "appear bewildered" (p. 36). Such bewilderment at the disruption of a one-sided interaction reflects the surprise the Fiedlerian viewer might feel if the Freak suddenly opened his mouth and spoke of the aspects of his experience that emphasized the radical differences between his life and the viewer's.

Moreover, Oliver (1996) argues that academic studies of disability have "consistently failed to involve disabled people except as passive objects." By "using the [disabled] person for someone else's ends—the person's actions do not belong to that individual, but to the researcher" (pp. 139, 140). We should be reminded at this point of Gadamer's statement that one must be open to other people "not in the sense of simply acknowledging" their, sometimes radical, difference from ourselves, "but in such a way that [they have] something to say to me" (p. 361). It is therefore fitting that Michael Oliver's solution to the problem of society's failure to address the needs of disabled people involves developing new interactions between non-disabled and disabled people based on "reciprocity [and] establishing dialogue" (p. 141). Thus, we must continue to work, in the words of the Modern Language Association's Conference on Disabil-

ity Issues in the Profession (2004), to "Recruit faculty members, staff members, and students with disabilities." We must also ensure, as Paul K. Longmore (2003) has recently written, that academic inquiries occur, "Between the disability community and research universities…The traffic of ideas and persons…should flow in both directions…The disability perspective, the insights, experience, and expertise of people with disabilities must inform research" (pp. 1, 223). Gadamer helps us understand that such a "dialogue" is not only crucial for genuine and productive human experience, but also a question of morality.

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Endnotes

[1] For recent examples of such interdisciplinary work, one might consider Susan Wendell's contributions to philosophy and women's studies, Martha Edwards' work in classics, Brenda Brueggemann's scholarship in rhetoric, and the recent History of Disability series launched by NYU Press and edited by Paul K. Longmore and Lauri Umansky.

[2] It may be important at this point to state that my choice of texts is not meant to imply that Leslie Fiedler's work on disability is especially worthy of negative criticism or that Hans-Georg Gadamer is the most useful philosopher for Disability Studies. Rather, both of these authors have produced highly imaginative, provocative, and at times sensitive works which, in my estimation, are well suited to an exploration of the particular issues I wish to discuss in this paper.

[3] For another discussion of how people with physical differences challenge conventional beliefs about humanity, see Elizabeth Grosz, "Intolerable Ambiguity: Freaks as/at the Limit," in Freakery: Cultural Spectacles

of the Extraordinary Body, Ed. Rosemarie Garland Thomson is the title here APA style? (New York: New York University Press, 1996).

[4] Paul K. Longmore discusses the manifestation of, and often the justification for, such fears in popular media in, "Screening Stereotypes: Images of Disabled People in Television and Motion Pictures," Social Policy 16 (1985): 31-37. APA?

[5] Similarly, Hegel claims one only achieves true self-consciousness when the "object for consciousness" is the consciousness of another person.

[6] For disability rights assessments and critiques of such movements, see James I. Charlton, Nothing About Us Without Us: Disability Oppression and Empowerment (Berkeley: University of California Press, 1998) and Joseph P. Shapiro, No Pity: People with Disabilities Forging a New Civil Rights Movement (New York: Times Books, 1993). For discussions of telethons as essentially "co-opting" the (perceived) claims of disabled people see Paul K. Longmore, "Conspicuous Contribution and American Cultural Dilemmas: Telethons, Virtue, and Community." In Discourses of Disability: The Body and Physical Difference in the Humanities. Ed. David Mitchell and Sharon Snyder. (Ann Arbor: University of Michigan Press, 1997) and [Anne Peters, "Telethons," The Disability Rag (May 1982). Page #s] APA?

[7] Gadamer does not use the term "dialogue" to refer solely to verbal communication but emphasizes there must be some interchange of ideas between all the actors of an experience.

[8] For a consideration of how deafness can disrupt contemporary literary and critical theory, see H. Dirksen L. Bauman, "Toward a Poetics of Vision, Space, and the Body: Sign Language and Literary Theory." In The Disability Studies Reader, Ed. Lennard J. Davis. (New York: Routledge, 1997). APA?

[9] As previously noted, Gadamer derives this idea, in part, from Hegel's Phenomenology of Spirit, specifically the second on the master-slave dialectic which demonstrates there is no self-consciousness without an encounter with another self-consciousness.

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REVIEWS

Book Review

Title: *The Sibling Slam Book: What It's Really Like to Have a Brother or Sister With Special Needs*

Editor: Don Meyer. Foreword by David Gallagher.

Publisher: Woodbine House, Inc., Bethesda, MD, 2005

Cost: $15.95 USD

Reviewer: Christine Su

While academic and medical textbooks on disabilities abound, and more recently, authors have created children's books to demystify disabilities to youngsters, *The Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs*, is an innovative work, intended specifically for teenagers who have siblings with disabilities and/or special needs. The format of the book follows what might be a typical "slam" book format: Each individual receives the slam book, a simple notebook filled with questions about teen-specific issues and spaces for replies, and he or she can add personal responses to those questions—be they angry, joyful, droll, or somber—to those already entered. While in *The Sibling Slam Book*, the text itself is typed, the entries are in different fonts (representing different handwriting styles), and some cross the paper's printed lines, often stretching into curves or looping into circles of text, as handwritten entries might. *The Sibling Slam Book* is an enjoyable, insightful compilation of the thoughts and feelings of teenage siblings without disabilities, eighty of whom collectively author the work, as they navigate daily life with their brothers and sisters with special needs.

Recent news reports have broadcast various debates surrounding "myspace.com," a website where teenagers can upload their own photos and profiles, and post comments about teenage life, on topics ranging from musical interests to trendy fashions, from romantic intrigue to peer pressure. Parents worry that teens posting their lives on the Internet for all to see is irresponsible and even dangerous. Teens counter that the site provides them with a venue to meet peers with whom they can discuss what is on their minds, to talk about things they cannot or will not share with parents or teachers.

The Internet may have helped myspace.com to flourish in the 21st century; however, the concept of a "teens-only" space—and the value of such space--is certainly not new. Middle school and high school teens have been using slam books to voice their thoughts and feelings for decades. Furthermore, in slam books teens not only record their own words, but also read the responses of others, many of whom have faced similar situations and experienced similar feelings in reaction to such situations. The unwritten rule that the slam book is a nonjudgmental, free space for expressing oneself means that the responses are usually frank—in response to the question, "What's the toughest thing about being

a sib?" for example, a *Sibling Slam Book* author writes: "The responsibility definitely stinks. I get few privileges for all the work I do for my family and my little brother" (p. 141). They are also poignant: "[I]t is the uncertainty, not knowing what's coming next, and the feeling of vulnerability if something does happen and that you're open to being really hurt," writes another. "Also, not knowing if my little brother will wake up the next morning or when a kiss I give him will be the last" (p. 141).

The book's simple question and answer format allows the reader to compare and contrast sibling perspectives on a plethora of issues—some disability-related, some more generally teen-related. Importantly, the *Sibling Slam Book* asks questions about the advantages of having a sibling with a disability, and some of the answers reveal teens' great pride in their siblings' resilience. "He's my special light in the darkness," writes the sibling of a brother with special needs, "There when all other lights go out" (p. 134). These responses offer support to others who may not receive such reassurance from school peers or friends who do not understand their circumstances. I call this book a reference work, for while it does not offer dictionary definitions or historical descriptions, it does provide, through its list of questions, an index of topics that teens can explore based upon the questions they have at a particular time.

The Sibling Slam Book may not offer new theories or medical breakthroughs, yet it is informative and would serve as a good resource for courses on disability culture as well as for teens' libraries. This heartwarming, honest, and humorous book will appeal to parents, teachers, practitioners, and others who seek to broaden their understanding of teen siblings' experiences with brothers and sisters with disabilities. It is definitely worth the price, and moreover, as suggested by the editor, himself the creator of hundreds of trainings for families of children with special needs, some or all of the fifty-four questions included in the book can be used to spur discussion in similar workshops or classroom sessions.

Book Review

Title: *A Reason for Living*

Author: Laurent Grenier

Publisher: Nardis Press, 2004

ISBN: 1589611659, 212 pages

Cost: $12.95 USD

Reviewer: Arlie Taganuya

Disability study is an evolving discipline. The postmodern turn in the United States academe in the 1960s onward has shifted a great degree of sensibility and sensitivity to issues confronting people with disabilities. A central preoccupation of many contemporary scholars is to capture the everyday and the institutional experiences of people with disabilities. However, most production of disability discourses and ideas are monopolized in universities, research institutions, and other social agencies; failing to incorporate stories of people with disability as a legitimate voice in providing knowledge. Laurent Grenier's (2004) *A Reason for Living* is an addition to the sparse body of literature responding to the institutional centrism of disability scholarship and putting forward voices previously silenced in academe.

This self-published book is an autobiographical sketch of the author's saga living with spinal injury after a diving accident when he was 17 years old in his native Canada. As the title suggest, this book is about finding a new purpose when disability strikes later in life. In what may appear to be another inspirational story, the book provides a rich ethnography and critical narratives of the ever present psychological battle and the societal reaction of a person living with spinal injury, how he deals the varying challenges of his new disability, and how he creates symbolic meaning that may ameliorate his daily struggle.

Laurent Grenier does an outstanding job describing the emotional stages he experienced after his accident. The first three chapters describe Grenier's early struggle over his disability, his sense of

denial and the frustration of being in a medical institution while recuperating and being housed in a long term assistive living. The feelings of bitterness, death-wishes, and the ignorance of people about his condition became his self-inflicted worries and mental preoccupation for years.

The remaining two chapters are the central tenet of his book. Grenier's introduction to poetry, art, and philosophy gave him a breakthrough to rediscover his creative expression, new-found athleticism, and social engagement in bringing up issues that affects people with disabilities. Through his poetry, Grenier was able to articulate his social difference and rebound from his feeling of hopelessness to mental victory.

Grenier's book does moral work in a number of ways. First, it provides readers deeper insights of the personal struggles of a spinal injury survivor and engages them through Grenier's lucid depiction of a contextual experience inside an institution. Second, it opens up a critical dialogue on how our systems of care and policies fail to provide the optimum space to empower people with disabilities to become active participants in our society. Although Grenier's story magnifies the importance of personal psychological change, it is in the change of people's reaction and other societal structures that make Grenier's living more meaningful.

The epic-like structure of the book allows the reader to follow clearly his personal journey. However, the book is organized broadly. Often chapters swing from his personal experience to his philosophical insights. This style of writing attempts to connect reality and the metaphysical and may not be for everyone. But Grenier's command of the language provides a more profound pictures and insights for his readers.

The detailed table of contents needs to be reflected as subheading in the main text. This allows the readers to have a clear idea of the logical flow without referring to the table. Yet, this minute flaw does not diminish the book's importance, especially for those who are studying the emerging discourses in disability studies or simply readers wanting to be inspired. The book is not short of realism and essence. It anchors hope and transformation to ordinary lives with or without disability. It is a must-read.

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Book Review

Title: *Deaf Identities in the Making: Local Lives, Transnational Connections*

Author: Jan-Kare Breivik

Publisher: Gallaudet Press, 2005

Cloth, ISBN: 1-56368-276-1, 220 pages

Cost: $49.95 USD

Reviewer: Steven E. Brown

Breivik, a Norwegian anthropologist, became interested in studying issues of deafness and Deaf culture in the 1990s. He learned Norwegian Sign Language and immersed himself in Deaf cultural events, both in Norway and around the world. The result is a fascinating book that examines deafness and Deaf Culture from local and transnational perspectives through the life stories of ten deaf individuals.

The ten stories that are shared with readers have commonalities and differences, but all relate tales of oppression from a dominant hearing culture. The controversy around Cochlear implants is a large part of the story, as is the ambivalence contained in both being a minority and representing a minority status. Breivik starts a quote from one individual by stating:

"At college, she was the only deaf student. Being once again immersed in a hearing world was a big challenge:

'In the beginning of the first year at the teacher's college, I rediscovered that being with hearing people was not an easy thing for me. To talk one on one was OK, but in groups, I was lost and fell out. For the first time in my adult life I realized that I didn't accept my deafness, and that I wanted to be a hearing person' (p. 128).

Another participant expressed shock at her reaction to giving birth to a child who is deaf:

'When he was diagnosed as deaf, I had a shock which lasted for half a year! This was something quite different. We had hoped for hearing children, thinking about what was best for the child in society. To be within the deaf community is safe and good, but we are a small minority with restricted opportunities, compared to the hearing society' (p. 139)."

Another individual summarizes the heart of the stories related in the book in the following two questions: "The all-important questions were: Where is my world? Where do I really belong?" (p. 169).

Like elsewhere in the world, cultural ambiguities revolving around who is deaf and who is Deaf are revealed in this work in a variety of ways. What is most interesting is how these conflicts are often assimilated into the personalities of the individuals whose life stories are being related. Breivik's tale of coming to terms with deafness, identity politics and the local and transnational characteristics of the Deaf culture form an absorbing read that could be used in a variety of disability studies and multicultural courses and would be an excellent addition to any library.

Book Review

Title: *Too Late to Die Young: Nearly True Tales from a Life*

Author: Harriet McBryde Johnson

Publisher: Picador, 2005

Paper, ISBN: 0-312-42571-6, 261 pages

Cost: $14.00 USD

Reviewer: Steven E. Brown

Too Late to Die Young is one of the best entries in the growing field of autobiographies published by disability rights activists. Johnson may well be the best-known activist in the country to the mainstream public because of her articles in *The New York Times Magazine*. The first of those articles is, "Unspeakable Conversations," about her fascinating interactions with philosopher, and proponent of killing babies with disabilities, Peter Singer, forms one book chapter. Just as fascinating is the following chapter, "Art Object," which is a narrative of how the pictures accompanying the preceding chapter came to exist.

I confess to prior knowledge of both these chapters. Harriet is a longtime contributor to a media listserv on which she has regaled us with her publishing exploits as they developed. This almost led me to skip "Unspeakable Conversations" in this book because I had read it before, both in some draft forms that she shared on the listserv and in *The New York Times Magazine*. I am glad I did not. There is a difference in reading these pieces in the context of this book. There is also the joy of reading the writing of a true Southern storyteller, who wraps her words around her topics, and visa-versa; who sometimes meanders, but never pointlessly, and always takes the reader back to her particular worldview.

Johnson is an attorney. She is also someone born with, as she puts it, a neuromuscular disability. Like many children with disabilities she feared she would never see adulthood because she did not see adults with disabilities like hers.

This is one reason she became an early protester against telethons. She describes these protests with relish and the reader almost feels like they are in Charleston, South Carolina, her home and one of her loves.

This is a book full of drama, on both the large and small stage. Johnson talks about her childhood, her use of and interactions with personal assistants, a political race she lost, and many other topics of a life. And that is her BIG point: With or without a disability, we all have lives of many parts. One of the descriptions I liked best was of a quiet moment:

"Geneva brings me my breakfast and then gives me a bedpan and then washes me, starting with the nighttime crusts in my eyes, all the way down to the spaces between my toes, and everything in between. It's a daily necessity, entirely practical and matter-of-fact. I sometimes think how strange it would be to do these morning things in solitude as nondisabled people do, and to regard, as many of them do, a life like mine as a dreadful and unnatural thing. To me it is so natural to feel the touch of washcloth-covered hands on flesh that is glad to be flesh. (p. 251)

There is so much to read these days I usually plow through whatever I can. But this is one of those books so compelling I can foresee going back to it again and again. It belongs in every library, every disability studies program, and beyond. Find a copy; read it!

Book Review

Title: *Eavesdropping: A Memoir of Blindness and Listening*

Author: Stephen Kuusisto

Publisher: W. W. Norton, 2006

Cloth, ISBN: 0-393-05892-1, 244 pages

Cost: $23.95 USD

Reviewer: Steven E. Brown

I have not yet read Kuusisto's earlier memoir, *Planet of the Blind*, so I picked up *Eavesdropping* only knowing that many of my colleagues have raved about the author's way with words. I agree. I found *Eavesdropping* delightful. Kuusisto writes prose like the poet he is. In two sections and twenty-nine essays he explains what it is like to spend moments and days in auditory "sight-seeing."

My self-perception is as a visual and tactile learner so I wondered how I would relate to a book called *Eavesdropping*? As it happens I read most of the book during a 2006 day Hawai'i experienced an earthquake and O'ahu lost all its electricity for many hours. At one point during that unusually quiet day I purposefully listened and realized I heard wind blowing through trees; pedestrians walking and talking; cars going by; neighbors' voices; and other sounds to which I generally do not attend. I also realized I did not hear the hum of a clock, refrigerator, TV, VCR, DVD player. I did not go on the computer all day, so I did not hear any of its sounds. We had no way to cook, so I missed all those sounds. But I did hear the following languages spoken: English, German, and Spanish. That is not unusual where I live. What is unusual is we all sat outside in the dimming light and conversed (including listening) for hours, while we awaited the return of electricity and our routine lives.

I found the descriptions of how Kuusisto listens to be fascinating. He describes his early delight, as a lonely boy, finding Caruso records in an attic. Caruso and his music continue to be a theme woven throughout the book. He also depicts what it is like to stand in a forest and listen to the sounds surround him. Kuusisto is adept at taking what many of us consider everyday sounds and exploring them in depth. The wind at a New York intersection is one such adventure. "I was working my way south on Fifth and eavesdropping as I walked…Then I was standing in the strange white noise of the west- going-to-east Hudson River wind" (p.

82). The narrative about this corner continues for the next two pages.

Much of *Eavesdropping* revolves around travel. Kuusisto describes travels as close by as the gift of a transistor radio and as faraway from his Ohio home as Iceland, among many other journeys. *Eavesdropping* is in many senses a travelogue—from learning as a young boy to travel outside of his apparently unhappy home; to physical travel as a blind man in venues as diverse as a concert hall in Reykjavik to a baseball game in Boston (and others in various cities); to a diner in Texas. Along the way, Kuusisto regales us with what he hears, imagines, and supposes.

Eavesdropping contains the kinds of stories that everyone wants to hear: informed, stylish, entertaining, and educational. The book belongs in libraries and at the very least in graduate programs about disability and literature.

Book Review

Title: *My Body Politic: A Memoir*

Author: Simi Linton.

Publisher: The University of Michigan Press, 2006

Cloth, ISBN: 0-472-11539-1, 246 pages

Cost: $25.95 USD

Reviewer: Steven E. Brown

Linton, well known in disability studies circles as the author of the groundbreaking, *Claiming Disability: Knowledge and Identity* (1998), takes the reader on a harrowing and redemptive journey through life as a young adult who acquired a spinal cord injury in the early 1970s, and as a disability scholar of the twenty-first century.

As Linton often explains this was not a simple journey. Aside from the tragedy of how she became injured, society itself was not nearly as friendly to individuals with disabilities forty years ago. Linton undergoes many transformations described within this memoir, yet maintains her outrage at what she perceives as injustice. When she is discovering disability studies, she explores a typical conversation:

"We would also talk about how ostracism is so often viewed as a natural, inevitable response to disability. It is said that disability makes non-disabled people anxious. Yet what is usually not discussed is whether those reactions really are inevitable. What situations allow those feelings to flourish? What is morally wrong with such ostracism, and what is undemocratic about such segregation? What can we do to change people's response, or show them that it is unacceptable to act on such feelings? Can integrated communities, schools, and work environments alter such behavior?" (p. 119).

One of the most interesting parts of the book comes from Linton's evolution to the use of a motorized wheelchair. As anyone who has gone from a manual wheelchair to a powered one knows, there are additional barriers to surmount. Linton discusses this from the perspective of interdependence and states:

"I don't feel the need to thank the federal, state, or municipal governments as abstract entities for the accommodations provided to me and other disabled people, as I believe they are our due, but I do feel the need to acknowledge the bus drivers, shopkeepers, bathroom renovators, Braille sign makers, curb cutters, door wideners, TTY installers, lawmakers, policy setters, and all the other human actors who make these systems work" (pp. 183-84).

My Body Politic is another in the ever-growing list of excellent books written by advocates with disabilities that needs to be in all libraries and is a great resource for classes about the disability experience.

Book Review

Title: *On a Roll: Reflections from America's Wheelchair Dude With the Winning Attitude*

Author: Greg Smith

Publisher: On a Roll Communications, 2005

Paper, ISBN: 0-9767111-0-9, 279 pages

Cost: $19.95 USD

Reviewer: Steven E. Brown

"I had always believed there was a major purpose for my life. There had to be some reason that God made me a skinny, crippled guy with a deep voice, who also happens to be black, stubborn, and aggressive" (pp. 147-48).

I recall the first time I met Greg. We were outside, in Washington, D.C., at a memorial for Ed Roberts. Greg had a microphone in his hands and he was interviewing Justin Dart. Neither Ed nor Justin are with us any longer, but Greg's interviews with them are. Greg has been the radio voice of disability rights for over a decade. During that time his vision has changed, but his ambition has not. He has done a great deal during his years on the planet and he envisions much more to come, despite being born with Muscular Dystrophy and, as he is quick to point out, being a 65-pound dude.

This is an excellent memoir, well written, full of ideas and memories and with valiant attempts to be fair to both positive recollections and ones less so. This is not always achieved, but Greg is willing to put his foibles as well as his outstanding characteristics into the book for the public to decide how he has done. There is a lot of name-dropping (you have to read far into the book to find mine) and he has more "best friends" than I can imagine, but that is Greg—an extremely personable kind of guy.

Greg has been a drummer (from his wheelchair); a sports fan; a salesperson; a radio personality, both in front of and behind the microphone; a husband; father; and speaker, among many other achievements.

His book is an excellent autobiography of an activist/publicist. It belongs in every library and in lots of disability and diversity courses.

Book Review

Title: *Moving Over the Edge: Artists with Disabilities Take the Leap*

Author: Pamela Kay Walker

Publisher: M. Horton Media, 2005

Paper, ISBN: 0-9771505-2-6, 243 pages

Cost: $25.00 USD

Reviewer: Steven E. Brown

This is an extremely important book, which not only describes the role of artists with disabilities, particularly in the San Francisco Bay Area, but also how the intersection of art, advocacy, and activism has moved forward disability rights. This story is told through the lens of the author who has been a vital player in much of the arts that occurred in the San Francisco, California Bay Area.

The book includes 20 chapters that look at various topics, such as "disability awareness," comics, dance, theater, and music. But to separate topics is in a way a disservice. Many of the artists described in the book are doing multitudes of art and other activities, including the author herself who is an actress, talent agent, fine artist, and of course, writer, among many other talents. Perhaps Walker's most salient gift to readers is her ability to integrate all the pieces of the Bay Area disability arts world and demonstrate how it evolved (and continues to do so) while life goes on. The interweaving of art and activism is the core of this book and of the shows that give the volume its title, *Moving Over the Edge*.

Walker looks at the work of numerous artists with disabilities, focusing on a few to explore in more depth. Interspersing personal stories, postscripts to each chapter, generally from someone Walker writes about in that chapter, vignettes from her knowledge of these artists, and analyses of how art and activism mesh and create something new, Walker shines as an author in this book. Yet, she also describes the long process she took to come to the realization that she could be both a person with a disability and an artist. In an engaging style, Walker mesmerizes with personal stories, activist rhetoric, and, most importantly, why for so long people with disabilities have been missing from both artistic communities AND art and what is being done to change that. My hope is not only that this book will find its way into many libraries, but also into many classrooms looking for texts about the disability experience.

Book Review

Title: *Encounters with the Invisible: Unseen Illness, Controversy, and Chronic Fatigue Syndrome*

Author: Dorothy Wall

Publisher: Southern Methodist University, 2005

Cloth, ISBN: 0-87074-504-2, 318 pages

Cost: $22.50 USD

Reviewer: Steven E. Brown

Encounters with the Invisible is a fascinating story about the author's personal experiences with a little-understood illness (to use her word), its impact on her life and that of her family, its role (or lack thereof) in the medical community, and its devastating effects on the lives of many others. Wall brings three great skills to this story: she has an ability to poke and prod into her own life and how Chronic Fatigue Syndrome (CFS) has taken hold; she weaves her own story with that of how CFS advocates have worked to legitimize their condition within their own lives

and within the medical community, and she writes with the poetic prose of someone who is both a poet and an editor.

My only real complaint about the book is that some of the anecdotes, particularly in relation to the medical community and lack of research funds directed toward CFS are repetitive. But I understand why. This is an advocacy book, as well as a personal story, and Wall wants more monies directed to CFS research. One reason for this less than subtle approach is the inability of others to understand that an unseen condition is not an unfelt one:

"For all the times I've tried to explain this illness to others, there have been just as many times I felt too tired to make the effort. I often preferred to shoulder the burden of illness in private rather than fight not only illness, but the battle for recognition and assistance" (p. 12).

One of the more interesting questions Wall visits and revisits is why the medical community refuses to believe that people are visiting their offices with real issues. She reminds us of a time prior to modern diagnostic techniques when physicians actually had to listen to their patients to have an understanding of their complaints. Disability rights activists and disability studies scholars will certainly recognize this pattern. At the same time these two groups are likely to be uncomfortable with the author's liberal use of terms like "sufferer" and "afflicted."

Encounters with the Invisible is an excellent introduction to CFS, its individual consequences, its social context, and an ever-unfolding story.

Book Review

Title: *The Language of Me*

Author: Musa E. Zulu

Publisher: University of KwaZulu-Natal Press, 2004

Cloth, ISBN: 1 86914 00370, 116 pages

Cost: $24.95

Reviewer: Steven E. Brown

The Language of Me is an appropriate title for this book. Zulu combines typical autobiographical writing with his own poetry and artwork. The book is divided into two sections. The first, "Life After the Storm," describes his early life and his auto accident in his early twenties. After the accident, as a paraplegic, lying in his hospital bed he wondered how he could possibly ever fit into the world he knew. "I was very lonely in that hospital ward, a stranger in a strange world—isolated from my own identity and the vital energy of society" (p. 23).

But Zulu learns how to reclaim his life:

"Tragedies take away from us, but they also present us with new opportunities and abilities….It forced me to write a different life story from the one of my early ambitions, allowed me to rediscover that I am an integral part of the human family, and not just an independent and self-serving individual" (p. 52).

Zulu is a black South African who has become a well-known motivational speaker in his post-accident life and his book sometimes reads like a motivational speech. But more often the author discloses many aspects of his life and thought. He does discuss how his color has an impact on his life, but for those of us who recall apartheid, it may seem a minimal part of his story.

The second section of the book, "The Scrapbook of My Soul," is exactly that: writings, drawings and more poetry sharing Zulu's own take on his life. I found the most fascinating part of this section to be his discussion of the symbols he uses in his pencil drawings and why he draws in pencil in the first place.

The short page count is misleading. One reason is the style of Zulu's writing, which packs a lot of information into each sentence. The other is the lack of white space in the book.

Each page is packed with text. Overall, this is an intense, reflective book well worth reading.

Music Review

Title: *Tear Down the Walls*

Artist: Johnny Crescendo

Produced: 2005

Cost: $18.00 USD

adaptdan@yahoo.com
http://www.johnnycrescendo.com/index.html
or send a check payable to Johnny Crescendo
800 Cottman Ave. Apt. B1
160 Philadelphia PA. 19111

Reviewer: Steven E. Brown

This is a compilation of earlier releases by British folk rocker, Johnny Crescendo, who now makes his home in Philadelphia. Johnny learned so well from ADAPT, the American street activist, disability rights group, that he helped found DAN (the Disabled People's Direct Action Network) in England, which shut down the national telethon. This mentality is evident throughout Johnny's songs. This CD includes about 80 minutes of songs. It is organized into Anthems; Love Songs; and Folk Blues. While I like all of Johnny's songs, my favorite remains, "The Ballad of Josie Evans," the story of a neglected woman in an institution:

> Josie was a wheelchair user
>
> She spent eleven years inside
>
> A short stay institution
>
> Where she was banged up without trial
>
> Eleven years the white coats met
>
> And talked & analysed
>
> Dispensed the drugs politely

Until one day Josie died

The compilation's title song, in keeping with this theme, begins:

This song is for all the people dying in a nursing home

This song is for all the people who are going to die in a nursing home

Tear down the walls

Tear down the walls of a nursing home.

The song continues to discuss the need for people to be able to choose where they live. In a similar vein, the song "Not Dead Yet" addressing physician-assisted suicide, states:

I'm lying at the gates of heaven

I'm not dead yet…

I was kind of amazed to see St. Peter roll up in a wheelchair

I said, "hey Pete, I want to go back."

He said "go and give shit to Dr. Quack."

On a more autobiographical note, "I Love My Body," offers the refrain that it's the only one he's going to get. And in the tender "Jasia's Song" Johnny offers this tribute to his daughter:

My heart is aching for you my little child

For you my little child

My heart aches for you my little child

My little child

Go to sleep now

Shhh

Hold daddy's hand

Go to sleep

If you are not familiar with Johnny's work this is a great place to start. If you know it and do not have this compilation, you may well want to add it to your library.

For the desperate and the damned?

And which people vote?

For injustice in the land?

Is it you or your mother?

Is it you? Is it you?

Josie left a letter

Which I found amongst her things

It said I am and I survive

& my heart still has wings

They can take away my freedom

They can drug me with their lies

But they don't have my permission

& I hang on to my pride

Audio Review

Title: *Lest We Forget: Spoken Histories, An Audio Documentary on State Institutions, Segregation and the Continuing Movement to Community Integration*

Producer: Jeff Moyer

Executive Producer: Judy Leasure

Publisher: Music from the Heart and Partners for Community Living, 2004

2 CD-Disc Set, approximately 2 hours

www.jeffmoyer.com

Reviewer: Steven E. Brown

Jeff Moyer has written some moving, emotional songs, one of which, For the Crime of Being Different, I often play in disability culture workshops. This two-volume audio documentary picks up where the song begins—a narrative of what it was like to live in Ohio institutions in the last half of the twentieth century for those with what these days we call cognitive disabilities.

Between the two discs there are 74 selections, from over 30 oral histories, many quite short, the bulk of which are stories offered by parents, siblings, and most importantly, those who lived, or maybe a better word is survived, these institutions.

Descriptions of smells, food, clothing, sexuality, and fighting are all included. The abuse apparently inherent in these institutions is depicted in great detail.

Jeff's brother, Mark, was one of the prisoners, the word often used to describe the subjects of these stories, of these institutions. He is the subject of For the Crime of Being Different and his story is interspersed throughout the two CDs, bringing continuity to all the stories included.

As someone who is not a great audio learner, I delayed listening to these documents. I am glad I did not wait any longer. This is one of the most important historical depictions of institutions in this time period I have encountered.

Jeff's songs, writing, and interviewing are clearly recognizable on this project. While he is an artist and the documentary is focused on Ohio, nothing about this narrative is unique. The stories have been heard from every state that had, or has, institutions.

The best reason to listen, and share, this work is so that we remember what happened at these abysmal places and try to ensure they never happen again—and that whatever takes their place is, and stays, better.

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The mission of the Center on Disability Studies (CDS), at the University of Hawaii at Manoa, is to support the quality of life, community integration, and self- determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai`i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawaii University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawaii, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawaii, the mainland United States, and the Pacific region with funded projects in several initiative areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.

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