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The stories of advocates in the disability rights movement remain largely undocumented, especially in the area of the arts. This research uses ethnographic fieldwork to document such stories in the interviewee's own words. The resulting portrait of disability, advocacy, and the arts also details the story of interviewee and interviewer, and of the fieldworking process as a whole.

This thesis focuses on the life history and life story of musician Jim Whalen and his contributions to the disability rights and arts movement. The fieldstudy explores the stories, creations, beliefs, motives, feelings, philosophies, thoughts, and life histories, of not only Whalen but also of the researcher and others intersecting with Whalen's life and work, including writer Steve Kuusisto. An ethnographic methodology, including both in-depth interviews and participant observation, comprise the research design. The researcher uses the interdisciplinary-research tools of fieldwork in order to document and represent his findings.

In this study, advocacy and art are understood as vehicles to reframe current notions about disability. In addition to insight into the disability rights movement at this point in time, the stories included provide an arsenal of techniques, concepts, and tools to help disability advocates understand, reframe, and renegotiate life experiences, in particular through art. In conjunction with reframing ideas such as "This is normal for me" and renegotiating experiences such as "Always stops right now," other advocacy tools discovered include "Summoning the dragon," "Not if, but how," and "Everyone has

a why.” The final product is part word portrait, part life history, part snapshot, part auto-ethnography, part biography, part oral history, part cultural history, part narrative, part ethnography —it is both an explanation and an ode to the two central themes from which the title

DISABILITY IS BEAUTIFUL,
DISABILITY IS MY CULTURE

by

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To Kenyon

APPROVAL PAGE

This thesis has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

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The thesis begins and ends with my son Kenyon. I must acknowledge Kenyon's impact, influence, and inspiration in my life, and in particular in my quest to understand, promote, and advocate disability rights.

Jim Whalen is more than a subject. Jim is a mentor and a new life-long friend. I hope to work with Jim often in the future to continue to change the world.

I must thank Steve Kuusisto, not only for sharing his insight, his writing, his hospitality, and his understanding of human rights, but also his wonderful sense of humor.

I embarked upon this endeavor because of the encouragement of Dr. Elizabeth Chiseri-Strater, who guided me upon this journey and, most importantly, introduced me to the concepts of fieldwork and ethnography. To her I owe many thanks.

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PREFACE

Disability is not a 'brave struggle' or 'courage in the face of adversity' . . . disability is an art. It's an ingenious way to live (Marcus, Disability Social History Project, 2006).

Disability is beautiful. Disability is my culture.

Is it? Is disability beautiful? Is disability my culture? Is it, really? These two statements on two different t-shirts started my quest.

Those shirts reflected the two themes of the 2007 Southeastern Disability Culture Festival (SDCF) in Asheville, N.C. With these slogans emblazoned in red and blue across the chests of their white t-shirts, event organizers and participants proudly displayed the two quotes during this day to celebrate the poetry, dance, photography, painting, music, film, comedy, theater, lecture, video production, and song of people experiencing disability. I attended the event not only to fulfill an assignment for a graduate class in fieldworking, but also to explore my role as the father of a son experiencing disability.

Perhaps curiosity led me there, too. My insatiable curiosity has often led me to stories outside the mainstream.

That same type of curiosity led me to become a journalist 20 years ago, covering stories of grandmas who murder, of preachers who molest, of dope-dealing moped riders, of bumbling thieves leaving tracks in the snow, of bumbling cops sinking police boats, of spelling bee winners, homecoming queens, centenarians, state champion wrestlers, self-proclaimed witches, and any and all of society's curiosities.

It's that same curiosity that I later used to transform a somewhat boring university public relations job into a venue for digging up and writing unusual stories about faculty seeking Blackbeard's treasure, staff members turning the cafeteria's kitchen scraps into compost, and students building better bodies by eating blueberries.

That same innate curiosity for a good story led me to graduate studies at The University of North Carolina at Greensboro (UNCG) and in particular to the Master of Arts in Liberal Studies (MALS) program. The MALS program had me at its brochure slogans: "No outside, no box, just think . . . Actually, great minds don't think alike . . . No answers, just better questions . . . At some point you learn there is no finish line" (Division of Continual Learning, 2006).

The copy on the marketing mailer piqued my curiosity. So, I began my graduate school journey. Now, looking back from the end of my graduate work these prophetic words symbolize my thesis work and my entire graduate school experience:

Curiosity is a funny thing. Like a child, it refuses to sit still in the corner of your mind. Dreaming when it should be listening. Asking why when all you need is how. . . . Unbridled, curiosity can lead you to the edge of you own experience. And challenge you to find a different way back. . . . Like that insatiable curiosity in the back of your mind, turning over chairs and rattling bookshelves while you were supposed to be focused on something else. It's time your curiosity had the best of you. (Division of Continual Learning, 2006)

Each MALS class allowed me to explore my curiosity of disability issues. I wrote poems about disability. I studied the history of disability. I sketched designs for better disability access in cities. I wrote the opening three chapters of a mystery novel featuring

a sleuth who uses a mobility chair¹. I created a documentary film² about disability for a class in fieldworking.

The MALS class *An Anthropologist on Mars*³ introduced me not only to fieldworking but to ethnography, as well. The Web site Ethnography for the Digital Age defines ethnography: “from the Greek *ethnos* meaning ‘foreigner’ and *graphos* meaning ‘writing’ . . . ‘ethnography,’ writing about others” (Coffey, Dicks, Mason, Renold, Soyinka, & Williams, 2002).

To simplify ethnography to “writing about others” won’t do, though it’s a start. The best ethnography takes time, perhaps more time than the year and a half I had to complete my thesis work. Ethnographer Ruth Behar spent a decade visiting her informant⁴ Esperanza⁵—the product of that fieldwork being the book *Translated Woman* (1993).

Behar begins by listening to Esperanza and her stories, but as the years go by Behar’s own tales—not only of the process of her fieldwork, but also of her personal reflections on self and subject—begin to intertwine with Esperanza’s story. Both subject and researcher know that the end product of their time sharing stories together will be a

¹ Mobility chair is preferred over the typical usage of wheelchair. One major aspect of the disability rights movement is to move people toward a people-first language. In her online reference for people-first language, author Kathie Snow suggests the following examples: instead of “she is confined to a wheelchair,” use “she uses a mobility chair”; instead of “he’s disabled,” try “he experiences disability”; Instead of “she is a Down syndrome child,” use “she is a child with Down syndrome” (2008).

² My 2007 film *What is Beautiful?* inspired me to expand the documentary in thesis form to explore the answer I found at the end of the film—that, “yes, disability is beautiful” (Purcell).

³ The class title is taken from the book title of the same name by Oliver Sacks (1995).

⁴ An informant is the subject or subjects an ethnographer interviews and observes.

⁵ Esperanza is a pseudonym chosen by Behar and her informant to be used in *Translated Woman* (p. xiv). Ethnographers often choose pseudonyms to protect the identity of people they study. I have chosen pseudonyms throughout this thesis unless the informant specifically asked for his/her real name to be used.

book. Behar writes, “As the one who is no longer just expanding her capacities to listen but sitting here snipping and snipping at the historias⁶ Esperanza told me, only to sew them back into this book as a life history, I fear I am somehow cutting out Esperanza’s tongue. Yet when I am done cutting out her tongue, I will patch together a new tongue for her, an odd tongue that is neither English nor Spanish, but the language of a translated woman” (p. 19).

Behar wrestled with the fact that the intimate stories she spent 10 years carefully collecting would become open to the public through the publication of her book. In the end, every ethnographer must break the intimate bonds of the relationship between storyteller and story gatherer to allow the stories to speak. But too, so must the informant let go. Esperanza refuses to take a copy of the book when it is finished, telling Behar, “I already know my historia” (p. 342).

Anthropologist Michael Agar describes ethnography in his book *The Professional Stranger: An Informal Introduction to Ethnography*, as, “an ambiguous term, representing both a process and a product” (1980, p. 1). Agar continues, “As a product, an ethnography is usually a book” (p. 1).

I didn’t set out to write a book, nor did I intend to spend 10 years in the field like Behar. While reluctant to label myself an ethnographer, I did set out to use ethnographic research techniques. Interdisciplinary in nature, ethnography mirrors the goals of my graduate department and my academic field of liberal studies. I aimed for a solid interdisciplinary process that would produce a solid interdisciplinary product.

⁶ In *Translated Woman* Behar explains her work as collecting a combination of life history and life story that her informant called historias (p. 16).

Ethnography suits my strengths. With so many years spent interviewing as a journalist, I felt very comfortable in my quest to gather data. However, most newspaper stories recount tales as thin as the paper they are printed on, so for my thesis I knew I wanted to “thicken” my writing and storytelling techniques, as suggested by Anthropologist Clifford Geertz in his book *The Interpretation of Cultures*:

[D]oing ethnography is establishing rapport, selecting informants, transcribing texts, taking genealogies, mapping fields, keeping a diary, and so on. But it is not these things, techniques and received procedures, that define the enterprise. What defines it is the kind of intellectual effort it is: an elaborate venture in, to borrow a notion from Gilbert Ryle [British philosopher], “thick description” (1973, p. 6).

Dr. Elizabeth Chiseri-Strater introduced me to ethnography and fieldwork in her class *An Anthropologist on Mars*. She co-wrote the textbook we used, *Fieldworking: Reading and Writing Research* (2007). I produced a documentary film⁷ about disability as my final fieldwork project for her class. She then encouraged me to continue and expand my film into written word as a thesis project. She volunteered to become chair of my thesis committee, and my quest began.

Before guiding me along the path of my thesis, Dr. Chiseri-Strater introduced me to four ethnographic writers whom I now love, admire and cite as inspiration for my thesis: Zora Neale Hurston, Oliver Sacks, Ruth Behar and Dennis Covington. Reading those four writers resulted in a major evolution in my life as a writer.

⁷ *What is Beautiful?* (2007).

As a journalist, I created stories based on research that gave readers what they needed or wanted to know. As a public relations writer, I created stories based on research that gave the best possible version of a story to protect and promote the image of the university. Learning fieldworking and ethnography allowed me to advance to the next iteration in my evolution as a writer and researcher—incorporating myself into the story.

In my life as a professional writer, I never became a visible part of the story. I only appeared in a byline or not at all. The subject took center stage. Looking back, I can reframe those writing experiences to see that, truthfully, the author is a part of any story, whether he or she admits it or not. Ethnography, as I have learned and continue to learn, demands the researcher to recognize his or her impact on the research.

We, as ethnographic researchers, are not in a room of one-way mirrors looking out at the world. Instead, as Sunstein and Chiseri-Strater (2007) suggest, we are standing toe-to-toe with our subjects in “the spaces they inhabit” (p. 2), observing, listening, interviewing, and living in the world of our informants (pp. 1-2). We become part of their stories, whether we admit it or not, whether we like it or not.

Accepting the fact that ethnography asks the researcher to recognize his or her impact on the data, the informant’s stories, and the process, stands as a big step for a former journalist. Typically, the journalist strives to stay out of the story. However, my journalistic background aided my research, too. I’m an experienced journalistic interviewer and writer, and I have a commitment to avoid predicting the outcome of a story before conducting the research. Just as a good journalist doesn’t decide the facts before doing the research, a good fieldworker doesn’t predict the results of the fieldwork before its completion.

Perhaps this is why I seemed to encounter a problem answering the inevitable question—“What’s your thesis about?”

I could put on my academic hat and speak intelligently enough to satisfy most people, who seemed to ask out of politeness. But, truthfully, ethnographers don’t know what the story is about until after the research, when he or she sits down to wrestle the fieldnotes into a readable work about the subject.

The basic subject of my thesis is easy—disability rights and the arts. “What is the thesis about?” Well, that is a bit more complex.

Going into my research, I knew I wanted to immerse myself as much as possible in the disability rights and arts community. I started with a typical literature review reading books, journal articles, and essays about disability, advocacy, and the arts.

However, I wanted to get beyond a review of literature and sink myself into this culture. One of my main avenues for exploring the realities and perceptions of disability culture was through consuming not only books but film, music, painting, sculpture, podcasts, journals, blogs, dance, comedy, theater, and poetry.

Over the past year and a half, I’ve only scratched the surface of the thousands of films about disability.⁸ I watched the story of surrealist artist Frida Kahlo dealing with her disabilities through painting exotic, erotic, esoteric self-portraits in the 2002 movie *Frida*. In the 2005 film *39 Pounds of Love*, I witnessed 39-pound Ami Ankilewitz—a 3D animator with spinal muscular atrophy—journey across America in his electric wheelchair and motorcycle sidecar as he found love, sexuality, and the doctor who

⁸ More than 2,500 films are listed at the disability films Web site: <http://www.disabilityfilms.co.uk> (Greenhalgh, 2007).

predicted the 34-year-old wouldn't live past six years of age. The 2006 film *Forbidden Acts* showcases the poetry and naked body of disability advocate Leroy Moore.

Documentary filmmakers follow 16 months in the life of a man with Down syndrome who works in a movie theater, collects comic books, watches porn, and falls in love with a typically-abled coworker in the 1998 movie *JeffTowne*. A sorority girl volunteering to help an intellectually-disabled young man falls in love and has sex with him, and deals with the aftermath in the 2002 film *Pumpkin*. The 1971 film *Land of Silence and Darkness* follows a woman who has been deaf and blind since her teen years as she works to make the lives of others better. The 2002 film *Cinemia* documents the out-of-control obsession of five movie buffs who attend as many as four movie showings a day every day of the year. Endorsed by the Special Olympics, *The Ringer* is a film featuring actor Johnny Knoxville of MTV's *Jackass* series, who pretends to have a developmental disability in order to rig a Special Olympics race to win money on a bet. As of today, I have watched more than 50 of the 2,500 films listed on the *Disability Films* Web site (Greenhalgh, 2007).

I began to see films that I had seen dozens of times in new ways—the *Star Wars* trilogies became a venue to explore ideas of assistive technology and disability as both Darth Vader and his son Luke become amputees. The *Smokey and the Bandit* movies provide a social commentary on stuttering. The endless *Star Trek* films morph into commentaries on assistive technologies and acceptance of those with differences.

I viewed videos of dance troupes, theater troupes, and comedy groups featuring people experiencing disability. I viewed hundreds of photos of paintings, sculptures, ceramics, fabrics, pottery, metalwork, and jewelry made by people experiencing

disability. I watched TV programs featuring disability, from *Life Goes On* to *The Secret Life of an American Teenager* to *Touched by an Angel*. I watched the PBS documentary *On a Roll*, which looked at the life of disability advocate Greg Smith, who tells us: “Disability is a beautiful part of the natural diversity that is human life” (Caputo, 2005). I tried in vain and disgust to document the number of jokes about people with disabilities on late night television.

I listened to popular music that reveals contemporary ideas of disability, including Joe Nichols’ oversimplification of becoming paralyzed in “The Impossible,” Bucky Covington’s sappy “I’ll Walk,” and self-described scum metal band Despoiler’s anthem of hate “The Disability Song.” I listened to several recordings of Mel Tillis’ “Ruby Don’t Take Your Love to Town.” In his song, Tillis, who experiences disability via stuttering, is patronizing in his description of Ruby and the war-wounded husband who begs her to stay faithful. The song reveals the anger of that patronization: “If I could move I’d get my gun and put her in the ground” (Tillis, 1969).

From the American opera *Porgy and Bess* to Randy Newman’s “Short People” to Devo’s “Mongoloid” to The Ramones’ “I Wanna Be Sedated” to The Who’s “My Generation” to Ray Charles’ “I Don’t Need No Doctor,” there is no shortage of music featuring lyrics about disability (Tusler, 2003). While not as extensive as the 2,500 films in the *Disability Films* online database, *Disability World* chronicles songs with lyrics about disability and performing artists with disabilities. The list includes such diverse musical acts as Jimi Hendrix, the Dead Kennedys, Tom Waits, Elton Britt, Doc Watson, Marcus Roberts, Fang, Nick Lowe and Marilyn Manson (Tusler, 2003).

I wanted my MTV⁹, too. Every song with a disability angle since the 1980s has come complete with video. Country crooner Garth Brooks hit it big in 1994 with “Standing Outside of the Fire.” The video features a father dealing with his son with Down syndrome who competes on his high school track team instead of the Special Olympics team. Natalie Merchant’s number-one 1995 hit-song “Wonder” became an anthem for the Down syndrome community after the video featured a young girl with Down syndrome dancing. The classic 1984 music video “Hello” by Lionel Richie features the singer falling in love with an art student who experiences disability as blindness.

Even after MTV switched from music videos to programming drama and comedy shows, disability appeared in episodes of the hit reality series *The Real World*, in which some of the contestants experienced disabilities ranging from cystic fibrosis to amputation to HIV/AIDS. Though I originally viewed this programming at the time the shows aired, I viewed the episodes again to gain more insight into the typical modern stereotypes of people experiencing disability.

In contrast to the stereotypical images of disability portrayed in pop culture songs, a whole world of music by disability advocates raises a different voice. I listened to Leroy Moore’s compilation of rap and hip-hop artists experiencing disability, *Krip-Hop*, Peter Leidy’s witty satires “Jerry Lewis Blues,” “The Ballad of Self-Directed Joe” and “Stacy Kerr is my Case Manager,” and Seattle’s openly-disabled punk band The Cripples.

⁹ This is a reference to the lyric from the Dire Straits song “Money for Nothing,” which praised the pop culture influence of The Music Television Network (MTV).

I listened to the monthly disability podcast *Ouch*. I explored the most popular disability culture and advocacy Web sites from *Mouth* to *The Riot* to *The Ragged Edge*. I viewed countless Web sites and blogs describing the disability experience. Some sites simply shared art created by people experiencing disability, while others offered advice to parents seeking to advocate for children experiencing disability. Some sites provided a venue to vent. Most sites simply connected the people of disability culture to one another.

I read the poetry of Neil Marcus—“I live disabled culture, eat disabled food, make disabled love, cry disabled tears, climb disabled mountains and tell disabled stories” (Disabled Country, 1997)—and Steve Kuusisto—“Our twin minds go walking, and I suspect as we enter the subway on Lexington that we’re a kind of centaur” (2000, p. 20). I read Jillian Weise’s collection *The Amputee’s Guide to Sex*: “He says he likes sleeping with me. He sleeps with metal rods and believes they are human” (2007, p. 8).

I discovered hundreds of books on disability, but none with significant insight into disability culture and the arts. The most revolutionary and transforming book I have encountered remains Kathie Snow’s *Disability is Natural* (2008). Snow’s book not only shaped the direction of my research, but it shaped the direction of my life as a parent of a child experiencing disability. Snow writes about the logo on her book of a bowl containing four red apples and one green one:

But what do apples have to do with disability? One of the five apples is green. One American in five is a person with a disability. (Which makes people with disabilities the largest minority group in the nation—and it’s the only group that anyone can join at any time!) A green apple is more like red apples than different. A person with a disability is more like people without disabilities than different. Apples are natural . . . and having a disability is a “natural part of the human experience” (as expressed in the U.S.

Developmental Disabilities Act). The sun shines equally on all the apples in the bowl, and it's time for the light of inclusion, opportunity, freedom, and dignity to shine equally on all people—including people with disabilities. (2008, p. 6)

For years I had been told, in so many words, by an array of well-meaning physicians, therapists, social workers, and specialists, that my son, Kenyon, was broken and needed to be fixed. On her Web site (<http://www.disabilityisnatural.com>) Snow describes the *medical model* of disability:

Today's conventional wisdom about disability is based on the medical model: identify the problem, then provide a cure. This paradigm places the "problem" of disability within the person, so treatments and services attempt to "fix" the person: helping him achieve an "able-bodied" standard through therapies and other interventions and/or placing him in special, sheltered, segregated settings in order to "get him ready" for life in the real world. In the minds of many, these efforts will resolve the "problem" of disability. But the problem never has been the disability; the problem is (and has always been) society's beliefs about disability. People with disabilities are not broken, and they don't need to be fixed! What will it take to ensure that people with disabilities enjoy first-class citizenship and live real lives: being included, having friends, being self-directed, enjoying both the rights and responsibilities of citizenship, and participating in and contributing to their communities? Our Founding Fathers were inspired to rebel, seeking freedom from the oppressive past—the old ways of doing things. They embraced radical ideas and created a new nation. Isn't it time for us to do the same? Isn't it time for a new way of thinking? (Snow, *A New Way of Thinking*, 2008)

After discovering the wisdom of Snow's book, we quit therapy—it was our first revolutionary step toward a new way of thinking and living for our family.

In addition to exploring how people experiencing disability express the disability experience through art, I explored through popular media how the temporarily able-

bodied¹⁰ (TABS) perceive those with disabilities. I found no better example than the TV show, *The Sopranos*. In one year I watched seven seasons of the award winning HBO series. It features dozens of characters experiencing disability and provides a commentary on contemporary perceptions of disability. Researcher Kathleen LeBesco writes of *The Sopranos*:

Many characters on *The Sopranos* have disabilities . . . mafia tough-guy, Tony, needed to seek therapy for his panic attacks. If panic attacks and dependence on psychological help are perceived to weaken a man, then Tony is understood as disabled by his peers. In other scenes, we learn that Tony has learned with age to be respectful of others who are disabled. He tries to comfort his nephew Christopher, who thinks he has cancer; when Tony says, “You’re just depressed,” Christopher rebuffs this possibility, stating “Me? I’m no mental midget.” Thus, Tony is again reminded how socially disabling any perception of difference can be. In therapy, Tony tells a story from his childhood about making fun of a neighborhood kid who had a cleft palate—Jimmy Smash, they called him—but says he finally knows what it is like to be used for someone else’s amusement. . . . Hercules [Tony’s uncle], who was institutionalized and thus Tony never knew him; he seems troubled to find out that Livia, his mother, found Hercules a charity home and thus segregated him from his family and the rest of the community . . . after one of his men, Richie, beats pizzeria owner Beansie Gaeta so badly that he becomes paraplegic, Tony insists that Richie build a wheelchair ramp on Beansie’s house, alter his toilets, and widen his doorways. Tony even tries to give Beansie fifty thousand dollars “to donate to the Spinal Cord Injury Association, pick you up, inspire people.” (Disability, gender and difference on *The Sopranos*, 2006)

The attitudes about disability on *The Sopranos* mirror the attitudes I encounter as the father of child with a disability: Coworkers who use the word “retard,” relatives and strangers alike handing out verbal well-wishes of pity—“I don’t know how you do it . . . What a special boy you have . . . God won’t give you more than you can handle”—a

¹⁰ TABS is an acronym used by people in the disability rights movement to describe those without disability—the temporarily able-bodied. Disability is a state anyone can move into and out of through life events. Most people living to old age will likely leave the status of TABS and join the ranks of the disabled.

whole medical system designed to keep people labeled as “disabled” in order to fund itself, a school system in which parents have to fight for their children’s right to sit at the same table as the “normal” children, and the second looks, sneers, forced smiles, and stares of people on the street when they see a person experiencing disability.

Immersion into disability rights and arts culture was easy. Making sense of the overwhelming amount of information therein proved more difficult. However, having a solid foundation in the issues, perceptions, and realities of those in the disability community allowed me to enter the human-research phase of my thesis work with confidence. I set out to investigate the cultural landscape of the disability rights and arts movement. But how was I going to tackle even this small part of the field? I had to narrow my focus.

I zeroed in on the most provocative, articulate and entertaining person I met at the SDCF—Jim Whalen. Jim is a songwriter, a performer, an advocate, a father, a husband, a counselor and leader.

I watched video of Jim being interviewed and of him performing his songs. I listened to MP3 files of his recordings. I read his lyrics. I Googled Jim. I did all the preparation a good fieldworker does before going into the field to conduct fieldwork.

Though I met Jim in the summer of 2007, I did not see him again face to face until I traveled to Iowa exactly one year after meeting him at the SDCF. My goal was to spend a week with Jim conducting interviews, collecting artifacts, observing, and reflecting, all in order to study the life of a disability rights artist and advocate in “the space he inhabits” (Sunstein & Chiseri-Strater, 2007, p. 2).

I wanted to live with Jim for a time to observe and ultimately describe his life, behaviors, language, and his culture through an ethnographic approach. I wanted to listen to Jim's story and "poke around at the edges" of it (Sunstein & Chiseri-Strater, 2007, pp. 3-4). I wanted to see the items he collects and values, and uses to go about his daily life, to learn what it is like to be part of his world, and thereby discover his "culture's way of being, knowing, and understanding" (Sunstein & Chiseri-Strater, 2007, p. 4).

I wanted to conduct contemporary fieldwork, a methodology shared by anthropology, sociology, folklore, cultural studies, and linguistics, according to Sunstein and Chiseri-Strater (2007). Rather than attempting to be a totally objective social scientist, I sought to acknowledge that a distanced, objective stance is dishonest when one is immersed into a culture (Sunstein & Chiseri-Strater, 2007, p. 4). I wanted to discover a new writing voice—to use "I" with authority and with the authenticity of my own fieldwork, incorporating personal feelings, emotions, sensory, and aesthetic details to create a final thesis true to my view of the best ethnography in form, function, and final product.

In this vein, I wanted to follow in the footsteps of Hurston, Behar, Covington, and Sacks. I wanted to create the sense of place and pace of storytelling of Covington's *Salvation on Sand Mountain*. I wanted to mirror the vibrant, narrative footnotes of Sacks' *An Anthropologist on Mars*. I wanted to write as beautifully as Hurston did in *Mules and Men*. I wanted to be true to my informant's stories with the same reverence and respect that Behar showed to Esperanza in *Translated Woman*, allowing the informant to tell the story in her own words.

I sought to collect an oral history of a marginalized group (those experiencing disability) that would help society “to understand the everyday experience of life,” (UNC Writing Center, n.d.) both in the past and in this culture today. My goal was to answer the questions: is disability beautiful, and is disability my culture? I wanted to challenge expectations and perceptions of people experiencing disability by showing realities not often seen, considered, understood, or completely accepted by society.

I wanted to do all this by exploring, documenting, and recording parts of the life and thoughts of one person—Jim Whalen.

I corresponded with Jim via e-mail and phone sharing stories, breaking the ice, and setting up a week-long trip to Iowa to meet with him in June of 2007. During my time in Iowa, I also interviewed a friend of Jim’s, Steve Kuusisto, who also happens to be a disability advocate and artist. However, the majority of my time was spent interviewing and observing Jim.

Sitting down with Jim at the dining room table for formal interviews was just the start. I listened to him jam on the guitar. I ate dinner with his family at a local Mexican restaurant. I saw a movie with Jim his daughters. We went to a pet store. We drove to and from Iowa City. We sat in on a summer school class with Steve Kuusisto at the University of Iowa. I watched Jim fix lunch, play with his kids, ride a bike, teach guitar to his daughter, write music, and consult with a center of independent living. I observed Jim in his life and in his space.

After gathering box loads of research that include more than 24 hours of tape recordings, half a million characters that make up nearly 100,000 words of transcriptions, and stacks of tattered yellow pages of personal fieldnotes, all of which represent more

than a year's worth of research, more than 2,500 miles driven, and countless café mochas, I sat down to begin creating a final product worthy of my informant and his story.

I had to choose a way to present the findings: history, biography, oral history, cultural history, life history, life story, storytelling, character sketch, ethnography, auto-ethnography, narrative, or some combination thereof. In the class *An Anthropologist on Mars*, we learned about telling “twin tales,” allowing the ethnographer’s story to intertwine with the story of the informant. The chapters that follow are a portrait of the experiences, perspectives, and stories of disability artist and advocate Jim Whalen. My “twin tale” rides along with Jim’s story as an auto-ethnography.

What follows this preface are stories: stories from Jim, stories from people who know Jim, my stories, and my son’s stories. These stories form a portrait of disability culture and the arts, the disability rights movement, and a journey many people with disability experience. It is a life history and a life story of Jim, of me, and many others.

What follows are my personal reflections on not just my fieldwork in Iowa, but reflections on my life and the life of my son, Kenyon. I hope these reflections provide the history and autobiographical perspective necessary to understand my journey with Jim.

I considered arranging these stories in chronological order, but that wouldn’t be true to the journey. I tried to mirror the way Jim tells stories, jumping around in time, but along a thread of commonality.

Through this research and writing I found a new way to understand disability culture, advocacy, and artistry—through telling the stories of those involved in their own words. I confirmed what I learned in my fieldworking class—that understanding a culture

is about stepping into that culture, stepping back out, and reflecting on the process (Sunstein & Chiseri-Strater, 2007, pp. 1-10).

I believe these stories and reflections form an important history of a few people in a large movement at a critical point in time. Documenting Jim's oral history provides inspiration, insight, hope, tools, and understanding for the people who follow in his footsteps as advocates and artists. Documenting my story and my son's story shows that the process begins again with each new person that joins disability culture. My family is just beginning to understand what it means to be a part of disability culture and to be advocates. Jim is now my family's mentor and this thesis is the story of the start of our travels together.

I began this process as a miner. Like most traditional graduate students seeking to write a thesis, I began with an axe, dynamite, and a wheelbarrow, hoping to find jewels and haul them back for "oohs" and "ahhs." Then, as any good miner would, sit down, and polish the stones before comparing them to others for sorting, classification, and display.

However, during my journey, I discovered that this process is not about mining. It is about traveling together. Not about bringing back jewels, but unlearning, relearning, and coming to new understandings about what jewels are. Not about wielding an axe, but holding up a mirror. Not about explosions, but about listening. I was not a miner, but a traveler trying to make sense of the journey with my fellow travelers.

What follows is the story of my expedition. Behar calls it "extracting confessions" (1993, p. 3). What I realized is that not only was I extracting confessions from Jim, but from myself. Like Behar, I have let the interviewees tell their own stories in their own words. Like Behar, I tell my own stories in my own words, too.

Each chapter title is taken from a song by Jim Whalen. I also include the lyrics for each of these songs. Each chapter is a collection of stories that relate to the chapter title. The stories are in a rough chronological order that reflect the nature of our interviewing process, which moved through subjects instead of along timelines. Each story reveals a discovery I made on this journey. Taken as a whole, I hope these stories will help others who undertake this grand adventure into the world of disability, advocacy, art, and human rights.

Along my journey, I discovered that understanding what it means to be a person experiencing disability is a journey each of us must undertake, if we ever hope to redefine, renegotiate, and reshape the world we all inhabit into a better place.

I discovered that I'm intricately tied to disability culture, not only through the birth of my son, but through family, friends, coworkers, and the more than 60 million people with disabilities in America (Snow, *A New Way of Thinking*, 2008).

I discovered that, yes, disability is beautiful. Yes, I am a part of disability culture.

How did I come to these conclusions? It begins with the first time I met Jim Whalen.

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CHAPTER I

I DON'T WANT TO BE NORMAL

"I Don't Want to be Normal"

by Jim Whalen, 2007

I don't want to be normal
I don't want to be normal
I don't want to be normal
If I gotta be like you

Chorus—I don't want to be normal
If I've gotta be like you
Follow social rules
Made up by fools
I've got better things to do

I don't need to be special
And my name it isn't Ed
You can pretend
Right down to the end
I'd rather be real instead

I'm not gonna spend half of my life
Worried about what other people think
I won't do back flips
For some hypocrites
Who think that their shit don't stink

No need for a Rolex or Mercedes Benz
Or gifts from all over the Earth
No silicon honey with a pile of money
Can tell me what my life's worth

Chorus

You think you're perfect as you stand in the mirror
And you dab on perfume and chrome
I'm thinkin' come on
Your light may be on
But I'm pretty sure nobody's home

My body it may be broken
But my heart it is quite whole
I use half my mind and
I try to be kind
And I never will sell my soul

Chorus

Sometimes you think I'm quite strange
You got discomfort with most of my friends
But they were there in the beginning and
They'll be there when this all ends

You're just mad because you can't fix me
And you don't know what to do
You can stand there and shout
You can scream you can pout
But babe, it's not all about you

Chorus

You've Got to Meet This Blind Guy

The first time I saw Jim Whalen, I wasn't sure I had the right person. I had spent the morning interviewing participants at the first Southeastern Disability Culture Festival¹¹ (SDCF) when my wife told me, "You've got to meet this blind guy that just brought the house down on the main stage."

I wandered around the displays of paintings, sculpture and photography until I found whom my wife had described as "a guy in a Hawaiian shirt." He was standing in front of a giant black and white photograph¹² of what appeared to be a noose. The photo stretched five feet wide and four feet tall. As I got closer to Jim and the photograph, I saw the photo was not of a noose, but of a chain with a hand pull. I thought the photograph was beautiful. I knew someone experiencing disability must have taken it, but I didn't know what disability the person experienced.

Beyond the main image of the blurry, blackened chain, a brick sidewalk led toward a road. Past that was the courtyard of a school with two buildings, one's architecture in a cold contemporary style, the other evocative of the 19th century. To me the photo symbolized the choice between the past and the future. The noose-like chain, a symbol of death, hung between the two buildings. The viewer had a choice to make—the old way or the new. I would later learn that a student experiencing blindness took the

¹¹ It was the first and last, thus far. Held June 7, 2007 at the University of North Carolina at Asheville, the event was sponsored by the North Carolina Youth Leadership Network. In 2008, the NCYLN chose not to pursue a second festival, but a leadership conference instead.

¹² The exhibit featured huge, blown-up reproductions of work from Visual Artist Tony Deifell's book *Seeing Beyond Sight*. The book and the exhibit showcased work by teenagers experiencing visual impairments ranging from low vision to no vision (2007).

photograph on the campus of the Morehead School for the Blind¹³. According to the photo description, “the chain connects to a bell heard across campus . . . it signals the beginning of classes . . . it rings at graduation . . . General Sherman’s Union soldiers gave the bell to the school during the Civil War” (Deifell, 2007, p. 36).

Hearing my footsteps on the cold, slick institutional tile, Jim turned, looked me in the eye and smiled.

“Jim?” I asked.

“That’s me,” he responded. I explained my project. Jim asked what I thought of the photo. “I think it’s presenting a choice between old and new,” I said. “I like it, but I’m not sure why.”

“Me, too,” said Jim. “Let’s get this interview done before my second set.”

Jim turned and led the way toward the main hall. I thought, “Is this guy really blind?”

Later, of course, I learned that, yes, in a purely medical sense, Jim is blind. But at that moment, I just turned and followed the blind guy in the Hawaiian shirt. I’ve been following him ever since.

Illegally Blind

JIM: I’m legally blind, or illegally blind. I don’t know what illegally blind is—I guess if you took some illegal substance and blinded yourself.

¹³ The school is located in Raleigh, North Carolina.

My name is Jim Whalen. Who I am and what I do are sort of all mixed together. In fact, who I am is what I do, and vice versa. I work at a center for independent living as a paycheck. And my job title is social imagineer. Job titles need to match what you do. I do the video projects. I do AT¹⁴ projects.

I have a campaign of disability education based on the idea that culture and art and history and the human spirit are a common thing that people with disabilities can use to change the world, and to stake out their identity, and to negotiate the most positive definition they can get. And that sounds all theoretical to people, but that's what I do.

I've been known as the "human speed bump," because I stop people from thinking of disability in that straight, linear fashion—that medical model.¹⁵ That's what I get paid to do. My boss will tell you that if I do nothing else, that's what I get paid to do.

I love music. I always have. It's always been in me. I'm a strong advocate. I'm a person who is basically a professional smart ass in many ways. The music gives me a way to integrate that. That creative juice gives me a way to integrate that and present it to others. It's not only integrating it for me, which is a great source of joy and enrichment, but then I can put it out there in a way others can share.

I've never really thought about it this way, but it's cool. It's really a powerful thing.

Kindergarten Round-up

JIM: This is going to sound really bizarre to you, and you're going to say, "How can this be?" I'll explain it . . . my vision impairment.

This is 1964, when I started school. I was five. So, it's a ways back now. It's not the same era. And I grew up in a poor family, so that's also part of the issue—part of the reasoning. My parents just thought that I sort of looked cross-eyed—that I had one lazy eye. And they really didn't give it any thought.

When I was three or four, when we were in the car going somewhere, my older brother would say, "Well, there's McDonald's," and apparently on the way home, I would

¹⁴ Assistive Technology is one of the many abbreviations that make up the language of disability culture. In addition to AT: ST (speech therapy), OT (occupational therapy) and PT (physical therapy).

¹⁵ The medical model of disability sees the person with a disability as not normal, as broken. Professionals who follow the medical model seek to fix, or return the person with a disability to a state of "normal". In this model there are two types of people: normal and those who need to be fixed, so that they can return to a state of normal.

remember just about where it was and say, “There’s McDonald’s.” And I had pretty good motor skills and pretty good dexterity, so I didn’t really look clumsy or fall down very much.

I did get in trouble, quite frankly, a lot of times for crossing the street without looking both ways. I really wasn’t looking. I was just listening. That was my gauge. But I got spankings often for not looking.

I’m talking about four or five years old when I went to kindergarten round-up; a day when you’re going to register for kindergarten. They call it kindergarten round-up here. Anyway, “we’re rounding up kids, we’re bringing them in.”

They had a basic vision and hearing screening. And they were asking, “What was this on the board?” And I’m like, “Well, I don’t know. I have no clue.”

So we went to the eye doctor. We never had regular physicals. My parents couldn’t afford that stuff. But, we went to the eye doctor and of course the eye doctor takes a look and says, “This kid has some retinal damage here or lesions or something. I can give him some glasses and that might take away the lazy eye effect, but I don’t know that this is going to change anything. Iowa City has one of the best eye clinics in the world, so we’ll send him there.”

My parents were devastated. My brother was six and half and up until this point in time he just had a normal brother. My younger brother would be born that year. We made several trips up to Iowa City and I became a patient.

The Velvet Hammer

JIM: I use music intentionally mixed with sarcasm about sacred topics or under-the-rug topics. I like to call it the velvet hammer.

One of the things that art and creativity does, it transcends—it transcends your everyday experience. When I’m playing my guitar, when I’m writing a song, even though the focus could be on injustice or being unjust, the disability aspect goes away. I can really focus attention on that particular topic—injustice or pity. People won’t listen to you say something about pity, but if you sing something about pity that strikes a nerve in them, you can go a long way. There’s no way a person can hear or see the art that we produce without getting affected. If you sit down and just write out, “To help people with disabilities, we need to have a better positive attitude,” it doesn’t do it. But if you catch them where they live, you can do it that way.

Down to the River to Pray

During the standing ovation, Jim unplugged his black-and-white electric guitar from his amp and left the stage nodding and waving to the crowd. The SDCF event organizers swooped in by foot and wheelchair to clear the stage.

I hovered by the video camera during Jim's performance to make sure it all got on tape. Now I sat down with my five-year-old son Liam to enjoy the next performance. I thought it was a lot to ask of a boy that young to sit through performance after performance of poetry, dance, music, speech, and video, over and over and over. We were at the end of a long day at the festival. I can tell when Liam is about to ask a big question. He scrunches up his eyes and leans in close.

I feared what he would ask. How could I answer? What did he think about the songs Jim just performed about not being normal, about peeing on the floor, and about getting run over by a truck because you couldn't find a curb cut?¹⁶ What is he thinking about all these people with disabilities: all these wheelchairs, tons of them, rolling to and fro; the woman sitting on the other end of our row who keeps taking off her prosthetic foot to scratch at the stump; the white artificial voice box peering out from under a woman's chin; the array of walking braces in institutional silver, sparkling purple, and cherry red; the cacophony of slurred speech, moans, excited yelps, and the hum of electric chairs engaging and disengaging?

¹⁶ Curb cuts allow a person using a mobility chair to roll smoothly from sidewalk to street level and back again. Curb cuts help all people from delivery drivers with hand trucks to parents with strollers to Cub Scouts helping little old ladies cross the street. Though we all benefit from curb cuts, getting governments to install standard curb cuts and refit old sidewalks remains an area of advocacy.

I had felt comfortable all day; but at that moment, I became overwhelmed to be a small minority in this sea of disability. I became overwhelmed with feelings from the past.

I felt that same uncomfortable feeling I had visiting my mother at Dorthea Dix Hospital for the mentally ill—being buzzed through countless doors with steel-barred windows escorted by burly men in green medical scrubs past the strip-search room for patients, moving deep into the bleeding heart of the facility where random screaming echoed through the tall corridors, all to get me to a visiting room where I would sit waiting to deliver Mom a carton of Kool cigarettes, a big hug and five minutes of human interaction.

It was the same uncomfortable feeling I had as a journalist visiting Broughton Hospital to get the facts to write stories about escaped mental patients.

The same feeling I had at the School for the Deaf haunted house when the students motioned for me and my girlfriend to come to the front of the line. Was it that obvious I was hearing? In the silent night air, a blur of American Sign Language stopped as we ascended the steps and entered the haunted house. The stentorian beating of chains inside metal trash cans combined with chest-thumping bass blaring from giant speakers suspended in the ceiling to create dissonance as we stumbled through a maze of hallways made of black plastic, sticky felt, and torn burlap. Only the visual stimuli of black lights and strobe lights guided our way.

It was that feeling I had at Christmas time circling the mile loop around the Western Carolina Center, an institution for the so-called severely mentally retarded.

Enduring bump-and-go traffic to see the giant holiday light display spread all around the cluster of buildings where every now and then a window shade would rise and a face would peer out. The irony is that if my son Kenyon had been born 10 or 15 years earlier, the doctors may have pushed us to send him there.

With these memories and thoughts spilling into my mind, I wondered what I would have thought at Liam's age, seeing and hearing all these people with disabilities.

As a kid I had watched Jerry's Kids on Labor Day weekend, heard jokes about retards, and grew up with a language chock full of negative disability descriptors—"That's lame," "He's an imbecile," "That's crazy," "You moron." And, more importantly, I rarely saw anyone with an overt visible disability. In the 1970s, many of those experiencing disability were still in institutions.

Liam cuddles up to me. His mother is on the back row breastfeeding Kenyon. Liam is still holding a note card of a painting with hearts that he bought in the lobby from an artist experiencing Down syndrome. I'm worried. We had told him this was a festival, but didn't really explain the disability part. He hears us talk about disability. We're careful, very careful, about what he sees on television. We use the right language at home. He has good role models for acceptance, for celebration of diversity. He has a brother with Down syndrome—though I don't think he knows it.

The next group is onstage already. Allison Krauss' haunting voice echoes in the auditorium as her *a cappella* version of "Down to the River to Pray" begins. Dancers in papal red tops and black leotards spin around the stage on foot and in mobility chairs. One dancer dressed in all white staggers forward from her turned-out position in the

back. Though I don't know what disability she experiences, it affects her gait. She bows, dances a gentle *jete* left, then right, and then into a stilted pirouette. The *corps de ballet* surrounds her lifting her into the air. She uses others' hands, arms and armrests for footholds as she seems to hover across the stage. She lurches forward and turns, landing on her back in the arms of her fellow dancers. In unison, the troupe rolls and strides into a semicircle. The dance ends with all the dancers in fifth position, some in mobility chairs, some standing. The room erupts.

Liam stands clapping. He leans in and asks, "Can we come back again tomorrow?"

Sitting By Myself

JIM: It's about my right, my personal right, to define who I am. Now, is that part of disability rights movement? Sure, absolutely. I think also, by sharing all this with other people with disabilities, you're saying, "Join me in that right."

But, I think it's also about recognizing the creative spirit as part of your experience. You know, you have the medical part of your experience, you have the education part, you have the family part—you have all those parts. It's about intentionally creating who you are. And is that part of the disability movement? Sure. But it's more a part of a shared experience of personal power—for me.

As an advocate, you could get burned quick—you get burnt out quick, if you don't have some way to integrate the creative parts of your life—if you can't fill up the well again. So, is art part of the disability rights movement? Yeah, it is. But I'm not sure that you can say the disability rights movement is more than the creative movement. The disability rights movement is the creating of a new social attitude, in a way.

To say that I go up there and sing those songs for the people out there, for everybody out there, would be a lie. Yeah, it's great, if they can come and share the experience. But if I were sitting there in that room by myself, like I was when I wrote those songs, that would still be a pretty full experience for me, I'll be quite honest. And some of those people in that audience wouldn't get that from me unless they sat in a room like this and asked me.

That's Nice

JIM: Art gives you an avenue to reframe your sensual experiences. I use that as a tool to reframe everything. And the reason I do that primarily is because if you see something and get a reframe, then what happens is you have to stand up and say, "No, I really believe it is the way it is," or "No, I can think about it a different way."

But it comes down to what you believe at that point. If I say to a person with a disability, "It's okay to be angry about these things, because when you really look at them, they're ridiculous," I say it in a way that makes people stop and really test their beliefs.

I think creativity pushes that limit. It makes that reframe happen. It also is an internal reframe. It also creates for me an internal reframe. It gives me a new way to look at things.

It's about negotiating your human experience and sharing with others. And I guess that's all. I view this in a very real way, the art of negotiation. This is the way you tell people where you stand. This is what I believe I am.

So, when I express my disability culture or my Irish culture, this is my way of saying, "This is who I am." For me, you can like it, hate it, but this is who you're going to deal with when I'm in a relationship with you. And if you're willing to say, "That's where we deal," then you're probably going to be my friend. I may not agree with you on lots of things, but that's that.

I think artists do this all the time. "I'm going to set this out there. I'm going to create this for you and you can like it or hate it." The worst thing that can happen to a creative person is for someone to say, "Oh, well, that's nice." Because you put a lot of spirit into that and I believe I show a lot of my spirit in my work.

He Can Walk

Jim weaves my story into his. I'm supposed to be the interviewer, but Jim inevitably gets around to asking his questions. Then, at the end of telling a story, or four stories, to illustrate an answer to my original question, he brings it back to me and my story and what it means to me. He is always thinking of others.

The first time I interviewed Jim, we sat in a literally and figuratively cold, institutional room on the campus of The University of North Carolina at Asheville (UNCA). Those campus rooms are all the same: gray institutional tile, gray walls, gray ceilings—even the artwork in the room used tones of gray, a painting of gray shirts on a clothesline and a painting of a gray chair, empty, facing inward to a black corner.

Jim even had on a gray Hawaiian shirt with tiny palm trees all over it. The shirt was unbuttoned to show his conference t-shirt, sporting in blue “Disability is my Culture.”

Whalen and Purcell are both Irish names. We talked of all things Irish as I hooked up his microphone, set the tape and began recording. Being of the same ethnic group got us off to a great start in the interview. Though, honestly, the Irish in me is a bit watered down through the generations by marriage into other ethnicities, I still think we Irish share a look.

Standing us both side by side, you can tell we're both Irish. We're both stocky men, though Jim would say “stout,” which is truer in his case than mine. I'm just two

inches taller than Jim. We're round in face and fair in skin, with hairy arms and ears. We like a drink and a joke.

But Jim is real Irish—old school Irish. Jim grew up with grandparents who came off the boat from Ireland. He grew up in an all-Irish, all-Catholic neighborhood.

Jim laughs a lot. And he smiles a lot, too. When he gets serious, the dimple in his cheek disappears. The bottom of his mouth turns up and in, and with a flinch, his eyebrows move to the center as he thinks.

That is when I listen. Not as a researcher, but as a student of disability. I listen as a father of a child with a disability. I listen as a parent desperately wanting to understand his son and everything possible to make the world a better place for him.

In telling his story, Jim always asks me my story at some point. This time he asked me whether my oldest son, Liam, “knows” about Kenyon’s disabilities.

WILLIAM: I don't think he knows. Liam is sharp. He listens to everything. But I've been thinking about it a lot lately. Not only does “he know,” but if not, when and how will he find out and what will his reaction be?

Liam's kindergarten class went on a trip to the zoo this year. We all took off work and went on the fieldtrip with them. Some friends of ours went, too. They have an 18-month-old named Sean.¹⁷ After spending the day at the zoo, Liam said to me, “Sean can walk so well. And he is only 18 months old. And did you hear him talking? He is doing so well. That is really amazing.”

Kenyon didn't walk until a few months ago at age three-and-a-half. He still is nonverbal. Liam thinks all children are like Kenyon. Kenyon is the norm.

¹⁷ Pseudonym.

One time after a physical therapy session when both boys were younger, Liam said, “I remember when I got to do therapy.” Well, he doesn’t remember that because it never happened. He just thinks all babies go to therapy.

He is going to be in first grade next year. I know at some point, someone is going to say something to him about his brother. Maybe a kid, maybe a teacher; I don’t know. But someone is going to say something that will be an epiphany for him. He will realize his brother is different.

We never got all those children’s books that explain to the kid, “This is your new baby brother and he is special and different.” We never took him to a workshop to help him understand that he has a disabled brother. We just wanted him to have a brother.

Right now is a beautiful time. Kenyon is just his brother. Kenyon isn’t disabled. Kenyon doesn’t have Down syndrome. Kenyon doesn’t have hydrocephalus. Kenyon is his brother who gets into Liam’s Match Box cars and scatters them, knocks down the towers he builds, follows him like a shadow. Kenyon is his brother who he kisses and hugs and gets mad at sometimes, too. I worry about the day that might change.

Stare into This Light

JIM: My blindness was from birth. It was congenital. And my parents, on the first visit to Iowa City, we ran around to 300 eye doctors and ophthalmologists. We went to the university. I was sitting in this chair and my eye was on the screen 20 feet high behind me. It was a classroom. Doctors were gathered all around me. And all these people are saying, “Stare into this light.” I was a five-year-old. I didn’t know what the heck was going on.

My mom was crying. I just didn’t get that. What’s the deal? They weren’t hurting me. My mom was just crying and I remember the doctor saying, “I’m sorry, there’s nothing.” I remember my mom just basically flipping out.

That was a couple of months before my younger brother was born. He’s five years younger than I am. So, in terms of sibling relationship with him, it never dawned on him at all during his whole life, until maybe he was 10 or 11, that his brother was any different from any other big brother.

I’m sure he knew I couldn’t see. We had specialists come to do this or come to do that, but it didn’t dawn on him at all that that I was any different than any other person. It just didn’t.

Now even today, when I picked up the guitar and started playing, this was about three years ago, he was like, “That’s so cool. I’m so proud of you for doing that.” And I’m like, “Why? Because I can’t see?”

He said, “What?” I go, “Well, are you proud of me [learning the guitar] because I can’t see?” And he said, “I didn’t even think about that. It’s because at your age [47], you decided ‘What the heck.’ Today’s the day to just go ahead and do it . . . I don’t ever think of that [your blindness].”

For my older brother, I’m always going to be this younger, smart-ass kid who has a disability, who doesn’t take his pity, which also was a problem for my older brother. And for my mom that’s a problem. It’s a problem.

But for my younger brother, it’s not a problem. For my dad, it’s not a problem. I think it has more to do with personality traits than it has to do with anything.

The best advice I give—and this is the advice I constantly give—is talk to the kids about it. Talk to Liam about, “What do you think?” I think although you can dread the day it’s coming, it’s going to come.

But don’t do exactly what you don’t want other people to do. You don’t want other people to assume. So it’s part of your job to explore. Kids are remarkable in what they’re capable of bringing.

Explain that it doesn’t change Kenyon. Kenyon hasn’t changed. You don’t have to change either. That’s your choice now. I go back to, “This is normal for me, so whatever problem you have with it, that’s your problem, not mine. Sorry.” And I know that’s sort of crass. But, no, it’s not.

This is normal for our family. Whatever problem you have with it—that’s your problem. That’s not my problem.

Look, Liam is going to have an idea of Kenyon that is different from the general assumption of what his brother should be. He has to change that negotiation somehow or he has to live with the difference between the way maybe some of his friends would categorize Kenyon and the way he sees his brother.

His Bending Sickle

Jim's youngest daughter, Cassie¹⁸, always hovered nearby during my interviews with Jim. She spent hours creating an intricate pet wonderland in the living room with her *Littlest Pet Shop* animals, but she was just close enough to hear us.

Every now and then she would come in and give Jim a giant bear hug, which he would always return no matter where we were in a story.

I think we talked about Cassie the least because she was always there in the shadows listening to her father's stories.

I told Jim the story of Kenyon's brain surgery. Toward the end of the story, Cassie ran into the dining room and jumped in Jim's lap to give him one of those bear hugs. As Jim rocked her, she turned back and I could see their faces side by side together. While his older daughter, Amy,¹⁹ is the spitting image of Jim, Cassie looks just like her mother, Melody²⁰. But Cassie has Jim's piercing, light-green eyes. My Grandma Dorothy would have said that Jim has wise eyes.

When Jim listens to you, he looks you in the eye with those wise, light-green eyes. When he really gets into a story, he begins to appear to fade away. He looks to the side. He looks up. When really intent, he looks down. At first I thought he wasn't paying attention, but I soon realized it was the exact opposite. The more Jim lost eye contact, the more into the story he was. He later explained to me that "eye contact" is just an illusion

¹⁸ Pseudonym.

¹⁹ Pseudonym.

²⁰ Pseudonym.

he keeps to make the person he is listening to feel comfortable. When he looks you in the eye, he is not really seeing you. When he is looking to the side, he may be trying to see your face with his peripheral vision. When he is looking down, it is a good sign every part of his being is into the story; and when he rises up nodding with eyes closed, perhaps crossing his arms, perhaps turning his head left or right, you know he is really into your story.

WILLIAM: Kenyon came two months early. He was 32 weeks at birth. Of course we found out he had Down syndrome. The doctor told us he suspected it. We waited two days for a test to come back, and bam—there it was.

But we had the prematurity to deal with. And we did. After four weeks in an intensive neonatal care unit, we took him home. A week later, the doctors told us he had hydrocephalus. It is when your brain will not drain the fluid that lubricates it. It is fatal, if surgery is not done quickly. The neurosurgeon told us he had only tried this operation on a baby this small three times before. One died, one had severe brain damage, and one was fine. But there really was no choice. There wasn't time to even drive to another hospital for a second opinion.

So, at five weeks of age and a total of five pounds of body, Kenyon had brain surgery. While waiting for the endless hours of surgery to end, my wife's 94-year-old grandmother called our cell phone. She recited a sonnet to my wife. She's like that. She has memorized dozens of sonnets. She plays the harmonica, too. My wife went to a public computer in the hospital resource room and Googled the sonnet and printed it out.

Once Kenyon was out of surgery and in the intensive care unit, we taped the sonnet to his bed. The next day, his neurosurgeon came into the room. This man spent five hours poking around Kenyon's brain, inserting a shunt, saving his life. I have no doubt he is one of the smartest people I have ever met. Fascinated with the sonnet, he asked what it meant.

I told him that, to me, it shows the power of unconditional love. He looked confused. It means, I continued, that though I've barely held this baby, though he may never speak, never walk, never return an ounce of love back to me with any outward sign, though he may die today, what I feel is eternal and unchanging despite how he looks, what he is or what he is not. The surgeon looked even more confused.

I said, "This poem gave me hope when I needed it most." He nodded and said, "OK," and proceeded to explain Kenyon's chart.

Kenyon is taking his first steps and saying his first words; but it's a funny thing. If the shunt the neurosurgeon put in his brain fails, he could die, if we don't get him to surgery within a few hours. It's not something you can dwell on. But Kenyon is no different than any of us. We all could die at any minute. It's just when you pat Kenyon on the head, you feel the shunt under his skin, and you are reminded how fragile we all really are.

Sonnet 116, by William Shakespeare

Let me not to the marriage of true minds
Admit impediments. Love is not love
Which alters when it alteration finds,
Or bends with the remover to remove:
O no! It is an ever-fixed mark
That looks on tempests and is never shaken;
It is the star to every wandering bark,
Whose worth's unknown, although his height be taken.
Love's not Time's fool, though rosy lips and cheeks
Within his bending sickle's compass come:
Love alters not with his brief hours and weeks,
But bears it out even to the edge of doom.
If this be error and upon me proved,
I never writ, nor no man ever loved.

Platform

JIM: I come from a state, I come from a nation, I come from a family. My heritage—I'm of Irish heritage. I'm a Catholic. I come from these things, which are parts of my identity. They give me a certain standing, a certain status, a certain outside understandability to folks. Also, a certain sort of pride.

I mean, I know a ton of Irish IRA songs and my uncles and my grandmother and the whole

bit. It's a source of pride, but it's also a source of "This is a platform I can stand on." I am a part of this. My human spirit is part of this. And that's where I think the concept of disability culture comes in.

And to make it a thing to be proud of allows us as people with disabilities to have a platform to always stand on. To say, no matter what happens, there are people out there like me who understand my experiences, who I can count on so I don't ever have to go back to fighting that fight to define who I am to the fullest of degrees. I can always pull from those tools. And that's what disability culture is for me.

And that's what I hope to create when I talk about disability culture—this idea that the disability rights movement or disability or the ability for people with disabilities to define their identity in our society has moved up to this certain point. And this is where disability culture is. And you never have to fall back down there to fight for that right to do that without help, without a peg in the wall, without a ladder to start up on. And that's what I see disability culture is. And I see all cultures as that.

Every day, in my opinion, we all do this grand game of social negotiation. You're a white male, you're a black female, and people are, especially in this society, in our society, quick to define who you are. And disability culture gives you a bag to say, "Here's how to define me. Define me as an artist. Define me as one of this group of great people who have come this far."

So this is where the negotiation starts, and you have a choice of whether to identify with that or not. And for me, let's make that culture something to really, really, really understand. It is something you have a choice to identify with. That's the concept for me.

But in my view, people with disabilities really need to define that culture intentionally in order to change some of the definitions that already exist. And lacking the motivation to do so detracts from those people who would otherwise share that experience. So I view it as an obligation to build the culture. That's where it ends for me. You can't do it by yourself.

Snake Alley

I left Peoria early Monday morning. The day prior, I had driven 14 hours with only stops for gas and a one-hour stop for lunch. Boone, North Carolina is a long way from Washington, Iowa, where Jim lives.

About an hour outside Peoria, the highways begin to shift from the four-lane open highways dotted with cookie-cutter stores—Dunkin’ Doughnuts, Wendy’s, Starbucks, Best Buy, Home Depot, Old Navy, and Wal-Mart—to two-lane highways absent of life. Long stretches of field and wood are divided by long, straight stretches of pavement reaching out of Illinois toward Iowa.

I crossed the Mississippi at Burlington where the river divides the Prairie State and the home of the Hawk Eyes. Thump, thump, thump, as I drove across the mighty Mississippi I could hear the tires hit the freeze-line gaps in the concrete; thump, thump, thump. It took forever to cross that bridge. There were no other cars, so I drove slowly, trying to get a sense of this smooth, wide body of water spread out like a tablecloth across the green landscape to the north of Burlington. Thump, thump, thump. I rolled the window down, but could not smell the water. Thump, thump, thump. I listened, but could only hear the highway under my tires. Thump, thump, thump.

Once on the other side, I stopped to take a photograph of the bridge. It was a monster—a suspension bridge with bright, white cables stretching down from two sets of tall towers to form a sort of skeleton of two teepees. Liam has a toy Geotrax set with a bridge just like it.

The highway awkwardly splits the town as though a child giant set it there by mistake while splashing in the mighty Mississippi. A green sign by the highway reads “Snake Alley” with an arrow to the left. My curiosity couldn’t resist.

Snake Alley is hidden on a hill between the antebellum three- and four-story brick homes in the Heritage Hill district of Burlington. It’s a steep, rough, blueclay brick road,

with seven hairpin turns that local marketers bill as “The Crookedest Street in the World.”

Snake Alley dumps you into downtown Burlington, about seven blocks from the river. Here the buildings are mostly empty, save for birds darting out of broken windows and the ivy growing skyward. As you drive toward the river, the activity picks up with coffee shops, antique stores and bars, until you find yourself on the waterfront bellying up to the river.

Standing on the side of the Mississippi, I picked up a rock and threw it. It seemed a drop in the ocean—it barely left the shore. I could see the other side, but it was a world away.

I bought a coffee, got back in the car and headed toward the small town of Washington. I just wanted to stop and see the town Jim was born in. And I wanted to stare, just for a moment, into the beast that is the Mississippi River.

Last Rites

JIM: I have lesions on my retina. They've never gone as far as saying it happened because of too much oxygen at birth, but I was a little over four weeks premature and that would be consistent with that. I was small—a little under 4 pounds. And I lost weight. So, I think at one point, I was 2 pounds and something. I survived it.

I was born in Mercy Hospital, which is ironic. The nurse, right away, when I was first born, within the first few hours, gave me the rites. In the Catholic religion, at the time, if you weren't baptized, then your soul was going to go to limbo, whatever that is.

So, if it were an emergency, anyone could do it. One of the nurses at the hospital did it.

They baptized me and did the whole thing. I was anointed. And since it was a Catholic hospital, then they administered last rites.

The Psychedelic Volleyball

JIM: My vision? It is like looking through a kaleidoscope. If I look straight ahead . . . I am looking right at your face right now, or I believe I am looking right at your face, or pretty close to right at your face . . . at the point, right here where my two fingers are, I can't see my fingers at all. I can't see the place where my fingers go together right now.

What I see there is this sort of psychedelic, kaleidoscope, psychedelic light flashes, yellows, whites, purple. That's interesting because I never really described it. There aren't any reds. I never even thought about that, ever. That's what I see there.

The pattern is more or less a circle. And if I'm just looking with one eye, it's still very much in the center and it's still more or less a circle. From about right here, my blind spot or whatever you want to call it, extends about to here. I do have peripheral vision.

The problem or the issue here is that your peripheral vision can't focus, so you can't see detail. And no one can. You don't think of it that way. You only focus with your central vision . . . when I turn to focus, it would be the blind spot.

I can't see that. But the motion—for instance, I can see my hand moving fine. I can see my hand moving that far away fine.

I often tell people I can see much better when I'm moving because you tend to use your peripheral vision more when you're moving. Or when something's moving, I can see it much better than I can if it was coming straight at me or standing straight in front of me. So, that's sort of my vision.

In terms of visual acuity 20/20 is normal vision, so to speak. You can see at 20 feet what normal people see at 20 feet. So my usable vision, in order for something to be big enough for me to see without focusing on it, fine detail, that's how they figure out what your visual acuity is, so mine is about 20/400.

Now, what that means is, with the detail in your central acuity corrected with glasses, if you could see at 20 feet it would look to me in the same detail as you could see at 400 feet. Basically, if it's something you could probably read at 20 feet fairly comfortably, I'd have to be a foot away or so.

A street sign, for instance; that kind of thing. I'm reading it with my peripheral vision, with the amount of focus you get in your peripheral vision. That's why things have to be large. The larger it is, the less you need to focus. That's exactly the way to put it. You have to pan, off to the side.

Sometimes I tend to not even think about it anymore and it causes some problems, quite frankly. That I've got this blind spot right here, because I never had this big thing about looking somebody in the eye. I don't want to look at them in the spot where I can't see them. I don't want to do that. And yet that sometimes has an effect.

I remember thinking one time in school, "If I look right at this teacher, I can't see them. But they seem to think I'm paying attention more." I just kind of picked up that as a technique. And I think it's become somewhat automatic, but sometimes I lapse out of it.

Many times, I just close my eyes and I don't even think about what the effect of that is. Or I'll look down. A lot of times, I'll look down. I don't think about looking down; I just am looking. I'm just not looking.

This thing does become irritating. For me sometimes, the kaleidoscope effect does get irritating. I guess that's the only word I can say. Sometimes, if I get aware of it, and sometimes I do, it does get irritating. And I don't know how to vocalize that in any other way. It just gets irritating.

I don't know, because if you then start trying to focus through it, maybe. And I'm almost 50, and so I should be used to it, right? And it is normal for me. But sometimes it gets irritating—go away!

On a big screen the movie is so big that focus isn't all that important. I mean, it's not as important as what you might think because the movie's this big. I really don't like exceptionally dark movies. Both dark in nature, but also dark in cinema because it's harder for me to pick up what's going on. We live in a society where there's lots of dark in movies, quite frankly.

The other thing about movies, the sound is so good in most theaters. In some theaters, in most theaters, the sound is so good. And that's really cool. And I enjoy that a lot.

If I watch sports on TV, I have to be right close to the TV to actually see what's going on, so most of the time it's a listening experience.

The psychedelic spot, it's more of a volleyball size. There's little spots within where I can see some things. Like I can see part of my hand here, like this part; and there's still more of that kaleidoscope down here, a little more than you can see out here, but not enough to pick up.

Could I hold a book right here and read it? No. So that's kind of how it works. I mean that's kind of how it is.

Creating Space

I spent most of my time interviewing Jim in what he calls his “creative space.” The kitchen and dining room of his house blend together with a wide countertop in the middle, covered with stacks of mail, a box of envelopes, a Hannah Montana notebook, an old hat, an MP3 player, spare nickels, pennies, an old watch and various kid’s meal-type toys. I felt at home, as would anyone with kids of their own.

A bathroom juts out into the space with its walls leaving a nook on both sides. On the kitchen side is the laundry. On the dining room side is Jim’s creative nook.

Flanked on either side by glass-door hutches, one displaying his wife’s collection of snow globes and the other filled with stacks of China and glassware, Jim’s creative nook is about five feet wide by four feet deep. At the back is a window covered by a lace curtain that allows in light and sound from the backyard where his 11-year-old daughter, Amy, plays with the other neighbor kids.

Amy and her friends often stand just beyond the window, watching a hot tub heat up. They keep pushing a button in hopes of heating it up faster and come inside to give us hourly reports of the temperature. Jim had just hooked it up and filled it before I got there and says it will take a couple of days to get warm enough for the girls to get in.

Two dusty acoustic guitars sit abandoned in Jim's nook, one needing to be restrung. The guitars rest atop boxes full of vinyl albums, stacks of books, and unemptied plastic bags from a recent shopping trip.

Dividing the boundary of Jim's creative space from the dining room is a stack of stereo equipment: two CD players, four cassette decks, two turntables, an equalizer and a receiver. Two large speakers rest on either side of the stack, and jewel cases—empty and full—are scattered about.

A snake pit of black, brown, purple and blue cords lead out into the middle of Jim's space to where a plain folding chair sits. To one side is his amp; to the other are two guitar stands, one with Jim's electric guitar and the other with Amy's blue bass guitar. Foot pedals form a semi-circle in front of the chair, where a microphone stand rises up.

A print of the oil rendition of Eric Enstrom's photograph "Grace" hangs on the wall behind Jim's chair. This is the famous oil painting of a bearded old man praying over bread with a large Bible sitting closed with a pair of glasses atop it. Hanging on the same wall only inches from this classic American painting is a framed print of Sponge-Bob Square Pants.

I Don't Want to Be Normal

JIM: "I Don't Want to be Normal" was completely born in that chair. And it's completely stayed in the space of that chair. And I probably need to sit over there to talk about it.

But the concept of it was born from a friend of mine who plays guitar down the street. We were sitting here playing, and I was playing one of my other songs and he said, “You know, some of these concepts you’re talking about are just normal for everyday life.”

He said, “Did I offend you?” I said, “No, but tell me more about this normal thing that you’re talking about.”

“Well, I didn’t mean to offend you.” And I said, “Well, what if I didn’t—what if I don’t want to be normal?”

And he goes, “Well, that’s an idea. I don’t even know if we want to go down that road.”

Well, of course, then the next morning I wake up thinking, “You know, what if I don’t want to be normal. What if I make a conscious choice to skirt back and forth across that line. If I just tell people, ‘I no longer care for your concept and I don’t want it anymore.’ And be right up front with it.”

Not too long ago, I sat down and I was working on this song called “The River of Money,” which is a really dark and evil song, which is okay too. A lot of my songs came from this song. I kept stealing things out of it and now it’s finished. Now it’s done. But, I thought that I should sing “I Don’t Want to Be Normal” in the same style.

I do this in sort of an Irish-English accent, which is something I heard a ton of when I was a kid from my grandparents. To the unknowing ear it would almost be sort of this Liverpoolish kind of thing, but it was the voice of my ancestry. And when you hear it, you’ll think, “That’s kind of strange.” But it adds some sort of almost Pink Floydian element to it.

Swimming the Mississippi

JIM: My grandfather on my mom’s side lived within a few hundred yards of the Mississippi River. There were places—we call them beaches, but they were sandbars. There were some that were in the water and there were some that were along the shore. And we would go visit them quite often on family picnics.

When I was in high school, I had friends who had boats. You know how in many towns, people cruise Main Street in their cars? We did that too, to some extent, but there were a couple of sandbars in the river, so we went there.

We’d fish. Catch catfish, bass, all along the river. We water-skied a lot. If you can learn to water ski on the Mississippi, you can water ski anywhere.

There were barges. You think of a barge as this thing that lumbers down the river not very fast. But it leaves a wake and an undertow of about three or four feet bumps in the river. If you're waterskiing over a barge wake, which you are often doing after you get fairly good, then you get on the lake and it's like waterskiing down smooth silk. There are logs and all kind of debris in the river. There used to be, down by the old bridge, public ski jumps.

There was a test of manhood to swim across the river from the Iowa side to the Illinois side. If you weren't 16, you didn't try. And it's a long ways across. Usually there would be one or two parents in a boat. Just in case.

The water would carry you about a quarter-mile downriver. If you would happen to tire out halfway through, the current would carry you a long ways.

I did it. You do a lot of swimming a third of the way, so you had a pretty good idea, if you could make it or not. Come to think about it, there wasn't a lot of disdain, if you didn't make it on one. I know one person who made it on the fourth try.

Generally, the big reward was to go to a Country Kitchen Restaurant afterward and then they would buy you a pounder hamburger. But the funny part about that is, after you swim across the river, by the time you get back, you're really too tired to eat anything. You're just about ready to go home and sleep.

CHAPTER II

ODE TO THE PITY MERCHANT

“Ode to the Pity Merchant”
by Jim Whalen, 2007

It's snake oil wrapped in pity
But you dress it up so pretty
And you make it smell like honey
But it still sells for blood money

You keep us on the edges
'Till it's time to ask for pledges
And you really wish that we were gone
Till there's another telethon

When you can
Sell her limp leg to the firefighters
Sell my blind eyes to the Banker's wife
You can pocket a cool grand or two
And all it costs is my shot at a life

Chorus—As you sell my parts and pieces
And you try to take control
But I won't be sold with pity
I am whole, as I am, I am whole, as I am,
I am whole

Now you pity merchants should be proud
In the daylight we see your face in our crowd
But at night you slither for your tainted salaries
And banish us from your social galleries
And you never sell our skills to your boss
Or never think not dating me's a loss
'Cause you're prejudiced and man I've seen it
You never say we're welcome and really mean it

Chorus—Cause you gotta
Sell our parts and pieces
And you try to keep control
But we will not be sold with pity
We are whole, as we are,
We are whole, as we are
We are whole

Now listen to me children
A storm it is a buildin'
And I don't want to alarm ya
But it's about to rain bad karma
And I wonder if the pity merchant knows
That there's a bell and for whom it tolls
When the lightning strikes and the thunder rolls?

God help you if it's your own son
Or it is your daughter
That you traded for some pity and
Left out for the slaughter
Because soon we'll all be rallied
And you sins will all be tallied
And forgiveness won't be found
When the truth spills on the ground
And righteousness sees the light of day
And the sword of justice swings this way

Cause we are not just parts and pieces
And we're going to take control
And we won't be sold with pity
We are whole, yes we are
We are whole, we are whole

Mining Versus Traveling

I found Jim's town of Washington just fine. The city is the county seat of Washington County. Jim tells me the county is one of the leading hog producing areas in the nation.

With just more than 7,000 people, Washington sits in the center of southeast Iowa. Much like other towns across Iowa, the people live along a north-south grid, and east-west streets that converge in an old-fashioned downtown straight out of a Norman Rockwell painting. Just outside the city limits, the sidewalks disappear and rolling farmland stretches as far as you can see.

Most of the farms remain unplanted. Unusually high amounts of rain have kept farmers from planting corn, soybeans, and other crops. The radio farm reports on the few and far between stations indicated this could be the start of a severe food shortage for America, if the rains do not stop soon. The weather report called for record rains this week. Combine the expected record rainfall with the already saturated ground, and add in a record snowmelt coming downstream; the resulting warnings for possible major floods for the Iowa area are already coming out. The rivers are rising slowly, but surely.

Once downtown, I called Jim on my cell phone and he talked me through the ten blocks east and four blocks west to his house. "I'll go outside and wave at you," he said.

His two-story house looks like the other homes in the neighborhood. The homes stand tightly packed in deep lots with small front yards and a ribbon of sidewalk connecting one to the other, often with garages in the back. Jim's garage door was wide

open. Classic album covers decorated the inside of Jim's garage, which looked more like a workshop filled with boxes, tools, bikes, and no space for a car.

We made small talk about the trip and then made our way inside the back door of the house, where three green Lawn-Boy mowers stood in line along the back steps.

We spent an hour talking about our families. As Jim began to tell his stories, I asked if I could go to the car and get my tape recorder. "Sure," he said.

JIM: Here's my question to you, then. And this is probably really unfair, but that's OK. I'm not worried about that quite frankly. I ask people this when they do research. Are you looking to be a miner? Like when you're done, these are the jewels you found here?

Or are you looking to be a fellow traveler? We went into this country together and we saw these things that gave meaning, seemed to give meaning to this person's experience, or seemed to give meaning to my experience with this person.

Both of these are perfectly great things. A miner or a traveler—you don't have to decide now.

Defective People Industry

JIM: Sometimes the professionals that work with people experiencing disability have a sense of "I can help you, and I'm better than you." But sometimes it's "I'm an expert. My expertise is worth this money. This is hard work, so I should get paid for it."

And it is hard work. Don't get me wrong. There's a term that is used by some called the "defective people industry." I started going through this personally because if I made my living dealing with disability issues, then I'm part of the defective people industry. If there are not defective people, then I don't have a job.

There are people in the defective people industry that work to keep the industry going. We should be wise enough and smart enough and creative enough to move everyone's life forward. But I'm not sure that our society in general is at a point where people recognize

that. I come back to “Are you going to participate in the defective people industry?” Or are you going to deal with the question “If not me, who?”

“Ode to the Pity Merchant” Can’t Be Happy

JIM: I listen to rhythms in the street and sounds, and the music comes from that. Then, the lyrics come from phrases that seem to be poignant. Phrases that seem to be poetic in a way, but also just sort of pointed things.

When I write the germinal idea for a song, I sit in a chair in my dining room—a folding chair—and sing the lyrics and play the sounds and think in my head. And I may play for an hour and write nothing, but it’s a process of ideas and music running around each other until they catch up. After playing for about an hour, a song will finish itself. There will be some touch-up; but generally, it’s a very open, flowing process. But words are a more structured process.

I have this song called “The River of Money.” It’s about how people make money from the disability industry by never moving it forward, but just siphoning the money off. And yet I’ve never sang it in public. I’ve never really finished it. It’s spawned a half dozen songs. I steal things from it. I’ve stolen the tune from it three times now. I’ve stolen some of the lyrics from it. I’ve stolen some of the ideas from it. It’s a wellspring of songs.

Like “Ode to the Pity Merchant”—one doesn’t think of caregivers or someone like that as a “pity merchant,” but if that pity doesn’t sell, that person loses their work.

“Ode to the Pity Merchant,” of course, can’t be a happy tune. I start maybe with an A minor chord, because that’s not a happy chord, and just start rolling some things from my head and that’s how the process sort of comes.

And I never force it, because I think you get crap. I don’t take an event and say, “I need a song for that.” I can’t. It loses the integrity for me. I listen. I listen. I listen, listen, listen, and listen. Listen to people talk. Listen to people in their daily experiences. My music is very daily experience-oriented.

I try to reach out and say, “I heard what you said” with my songs. And that’s how it comes. It’s hard work. I mean, it’s easy work, but I am a slave to that process.

There Was No “Jim the Disabled Kid”

It had been a year since I said “goodbye” to Jim at the festival in Asheville. Though we had corresponded by e-mail and talked on the phone right before my trip to Iowa, I had not seen him face to face in a year.

At the SDCF, his hair was cut short, so short that I didn’t realize he was balding a bit on top. Seeing Jim for the first time in Iowa, I did a double-take once I got close enough, because his hair had grown out on the sides and in the back, emphasizing the bare spot on top. At the SDCF Jim had looked hip with his buzz cut, Hawaiian shirt and jeans. Now he looked very Midwestern. He wore a dark blue t-shirt and black jeans held up with a set of black suspenders. His work boots were dirty. He had a thin layer of stubble on his face and the wind blew his hair into a wild bird nest shape. He could have just gotten off work from the steel mill, the barge, the automotive factory, or the hog farm. He looked like the stereotypical hard-working Midwesterner I knew from television and movies. His handshake, though, hadn’t changed—it was still strong. And his voice was as welcoming and warm as the first day I met him.

We always started with small talk about the weather. The rising rivers were on everyone’s mind, it seemed. Most of the yards, including Jim’s, had not been mowed in a while because of the constant rain. Those that had been mowed were dotted with green clumps of wet grass. A light rain always seemed to fall from the alabaster sky. Heavy drops from the tall oaks and maples outside Jim’s house soaked through your shirt.

It would have been nice to interview Jim outside under the wide open Iowa sky, but the weather never allowed it.

JIM: I've never lived anywhere but Iowa. I grew up in Burlington. Hard working people in Burlington: German and Irish.

Some of the Irish people married some of those German people. And in the good Catholic tradition, they had 8 or 10 kids—maybe not so much anymore. But in my high school, for instance, there were only three people who didn't have a relative. I was one of them. And that was weird. Now this was a high school of 300 people, and there were only three kids who didn't have a relative who was in their class. We had 12 families that had over 10 kids in school at the same time. It was not an unusual circumstance to see a parent of one of the high school students to be 68 or 70 years old.

The other thing that probably had an impact on my music as far as the normal/not normal thing is my family dynamic. There was not this "There's Jim the disabled kid. He's not going to work." There was no such option.

I was going to make money cutting lawns or having a paper route or doing dishes at some restaurant or whatever. You're going to get some money somehow. And that went along with this attitude of the Catholic schools that "You're going to learn this somehow; every kid is going to learn this somehow."

And I will thank those nuns until the day I die. Especially in my grade-school years, because there was not a question of whether one, you were included, or two, whether you were going to be given a pass, or three, there were no special circumstances under which some kid who stepped through that door wasn't going to learn, whatever it took. And it was whatever it took.

One Hundred Problems

JIM: We had these mathematics worksheets that all the kids had to do at a certain speed. They were laminated and you had to get through 100 problems in 160 seconds. They worked on this mastery idea.

Well, I couldn't read them fast enough to get through 100 in 160 seconds. There was no way I could. They knew I knew the answers, but instead of saying, "OK, you can have

three minutes,” or, “You can have four minutes,” they had one of the nuns sit there and read them as fast as she could while I answered as fast as I could to make sure I could do it in 160 seconds.

They would sit there during recess time with me reading these to see if we could get it, with reading, in two minutes. So, this nun was just sitting there and I had to know the answer practically instantly. When she would say, “Four time,” I’d be clicking through the table in my head to say whatever came next just to get this done.

They had the patience of Job. They didn’t care. They were going to get this done. There was no doubt that every kid was going to do this. And it was a matter of resolve that every kid was going to do this. It was just going to happen.

We Have a Kid Like “That”

Jim is a good listener. He gives visual and verbal feedback. He nods his head or says “yeah, go on, that’s right, I know, I see, oh, interesting.”

The more time I spent with Jim, the more our interviews slipped into story-swapping. I found myself abandoning my carefully crafted list of questions for stories that posed problems. I hoped Jim had the answers.

WILLIAM: When I told Stacy²¹, that I had started graduate school in liberal studies, he joked, “What is liberal studies? Do you sit around studying Bill Clinton and Al Franken all day?” That is Stacy.

I have a dozen nieces and nephews and the oldest one, Mary²², graduated in May. She is Stacy’s oldest daughter. The family all gathered to celebrate at Stacy’s house. We were sitting after dinner having the usual small talk of the day. I had Kenyon in my lap. My wife was sitting beside me.

Stacy said, “You know, we have a kid like *that* in our scout troop.” That was the moment of

²¹ Pseudonym.

²² Pseudonym.

decision. I've always struggled with it, and my wife struggles with it, too. This was Stacy's day—the day his oldest child graduated from high school. Should I strike back? Should I try and put him in his place? "What do you mean a kid like *that*?"

It is that word, "that." Like Kenyon is an inanimate object. It is pointing out that he is different. It is insulting. It is also lumping Kenyon into this stereotype that every kid with Down syndrome is just alike. And because he knows one kid, who he probably is afraid to interact with, he thinks he knows our experience. And he thinks this is a way to talk to us—to *bond* with us.

It's like Kenyon isn't even there. He didn't first come say "hello" to Kenyon, or ask to play with him. I don't think the man has ever held or even touched Kenyon.

I think the next time I see him, I'll tell him that scientists discovered that Down syndrome is transmitted by particles in the air, then watch him go around trying not to breathe.

Relatives always say the worst things. I think it is easier to speak up and correct someone who is not a relative. Maybe it is because you've got to live with this relative for the rest of your life. But that seems all the more reason to speak up and set them straight.

But, no. Not today. This was Mary's day. This was her graduation moment. "That's great, Stacy," I said, and forced a smile. "That's just great."

Dealing with It

JIM: People think that by standing up and taking a role in the situation that they're creating a conflict. I would argue that the conflict was already created. If they choose to be absent from how it's going to be resolved, that's their choice.

By the school system's lack of understanding, they've created the conflict. The conflict is in the path of that kid learning. Now, who gets in the way to sort it out? That's a whole other situation.

It's a bit naïve to think that, if you weren't in the situation, the conflict wouldn't exist. It's there. The conflict that your wife and thousands and millions of other parents experienced—it's already there. People feel stepping in creates something that would be more harmful in the situation than helpful. But in reality, that situation already exists.

It's really important in terms of being an advocate. It's important to understand that for the most part, the advocate coming into the situation, whatever it is, isn't creating the situation.

They may be pointing out the situation and changing the situation, maybe disrupting the situation, but the situation exists.

It doesn't make it any easier or harder to deal with. It's a different thinking. Sometimes, by not stepping in the situation, a person just adopts a lot of internal conflict. And it may feel better to deal with the internal conflict than trying to deal with the external one. It may feel better to say, "I can take this on. I'm a big person." But the person better darn well have a way to refresh themselves while they're eating their guts out inside.

You got the feeling when your brother-in-law said, "I've got a kid like that." That conflict exists. That conflict exists between what your brother-in-law thinks and the relationship that he will have with Kenyon. He's already identified that that conflict's there. So, while it's uncomfortable to step into it sometimes, it's there.

You didn't create it. And guess what: He'll say things like that again. I don't know him, but there will be an opportunity again to say, "What do you mean?" Because that's the conflict that his assumptions create.

And so it comes down to choosing to place it somewhere else. It comes down to choosing where the conflict exists in a more honest and genuine way. And then, once you've done that, of course, you have a responsibility to act based on that.

Summoning the Dragon

JIM: When you run into that conflict situation that is what I call "dragon fuel." The thing about dragon fuel is that you can eat it and burn all that fuel in your own vat—and what does that do? It burns your guts. It doesn't do a whole lot.

Or you can summon that dragon, who knows how to use that fuel. And not that the dragon is going to smoke everybody off the path, but you turn that around saying, "You've created this situation for my son, and as his parents, as parents who participate in our kid's learning, you've created a situation where that's just not possible for us to help in that process now."

And so you put it where it belongs—that dragon fuel. You have to sometimes think about that as summoning that dragon instead of eating that fuel.

I did a workshop called "Summoning the Dragon." I went around the workshop and asked every parent, young adult, and kid who was in there—what is a situation where you ate that fuel, where you should have summoned that dragon? And everyone had more than

one example. I used to eat the fuel, too. But I remember the day specifically when it reached a critical mass. I wasn't going to eat that fuel anymore. I summoned the dragon.

Always Stops Right Now

JIM: I had a paper to do. I did it and took it to the office of Special Support Services because I heard they typed papers. This was when I was a student at Central College (Pella, Iowa) in the late seventies. Quite frankly, I should've typed this paper on my own. But I had not managed my time particularly well, and I had this rough draft of the paper that I asked them to retype.

I dropped it off and went back later to pick up my typed copy. Right on the top, it had, "This paper was completed with assistance from Student Support Services," and it had their logo—the Superman logo—right on top of the paper. I told them, "I don't want this on here. I don't want this on my paper."

"Well, the professor's not going to mind that," they said. And I said, "Well, can you put on there, 'Final copy typed by so-and-so' instead?" They said, "No; this is what we use." And I said, "Then this is not acceptable to me."

Because they hadn't helped—they had just typed it. They had retyped a paper that was fairly well-typed, but not perfect. That's what they had done. And I just thought, "No!"

I said, "I'm not going to bring anything here again." They said, "Take your paper." And I just threw it down and said, "I'm not doing this, do you understand? And I don't think this is what you should do to people's papers."

"Be specific," is what I said. "Well, we're sorry you're unhappy." "Well, I'm more than unhappy. I'm going to go to my friend Mark Coates who runs the student newspaper and I'm going to talk to him about this. I'm more than unhappy. You don't understand what I'm trying to get at here." I don't think I was particularly good at teaching them, quite frankly. But I wasn't going to eat that.

Central College is a small college and this was in the student affairs building and the dean of students had his door open. At the point I threw the paper on the floor and said, "I'm not going to do this," he came waltzing over there and said, "Is there a problem?"

And I said, "Yes, there's a problem. I'm not going to turn in a paper with this on here." And he said, "This is how we always do things." Well, that was the wrong thing to say to me at that point. I said, "Always stops right now."

Superman

JIM: Dean William Hines²³ knew that my friends on campus were the people at the radio station. We were an outspoken part of the campus. People knew us. And he knew that I would go to all of them and say, "Look, I'm real irritated at this."

And he goes, "Well, look, is there anything that can make you happy about this?" And I said, "Quite frankly, no. There isn't. I will turn in my original paper the way it is."

They didn't have my (original) paper. They had thrown it away. They were done typing it. So I had nothing even to compare what they'd typed with what was on the paper at this point. All I had was this paper with Superman on it.

The student editor wanted to do a regular story. They wanted to call the sources and see what happened. And hey, that's cool. That's what they should do, right? That's good journalism. Well, they got the dean involved and the professor and all. And we had this meeting. The idea that this was going to be in the paper got the attention of lots of folks, because the paper was read by lots of people.

In this meeting, the professor said, "Well, you know, I do look at those papers that have that symbol as a little suspect sometimes. I'll be honest with you. Sometimes the language is the same, or a little bit the same. Also the same writing style across the board of these papers I get with the Superman on them. Now, that may be because this person helps these people write. But I do look at those as a little suspect."

These were great points for me, because that's not even what I was thinking. The dean of students, to his credit, said okay. I said, "So my papers aren't going to have this?" And he said, "No. No papers are going to have this."

At some point, you just speak out, and that changes policy.

Dean Hines knew I worked at the radio station. He said, "How would you like to interview people on campus who have influence about issues, including this?" I did this series called "Meet the Administration." We talked about a range of issues and that disability

²³ Pseudonym.

topic always came up magically. I did it on the radio station, so it did get a public airing, so to speak. But the story never made the paper, which still bugs me a little bit.

I almost immediately realized that if you don't just eat the fuel, sometimes it changes the whole story. And I want to tell you one other experience that fits, but it's not the dragon experience. It's about this negotiation experience. It ties into this shared meaning kind of thing. It occurred during this same timeframe.

I Did What I Had to Do

JIM: The central administration building, at Central College, was called the administration building, so it was the Central Administration Building. What a great term, right?

Anyway, there were poorly lit hallways and it was an older building on campus and I didn't spend much time in there, so I didn't know where the restrooms were. I had to go to the bathroom. I've figured out, in most buildings, the restrooms are close to the drinking fountain. I don't know if you ever noticed this, but most of the time, a drinking fountain is between the two restrooms.

I didn't know which one was men's and which one was women's. So I was standing there at the drinking fountain trying to wait for somebody to come out. And nobody came out. "I'm just going to have to pick," I thought. So I picked one and went in.

I was really relieved that there was a urinal there. I did what I needed to do and came out and stood in front of that drinking fountain thinking, "Why in the world was I so worried about picking the right one?"

I knew there was a restroom on either side of me. I'm blind. I'm not going to see anything anyway. Why was I worried about which one to pick? At that moment, I realized that this was a self-negotiation thing.

It seemed more important that I might risk public embarrassment to go into the wrong one—because I couldn't see the sign. At what point is that my responsibility? But at that point, that was the negotiation I was doing with myself all the time.

I was worried about how that would look all the time. How would it look, if I went into the wrong bathroom? And the reality was that it wouldn't look like anything. Somebody might be briefly embarrassed for a moment and that would be done. But I made this huge thing about it.

And that, coupled with that other Superman experience I would say by the end of that year or so, and with the support of a group of people who worked at the radio station that had become my friends, was a transformative time. Of course, I wasn't able to articulate it as well as I do now, but I had that sense of transformation.

Grandma Daisy

Kenyon may have been my “passport” into the world of disability culture, but Jim quickly pointed out that from the stories I told him, I had been experiencing disability issues with relatives since childhood. Jim had requested that before I came to Iowa, that I send him an e-mail detailing my life experiences. He left it open-ended with the exception of wanting to know what music I listen to. I felt compelled to tell him about my mother, who experiences mental disability in the form of manic depression. Then there's the story of the first time I experienced disability, too.

As for music I like? A short list would include Nickel Creek, Allison Krause, The Rippingtons, Chuck Mangione and most recently, the soundtrack to the Broadway musical *Wicked*.

WILLIAM: I could start with my mother. She is manic-depressive and severely disabled from it. But I think I would have to go back further to before I was born.

Think of it this way—half of my chromosomes sat in an egg inside my mother from the time she was *in utero* until the time they combined with the other half of my chromosomes from my father's sperm. At that point, they became my first cell.

Some people wouldn't call that life. But I like to think that our mothers did not only carry us through nine months of pregnancy, but that our grandmothers carried us, too. After all, when my mother was a fetus inside my grandmother, all her eggs were there, fully formed,

too. And I, or at least half of the chromosomes that would become me, were inside one of those eggs. So in a sense, I was there, too.

I think that is why most people are so attached to grandmothers, because for nine months, she kept part of you alive. And even more so, we are attached to our mothers, because they carried us around as one set of chromosomes until our fathers came along and provided the second set. That's a long time to be carried around. Eighteen years, in my mom's case.

So here I am as half a set of full chromosomes inside an egg sitting inside my mother. My mother is a baby. My Grandma Daisy is holding her at the top of the stairs on her way to put the baby to bed. Then she just turns around and throws the baby down the stairs.

My grandmother experienced violent paranoid schizophrenia. My mother survived the fall, but was taken away to a foster home right after that. My grandmother was taken to an institution. My first experience with disability—me as 23 chromosomes bouncing around inside an egg as my 18-month-old mother tumbled down a set of stairs. That was it. It wouldn't be the last experience, either.

Even the Rotten Ones

JIM: Everybody knew everybody growing up in West Burlington (Iowa). My disability wasn't ever an issue with the kids that I grew up with. When we played baseball or sandlot ball, I was usually the pitcher or one of the infielders so I could see the ball coming off the bat. And everybody knew that. I guess that was just a matter of function.

All our family had good arms. The person who lived next door to us had a lot of grandkids and his comment was, "Those Whalen boys could go duck hunting with rocks," because we could throw.

We were known sometimes for throwing rotten apples from our apple tree at folks, at other kids. We'd have a spotter. Our apple tree was strategically positioned, so that even if you were sitting in the tree, which was a great place to get apples from, you could throw from the tree and hit the sidewalk either straight ahead or down the alley.

If somebody happened to—unfortunately for them—come down the alley, that was not a good thing. And I guess throwing fruit at each other was something that happened quite often in our neighborhood. That was kind of a common thing.

I guess if you didn't have some sort of fruit bearing tree in your yard, you were kind of out of luck. Thinking about it, I participated in all my neighborhood activities, even the rotten ones.

CHAPTER III

THE BRAILLE SONG

“The Braille Song”

by Jim Whalen, 2006

Went down to the midtown hotel
No Braille on the elevator yet
So I punched a bunch of buttons and lit
Up a doobie
Just to see how high I would get

Now I went down to the public restroom
No Braille there either it seems
I pushed the door open and the bumps
That I felt
Are still part of my Freudian dreams

Chorus—Oh, oh well
There's six dots in each cell
Three straight down is an L
And just touchin' it makes me feel well
Oh, oh well,
There's six dots in each cell
Three straight down is an L
That's Braille

Went down to the local restaurant
The waitress said, “How do you do”
I said, “I'm fine, little darlin’;
Can I see a Braille menu?”
She said, “I'm sorry”
So I got up and left
And it probably seemed rather rude
But if there's one thing I really like in life
Is to pick out my own food

Chorus

A Braille medical release, doctor, please
I know I'm driving you nuts
But I'd like to read the “legalese”
Before you cut into my guts
Man I've got the hots
For those readable dots
Now and then I feel the need to get
Some bumps to read

Some people like their Braille Bible
The hallelujahs and the glories
I prefer my Braille *Playboy*
I read it just for the stories

Chorus

Meet Steve Kuusisto

It's a small world. I told my thesis advisor all about Jim, but I never mentioned that he lived in Iowa. By the time I mentioned the fact to Dr. Chiseri-Strater, my weeklong trip to Iowa for fieldwork was only three weeks away.

During Dr. Chiseri-Strater's class *An Anthropologist on Mars*, I read her textbook *Fieldworking* cover to cover and listened to her tell stories about her co-author Dr. Bonnie Stone Sunstein. However, the fact that Dr. Sunstein teaches at the University of Iowa never connected in my mind.

Dr. Chiseri-Strater told me I should try to set up an interview with author Steve Kuusisto, who also teaches at the University of Iowa and happens to have a faculty office right next door to Dr. Sunstein's. Dr. Chiseri-Strater had taught Steve's book *Planet of the Blind* at UNCG. Though she had never met Steve, she had heard a lot about his advocacy and academic work from Dr. Sunstein.

I contacted Steve and he agreed to an interview. Turns out Steve knew Jim, too. So Dr. Chiseri-Strater knew Dr. Sunstein who knew Steve who knew Jim who knew me. Six degrees of separation—what a small world!

To me, it seemed like everyone knows everyone else in Iowa.

A Columbo Kind of Thing

JIM: I was one of Steve's voc [vocational] rehab counselors around 1985. Steve left the University of Iowa because of issues with the university. Now he is back. He'll be much better telling you the story than I do. And much better telling my story than I am, probably.

I knew him back when, in the mid to late '80s before he was famous. I always had a sense he might be someday. He is extremely bright. He was a Fulbright Scholar.

But at that time in his life, he was having some difficulty with the university. In terms of the other consumers I was working with at the time, he was head and shoulders above them. Seemed to have his act together and had an edge. He had something to say.

Also, he was, and this is going to sound strange considering technology today, one of the people in the mid-'80s who got right on the computer technology when it became available for people with vision impairments.

I e-mailed him a few years ago when he was at Ohio State. Actually, in my e-mail, I apologized to him. He sued the university over accommodations and discrimination. And while, in the end, he actually won his suit—I don't know what the actual deposition was, but what he was demanding in the suit came to pass—but it didn't help him at the time. He had already left. So I apologized because I thought that had been a failure of mine as his rehab counselor.

In the end, I know, my ego is too big and it really had nothing to do with me. But I just wanted to say, "I've always remembered that this happened." I didn't know if it would have any meaning for him at all, but I thought, "Well, it did to me."

So I did that—reconnected then. And then, lo and behold, last fall someone said, "You know, Steve came to do a reading at the Prairie Lights." It's a bookstore in Iowa City where world-renowned authors, most of them with an Iowa connection of some sort, come to do book readings. They said Steve was coming back to Iowa University.

I waited until the beginning of the semester and e-mailed him. We've only gotten together a couple of times. I wanted to give him some space. He has a—I don't know how to describe this—he has his method of finding out things about disability and connecting with folks. It's almost a Columbo kind of thing. He kind of wanders into situations knowingly.

A Painting by Pollock or Kandinsky

Jim and I traveled 30 minutes north of Washington to Iowa City to sit in on a film class taught by Steve Kuusisto. Record snowmelt combined with record rainfall created a flood billed as a *500-year flood* event. The waters left the city of Cedar Falls underneath the rising the Iowa River. The forecasters predicted the flood waters would move south from Cedar Falls to crest in Iowa City in just two days.

Steve's academic building at the University of Iowa sat right next to the Iowa River. The steadily lumbering, brackish water already had moved up the green banks, leaving the tall trees that lined the river looking more like strangely large deciduous bushes. From the front door of the building you could chuck a rock easily into the river. Every once in a while, a giant log or a two-by-four board would surface in the brownish, mucky water, turn over a couple of times, and disappear again into the deep.

Two bridges crossed the river here. As it rose toward the roads, the churning water looked more like a football field of chocolate icing with two concrete end zones filled with gawkers stopping on the way to class, from class, or just plain skipping class to see the mess.

We met Steve and his guide dog Nira inside the building. After quick introductions, Steve led us to the classroom, as we were all running late. It was the first day of class and the river outside was steadily rising.

After class, I sat down with Steve for an interview over lunch.

STEVE: [I graduated from] a little tiny liberal arts college in upstate New York called Hobart and William Smith. I came here [University of Iowa] for graduate work. They have a famous creative writing program here called the Writers Workshop and I came and studied poetry-writing here. I did Ph.D. course work here and then I didn't finish it.

In the early 1980s I first met Jim Whalen. Jim was a voc rehab counselor working for the Iowa Department of the Blind. And I was here doing a Ph.D. and I was having trouble with getting accommodations, because at that particular moment, the university wasn't very good in that area. Seven years before the ADA²⁴, they weren't up to speed.

Who knew that there would be good, ever better, assistive technology for people with disabilities? In 1983, there still wasn't—there wasn't yet an ADA. Who knew that there would be laws that would compel universities and colleges to start taking this stuff seriously? Are they as good at it as they should be? No. But do they sweat when confronted with their failings? Absolutely. Yeah, they do.

And [Jim] befriended me and saw what my problems were. And we weren't necessarily able to solve all the problems, but we became friends. He's a terrific guy—very talented, very smart, very witty. Really gives a shit. Gets what the issues are. I mean, really a lovely person.

The Master of Fine Arts degree from the Writer's Workshop is considered the equivalent of a Ph.D., so there was a certain point at which I just started writing books. And then the door opened for me and it didn't matter.

I was a tenured professor at Ohio State University in Columbus, Ohio, where I was integrally involved in developing their disability studies graduate and undergraduate programs over the last decade. And the University of Iowa recruited me to come here as a full professor and help them develop disability things. So that happened pretty quickly. Last year, I was still at Ohio State. I came here at the end of August to start the fall semester.

In *Planet of the Blind*, I describe my residual vision as being like living inside an abstract painting—like a painting by Jackson Pollock or Kandinsky. And I do have a very beautiful strange way of seeing the world that is lovely and not particularly useful.

So this gives me lots of opportunity to describe things in fresh and interesting ways. And that, in turn, allows me to play with language in my writing in ways that I think allow me to be aesthetically progressive and different. So that's beautiful.

Because of working on blindness and blindness issues, I've had the opportunity to meet an awful lot of beautiful people that I wouldn't have met if I was just some schmuck. The people who raise guide dogs when they are puppies for the guide dog school are beautiful

²⁴ Americans with Disabilities Act.

volunteers who then have to return the dog to the school so he can go get the training and go be a guide dog. And those are very generous and beautiful people.

So I've met some spiritually evolved amazing people who weren't narrow or selfish. And that's been because of my disability. So I think that's beautiful.

Shortly after *Planet of the Blind* came out, I published the book of poems I just gave you. I'm lucky because, at this stage of my life, I still have literally hundreds and hundreds and hundreds of pages of material I've been working on all along.

And I'm working on a small book of nonfiction that I'm hoping to have done by next fall on the art of conversation, which is a real tour de force. And it will be published by the AARP, which is producing a series of books on the arts of life. So I'm the conversation "go to guy."

[Iowa City] is an awfully good place to be. If you're interested in contemporary creative literature, creative writing, then this is Harvard. And every night, there's a great literary event going on in this town, sometimes several at once.

I play six- and 12-string guitar. And I play it passively. I know a zillion folksongs. If forced to stand up and do it in public, I can carry a tune. Yeah, I'm an amateur musician.

I talk about disability, disability rights, public policy, disability and the arts, literary events, poetry readings, nonfiction readings. So I have a lot of different things that I do. And I'm lucky to have that opportunity.

A Life Raft for a Wedding Present

On the surface, the students in Steve's film class looked like any and all college students. You had the rocker, the older student, the class clown, the beautiful one, the athlete, the smart one, and the one with the hangover.

Steve asked each person to introduce him or herself and share something personally quirky. Their stories dispelled the stereotypes. One played the didgeridoo, another was a disc jockey, one worked for the Veterans Administration, another taught herself to play four different musical instruments, one had been skydiving, another had

been a waitress for 20 years, another had kayaked in the rising river, and another said she prefers to eat pretzel sticks in pairs. “It’s always the odd one that kills you,” Steve responded.

The exercise broke the ice with humor. Steve uses humor at just the right moment. He hits you over the head with a concept about disability or human rights, takes you just to the edge where you’re ready to jump off, and then he slips in a joke.

Sometimes, instead of a joke, he puts you on the spot with a question. Jim was right. Steve is a lot like the TV detective Columbo. Columbo caught the criminals by getting them to tell their own stories. Just as Columbo turned to walk out of the room he would ask one more question—a key question—where the resulting answer solved the crime.

This diverse group of students sitting in a semi-circle all came together for a class about disability and film. What brought them here? What did they hope to learn?

I sat near the window and Jim sat opposite near the door. We got to introduce ourselves, too. My quirk—I have no feeling in the left side of my tongue. You could stick an ice pick in it and I wouldn’t feel it. It’s a strange complication from wisdom teeth surgery. The surgeon hit a nerve.

Jim’s quirk—that he’s known Steve since the Reagan era. Steve didn’t share his quirk. He did tell the class he once bought a life raft as wedding present. He did mention he was blind, but halfway through the class I still think many students didn’t believe him. He asked how many had read *The Disability Studies Reader* and there was no response.

“What, am I blind and deaf now? Come on, speak up! I can’t see your hands.”

The Art of Spectatorship

STEVE: Now, being blind, I have no idea what order these things are in, but I think this is the syllabus. Does that look like a syllabus? Alright, so that's the syllabus. Don't get a paper cut. There was a pope who died of a paper cut—one of the early popes.

This is the definition of disability studies as written by a friend of mine. I have no idea what this is—it's a laundry list! This is an essay called "Gawking, Gaping and Staring." And then, by process of elimination, I think this is the essay on Darwin.

Well, I'm Steve Kuusisto. I teach in the graduate program here. And I am also a dual professor in the College of Medicine, where I'm involved in the development of a disability studies program where I talk about disability, public policy, ethics, the history of science, the history of disability, and wear many rotator beanie caps.

This course was sort of cobbled together out of a variety of ideas that I've been having. And I think in no small measure it will be interesting and helpful for me, as a person who can't see movies, to hear from you, as people who can see movies, what you think about the dynamics of the body and difference in film as you engage in the art of spectatorship over the course of this altogether brief summer semester. In other words, that was a long-winded way of saying I'm having an experiment. And you guys are part of it.

Whatever we happen to toss up together as a means of establishing some feeling, some sense of the terrain, the complex terrain of the crippled body as a cultural phenomenon—in its place in the world of artifice and display and drama both productively and pejoratively.

What I'm hoping is that you will begin forming your own richly articulated reactions to some of these films. In whatever particular language of cultural theory, social theory, literary theory, creative writing, graffiti making, or Morse code that you particularly like. Because I'm open to all forms of analysis and persuasion I want the most maximum kind of intellectual, imaginative possibility for everybody in here. Particularly since this is the summer course and we have almost no time.

Cinema of Isolation

STEVE: I'm thinking of each of these films as an arch into ways of analyzing how culture manages to display, inform and disinform us about the disabled body.

The Cinema of Isolation is just a really nice book because it details how, from the very earliest moments, filmmakers have treated disability in relatively odd ways. The films we'll be looking at are relatively contemporary. But I think [Martin] Norden's book gives us a sort of historical portrait—the early launching of disability as a subject in movies. And that early launching is something that contemporary film is still struggling with. And, by extension, real people with disabilities are struggling with these problems.

The Bell Curve

STEVE: The first chapter in *Disability Studies Reader* is a famous essay by Leonard J. Davis called *The Bell Curve*, in which Davis talks about how disability gets reinvented in the 19th century as a kind of coefficient, or product, of the industrial revolution.

[Davis] grew up with deaf parents. Both his mom and his dad were big “D” deaf. And he saw that their lives were particularly marginalized, and that they struggled mightily to make a living in the American mainstream. He was not deaf. He was born into the hearing world. And as a result, he grew up in both worlds—signing to them and then leaving the house and going out into the wider world of the Bronx.

He began to wonder as any scholar does, right? How did this come about? Why would they be so marginalized and isolated in the midst of a great city, in the midst of a great century? What is it about their particular difference that is so extraordinary? And so culturally steep, so difficult? So freighted with problems? So, as any scholar does, he begins to poke around and begins to realize that something happens in the early 19th century that completely transforms our cultural sense of the disabled body.

The Figurative Palimpsest

STEVE: And it happens almost overnight. Which is to say—alright, this is a long arc of conversation—that in the ancient world, while the disabled may have been different, and may even have been symbolically arranged according to their difference and according to politics and social attenuation, the disabled were considered a central factor in culture.

The blind, the deaf, the lame, the disfigured, were part of the carnival of the streets, if you will—the circus maximus. They were part of the ethos of the culture. They were not isolated or marginalized. They were not walled up. They were not put into asylums. They

were part of the mainstream. This is to say that, throughout human history, the disabled have been part of the fabric of our tribal life. Not marginalized or segregated, but part of the fabric.

Now, there's good reason for this, right? How many of these can I list quickly? Cholera, typhoid, yellow fever, influenza, quick help me—[a student calls out “polio”]—name a few more—disease du jour, deafness—[students call out “mumps,” “rubella,” “small pox,” “diphtheria”]—monkey pox, cow pox, chicken pox, poxy pox, cataracts, pertussis, okay, you get the point. There are tens of thousands of ways to become disabled, both from illness and obviously from the travails of regular life.

Thomas Jefferson fell off his horse while visiting France and broke his wrist and was never able to play the violin again. Sounds like a joke, but he was an ardent violinist and once his wrist was broken and badly set, he never had functionality in that hand again. It's possible that that led him to become a more ardent scholar of politics. Whereas, prior to that, he was a bit of a drinking party boy.

But I only offer this up as an example. You could twist your ankle and become crippled; you could break a leg, and be crippled. You could be wounded in battle and become crippled. How many of you have seen Matthew Brady's famous photographs of the severed limbs outside the Civil War army hospitals? Arms and legs stacked outside the tent. And it's very chilling.

So throughout human history, disability has been a major part of the regular fabric of life around the village. This doesn't mean that disability wasn't a complicated, unhappy, or difficult dynamic. It doesn't mean that, in the ancient world, it wasn't freighted with certain kinds of inscription.

For instance, in Greece and Rome, the punishment for thievery was to blind a person and set them loose in the streets as a beggar so they would be a visible advertisement, if you will, for thievery. You could go blind in old age, as Homer did from probable cataracts. And be venerated as a wise old blind man. Or a wise old blind woman soothsayer. Blindness could be metaphorized as wisdom, but it tended to be metaphorized that way alongside a coefficient or paratactic metaphor of age.

If you were a young person and you were walking the streets, the chances are that they blinded you. So you were, as I say, a walking presentation of dishonesty and thievery. Similarly, people had their hands removed. So the maiming of people as a juridical punishment was commonplace.

So, you could meet disabled people on the streets and you would have to make the determination—was this a person who had been blinded or maimed as a juridical punishment? Or was it a person born that way?

“Oh, they were probably born that way, or they arrived that way through age or warfare or something of valor.” You see, the body, the disabled body, was always a figurative palimpsest, a *tabula rasa*, a place for speculation, projection, and interpretation.

A Gift from Karl Marx

STEVE: What Leonard Davis discovers—and he finds this out through his work as a Marxist literary historian—that in the 19th century, as the Industrial Revolution is becoming the major social-industrial-architectural engine of modern culture, disability becomes a problem.

He discovers that one of the first people, if not the first person to use the word “disability” was Karl Marx. Marx’s writing about disability as an industrial problem. The new factories demand a certain type of body. One size fits all. The new body of labor must meet certain physical, and I would even daresay, intellectual standards.

The standardization of the body and the standardization of machinery in the 19th century are intimately and profoundly connected. And social movements begin to spin off of that connection. Statistics, intelligence tests, eugenics, actuarial tables—all of these happen at the same time and are part of this dynamic, this marriage of industry and the body, and a new idea of utility.

Thanks, Jeremy Bentham

STEVE: What does utility mean? It’s an economic term. Applicability. Does a person have utility? Does a machine have utility? Is it serviceable? Does it work? Does it provide us with goods and services? Is it productive?

Karl Marx says, “The disabled body is no longer able to work in the factory. Sorry, you just don’t measure up. There’s no job for you. You’re too short. You don’t have legs. You’re missing a hand. Whatever it is. You’re blind. Whatever it is, you can’t work in the factory.”

And guess what? By 1850, the factory is the single utilitarian economic engine of modernity. And therefore it is the new template—social, financial template—around which the body will be measured.

Bovary's Problem

Nira stayed on the floor in front of a metal desk during Steve's lecture. Her golden fur would rise and fall with her breath, and a puddle of drool formed on the floor below her mouth. She seemed to sleep soundly through even the most animated parts of his lecture. But she was the only one sleeping.

Steve bounced around the front of the room, punctuating his points in air with his hands. He was always smiling. And he would shift into characters as he told us the history of disability. He used a deeper, gruff voice to animate the thoughts of Jeremy Bentham or Hitler. He would shift into a high tenor to recite lines from *Madame Bovary*.

He also seemed to look everyone in the eye. He scanned the room as he lectured, making sure to look toward each part of the semicircle of students in front of him in turn.

You had to listen. You had to think. Both Jim and Steve have some of the largest and most complex vocabularies I've encountered. I figure I have interviewed more than 5,000 people over the past 20 years as a journalist, public relations writer, freelancer, teacher and student. I recall very few interviewees that could pull out "palimpsest," "ameliorate," and "proscenium arch" at just the right moment.

Steve is more than a talker. He listens. He is a master of conversation so much so that the AARP asked him to write a book, *The Art of Conversation*. His book *Planet of the Blind* won critical acclaim as a *New York Times* Notable Book. It has been translated into 10 languages. He has two other books, *Eavesdropping* and *Bread and Light*.

I sat in that classroom thinking, “I could listen to this guy all day.” But it wasn’t because of his rich vocabulary and intricate weaving of language. Like Jim, Steve has the knowledge, the wisdom, and the experience to be a teacher in my quest to begin to understand disability, disability culture, and disability rights.

Steve is more than a teacher; he is a guide.

STEVE: You all know *Madame Bovary*, right? Medical doctor lives in the country, marries this hot dish woman. She’s really beautiful. He’s kinda dopey. But he’s an earnest medical doctor in the village. And what does she want? She wants a bigger kind of life. She wants to move into the city, she wants to dress up. She wants the whole thing. Why? Because the Industrial Revolution has hit.

With disposable income comes theatre, comes opera, comes the ballet, comes dining out, comes dressing up, comes all of the accoutrements that come with the new middle class. The middle class, the Industrial Revolution, and the crippled body as a problem—they’re all happening at the same time.

There’s a scene in *Madame Bovary* where Charles Bovary, the never-do-well poorly educated, rural medical doctor who is married to Emma Bovary, who is having an affair with a man in town, and can’t be troubled to spend time with her husband.

Emma Bovary’s cheating on him. He knows it and he doesn’t have enough sensibility to confront her about it. He wants to win her admiration. A small town French druggist says to Dr. Bovary, “Haven’t you been keeping up with all this medical news? It’s possible to cure people of all kinds of infirmities and deformities.” There’s a man in town named Hippolyte with a clubfoot.

So [Hippolyte’s] foot is turned in. He’s developed a kind of carapace over the foot, kind of like a horse’s foot. The leg is twisted. He walks at kind of an odd angle. He’s a cripple. But he’s also learned to live with it.

He’s strong as an ox. He’s part of the town. He’s a happy man. He’s gainfully employed as a carpenter. There’s nothing wrong with him. And this small town druggist convinces Charles Bovary that they should perform an experimental operation on this man’s clubfoot.

“Think of the notoriety you’ll gain then, [the druggist says] you’ll have cured the infirm.” It’s an amazing scene, because the druggist is speaking the language of the Industrial

Revolution and the industrial medical model that goes with the industrial machine model of the new body.

And these languages are interconnected. Bovary goes to cut the tendon in this man's leg without anesthesia. It gives him gangrene and the man dies.

It's a brilliant moment on the history of disability and the history of medicine. Because it illuminates what's happened in the early 19th century. Suddenly, that crippled man in the middle of town is a problem in a new kind of way.

Abject Subjects

STEVE: So, disability studies articulates two ways to think about the figurative life of the body that come about as a result of the Industrial Revolution. The first is what we call the medical model of disability. In the medical model, the person becomes a patient in a singular one-on-one relationship with a physician. The physician says, "I can cure you. I can transform you. I can alchemize you into a different kind of body and thereby render you of utility, of value."

The medical model isolates the human being, makes them a subject. Abjection is that place where you have no language, no power, no autonomy, no politics. The doctor renders you an abject subject. You are incurable. If you could be cured, you'd be rendered of utility, of value. But if you can't, then you are now a new kind of problem. You are without value. This is what we call the medical model of disability.

There is also a social model of disability in which we understand that this medical model in which people are rendered industrially useless is, in fact, a social and historical construction. No different than other social or historical constructions that we're familiar with from studying feminism or the history of ethnicity, race or gender. The disabled body becomes a manufactured social problem as a coefficient of the Industrial Revolution.

Hitler Had One Testicle

STEVE: So almost overnight, you have the construction of factories and for the first time in human history, the construction of asylums for the disabled. These come at the same point in history. And it's a comparatively late development if you consider that human kind has

been living in tribal arrangement for over 50,000 years.

But the Victorians are the first great social builders of hospitals for the incurable. They also build hospitals for the blind, the deaf, asylums, prisons for the poor who seem to be pathologically incapable of work.

The history of disability is tied to the history of the Industrial Revolution. [Leonard Davis] does an excellent job showing how our contemporary ideas about IQ—the socially acceptable body, the aesthetically acceptable body, what we call the Bell Curve in terms of intelligence quotient, social, and political policies that ameliorate or not ameliorate, attenuate those processes—how these all come about as a product of the Industrial Revolution. And how we view these things and are living the consequences of these things today.

The captains of industry and the captains of Victorian government become fascinated with the idea that the defective body is a social and cultural liability. I think what I'm aiming at here in a way is that when Adolf Hitler rounded up people with disabilities in 1939, took them to asylums, and exterminated them as part of what they called the T-4 project, which was the warm-up to the Holocaust. Hitler got his ideas about the disabled from the Victorian English and the Victorian American captains of industry. And, you know, Adolf Hitler had only one testicle.

Useless Eaters

STEVE: Essentially in 1939, [Hitler's armies] rounded up all the people who were blind, deaf, or had intellectual or learning disabilities, and then they put them in gas chambers and gassed them. Before that, they performed medical experiments on them. Then they gassed them.

If you went to the movies during the Third Reich, you would see an ad. And it would show healthy, strong, young German children jumping and playing. The Hitler Youth doing their pushups and sit-ups and climbing ropes and that sort of thing. And then they would show the disabled kid, dull and disfigured, and the voice-over narration would say, "These crippled people cost our great German state this amount of money. They are useless. They are useless consumers." "Useless eaters," they would call them.

And so the notion that the deformed, the disabled, were a burden to the culture because they had no utility was driven forward, pounded into the skulls of the German middle classes. This idea that we have to protect the state. We have to select out these people. We have to improve the race.

Proscenium Arch

STEVE: We also passed laws in the United States as early as the 1880s that are called Ugly Laws. State laws were passed that said that people of deformity needed to be housed separately from the [mainstream] culture. They didn't want to see disfigured people.

If you were wealthy, you hid your disfigured person. If you were middle class or poor, they would come and take your disfigured person away. Typically, when you brought them to school.

The schools for the blind and the deaf, which continue today, but in a very different circumstance, began at this time, as did the institutes for the imbeciles. This is not a story that's over yet. It's mostly over, but not yet. There are people here in the state of Iowa who are being held in hospitals against their wills because there's insufficient state funding to help them live on their own. But they're being held in really remarkably subpar, horrific conditions, and they don't need to be there. This warehousing hasn't ended.

The Freak Show is the direct progenitor, if you will, the ancestor of the movies. Early film treats people who are disfigured or disabled as spectacles. Ugly curiosities. As carnival oddities that comes right out of the 19th century traveling theaters. The traveling performers are part actors, they're part thespian, they're part opera singer, they're part dance hall performer, they're part vaudeville, and, yes, they are also physiologically different.

Uncommonly ugly, deformed, remarkable for their physical difference. Sometimes, such people are trotted out under the rubric of a new kind of language, the language of social Darwinism: "Meet the missing link. Meet the elephant man."

So: the proscenium arch of the traveling stage, the narrowing of the acceptable body and the utilitarian body, the notion of physical difference as a kind of pejorative deformity, its place as a form of abject spectacle, its new haunted, medicalized display. All of these things happen overnight, very quickly.

Like Shit through a Goose

A gust of wind blows a sheet of rain into the classroom windows, sounding like quick syncopated fingers tapping a desk. Steve's guide-dog, Nira, looks up quickly, then

puts her head back down onto the floor. The erratic rain comes and goes, as does the wind, but the gray sky remains constant. Looking at the river, you can't see it rise. But out of the window I can see the high brown waters of the river and tell that over the hour of Steve's class, the river has narrowed the gap between water and the concrete bottom of the West Burlington Street Bridge.

The history of disability is heavy material. When reading historical accounts of disability, my wife gets not only upset but angry, and will often skip over the background to get to the meat of the book. I can tell some students in the class feel the same way: eyebrows scrunched, lips pursed, arms crossed, foreheads wrinkled. The bottoms of open palms rubbed eyes; some clinched their hands together, and every once in a while, held breath would escape in a quick huff or heavy sigh.

Steve seemed to sense these moments when the anxiety of taking in centuries of disability history became too much. He would then ask for questions or throw in a joke or tell a personal story.

Out the window I spy a sand-filled dump truck pulling up to the river outside of the building. A large group of volunteers wielding shovels stand at the back of the truck. The sandbagging begins.

STEVE: The deaf who speak sign language had to fight very hard to get that right and to get that sign language introduced into their education. And we know that ASL is, in fact, a language. You can say things in ASL that can't be translated effectively into spoken or written form. It has its own syntax, its own shorthand, its own metaphors. It has its own delivery systems. So it's a language.

Many deaf people fear that if deaf kids are brought up without sign language and the

opportunity to speak it, then they lose something culturally. Just as those same folks often believe if a child is given a cochlear implant and brought into the hearing world, they lose that cultural connection.

It's a very compelling argument. It's an argument for which a simple analogy like blindness has no answer. There is no similar sense of unifying culture for the blind. Braille is not a language. It's just a raised alphabet. It's the same language that the rest of you all write and read.

If we define culture as shared experiences around which we can organize social, political, or historical understanding or relation, then sure, there's wheelchair culture and there's blind culture. But if we think of culture as being, in large measure, a coefficient of language the deaf probably have the most highly articulated culture among disability groups.

We're in a summer session. It's going to go by really quickly. As my Boston Irish grandmother used to say, "It's going to go by like shit through a goose." My Boston Irish grandmother was naughty.

Anybody want to pet the dog? Alright, I'll take her harness off. She says, "I know what's coming. This is my moment." Nira, can you say hi?

CHAPTER IV

RIVER OF MONEY

“River of Money”

by Jim Whalen, 2008

Chorus—Yes, if it were a candle
You'd hover like a moth
And if it were the grains of feed
You'd stand at every trough
But it's more like a river
And everybody knows
We drown in pools of apathy
While into your banks it flows
You are a joke
But you're not very funny
Your collective souls gone broke
As you drink from the river of money

You make up a shiny brochure
And exaggerate your claim
And you fly to fancy conferences
And you do so in our name

There is case manager Johnson
And of course there's Doctor Mud
Don't mind that red stuff on your check
It's probably just my blood

And you've taken my whole life
And you've chopped it into parts
And you've made me pitiful
And you've robbed my checks

So when you lay yourself to sleep
And put your head to rest
May you have a thought
Of your heart rotting in your chest

And may your nightmares be filled
With very vivid visions
Of the cries of those you've hurt
And debacled circumcisions

See you've put us in these places
Where no friends or visitors phone you
Because they can't take the stench
Of death, urine and ammonia

Yes, if it were a candle
You'd hover like a moth
And if it were the grain of feed
You'd stand at every trough
But it's more like a river
And everybody knows
We drown in pools of apathy
While into your banks it flows
Oh, Lord, you are a joke
But you're not very funny
Your collective souls gone broke
As you drink from the river of money

Invincible

Sitting at Jim's dining room table, he and I shared the birth stories of our children. It took a long time to share all four stories. I believe birth stories are the most important stories people share and deserve time to be told and listened to fully. Perhaps this is because my wife and I teach natural birth classes and are always seeking more information and inspiration to share with our students. I have also found the fear of disability is intricately tied to birth. The medical community pounces on that fear of disability to create mechanisms of intervention in the birth process. Pregnancy is considered a disabling condition in medical terminology.

The intervention of the medical community both into the natural birth process and into the lives of people with disability are both examples of the river of money that keeps the practitioners afloat.

Most of Jim's major stories relate to the concept of the river of money and the song it inspired. The river of money feeds the defective people industry. It is the stream of funding that locks people experiencing disability into lives that fit into and keep funding the very river from which they are trying to escape. The river of money is about the millions of people employed to manage people with disabilities. The river of money is about keeping people labeled, because without labels, there is no funding.

My second son, Kenyon, was born into that metaphorical river of money. Looking back, I can see that now. I felt the river trying to drown us, but never had the words to

articulate it until I met Jim, who explained it to me through his stories as well as his lyrics.

Sitting with Jim, I realized that I am not a great storyteller in person. I ramble. I forget things. I don't have the drama, the patience, the flow, the ability to turn a phrase. Jim is the exact opposite. He lures you in with pauses at just the right moments. He repeats key phrases to emphasize points. He is a master of pace.

But on paper I do well as a storyteller. I guess that's why I'm a writer. Looking back at how I told people of Kenyon's birth and of his disability, I can see that, from the beginning, I was standing knee-deep in the river of money. I was using the language of the medical model. I was buying into the stereotypes I had learned throughout my life. I was qualifying and quantifying Kenyon in medical terms of retardation and IQ. But I also sense the defiance that led me to seek out Kathie Snow's *Disability is Natural*, to seek out the SDCF, to find mentors like Jim to guide me out of the river. In my words, I can see that, even then, I was starting down a path to unlearn what society has taught me about disability. I was starting the renegotiation. I was swimming out of the river of money.

I told Jim Kenyon's birth story. Kenyon's birth set in motion the long series of events that led me to Jim. But I told the story much better in writing shortly after Kenyon was born. Below is an e-mail I sent to family, friends and co-workers announcing Kenyon's birth:

WILLIAM: We had a baby! Eight weeks early! The second surprise . . . it's a boy! He was born Monday, July 26 at 6:41 p.m. He weighed four pounds and one ounce.

We were and still are in total shock about the prematurity. We had no idea he was coming early. Jan had a big workshop she was preparing for on Tuesday and I was making a long list of projects to get done around the house before our Sept. 3 due date. Jan started feeling funny around lunch time. Three hours later we were in the hospital. Three more hours we had a baby.

For the past 12 days, we have been out of touch with everyone. We have really had to circle the wagons and focus on our new baby. He is still in Frye Regional Hospital in Hickory, where they have an intensive care nursery that specializes in premature babies. It has been two weeks of oxygen, blood work, tubes, IVs, monitors, antibiotics, doctors, nurses, fast food, and little sleep, and to say emotional roller coaster is an understatement.

His current status is good. He has gained six ounces of weight and was off oxygen for a couple of days before having to go back on it Monday. He is no longer on an IV, and the next step is to wean him off of the oxygen machine so that he can breathe on his own. It sounds like it is going to be another two to four weeks in the hospital at least.

We have one more surprise. Our new baby has Down syndrome. OK, what is that? For the past two weeks we have been learning all we can about Down syndrome and unlearning some of the old stereotypes.

Understand first that the Down syndrome and the prematurity are separate issues. One did not cause the other. What we are dealing with now are all premature issues that are keeping him in the hospital. The Down syndrome issues will be for a lifetime.

One in one thousand births results in a baby with Down syndrome. It was a totally random event. Nothing we did or didn't do caused it. Our baby didn't inherit it. Think of it as a roulette wheel with a thousand spaces and we hit the one space labeled "Down syndrome." If there is one thing that is clear, and somewhat of a relief, it is that nothing we did or didn't do caused the Down syndrome.

In a semi-scientific nutshell, you need 23 chromosomes from the sperm and 23 chromosomes from the egg to make a baby. Our baby is not missing any of those 46 chromosomes. Babies with Down syndrome have extra genetic material that gives them their unique qualities.

Either my sperm or Jan's egg had a "sticky" chromosome, and instead of our baby getting just one of chromosome number 21, he got two of them. Thus the extra genetic material, thus the Down syndrome.

There is no cure and no one knows why Down syndrome occurs. Down Syndrome is the

most common birth defect (I generally dislike euphemisms, but I can really understand now how “birth difference” instead of “defect” can really make a difference to a parent).

So how did they know our baby has Down syndrome? You can't really tell by looking, unless you know what to look for. In our case, the doctor noticed his ears were slightly smaller and lower on the head, he had a crease straight across his hand, his skin gathered in folds about the back of his neck, his eyes were more set apart, his mouth was slightly smaller. The doctor ordered a test and after two of the longest days in our life we found out.

Down syndrome means our child might have any, all, or none of a dozen or more unique physical characteristics that these children share, such as broader and flatter noses, eyes that slant upwards, slightly smaller mouths, and smaller ears set lower on the head. He may be shorter as an adult.

Overall, these children are more alike other children than not alike. And the number of physical characteristics of Down syndrome does not correlate at all to his mental ability. He could have one physical characteristic of Down syndrome and have moderate mental retardation. He could have a dozen physical characteristics and have only mild mental retardation. It is very likely that our child will have some degree of mental retardation, although the severity varies tremendously from child to child.

In general, we can expect his IQ to fall within 50-70 points. About 95% of us fall somewhere between 70 to 130 IQ points. Two and one-half percent of the population are above 130 IQ points and are considered “geniuses”. Another two and one half percent of the population fall below 70 IQ points and are labeled mentally retarded.

It was important for me to remember middle school band at this point. And that the word “ritard,” whether you are speaking about music or about the dictionary definition of “retard,” means “to slow down.” It does not mean “can't.” It does not mean “unintelligent.” It does not mean “unimportant.”

Think of it this way: Babies with Down syndrome learn more slowly and have difficulty with complex reasoning and judgment. He will learn and will not lose what he learns. His IQ score will not preclude him from taking care of himself, performing productive work, and enjoying life.

Today, with appropriate treatment for medical conditions, early intervention, better education, higher expectations, and better social acceptance, mental achievement for children with Down syndrome is on the rise. We will do everything we can for our baby (everything we did for Liam and maybe more), from breastfeeding to reading to co-sleeping to attachment parenting, to give him every chance to have as high an IQ as possible.

Many children with Down syndrome learn to read, write, swim, or even ride a bike. We can expect our child to have friends, go to school, watch movies, have a pet and blend in with our family. We won't treat him any differently than Liam, and we hope you don't, either.

With trends toward community living options like group homes and apartments that foster independence and self-reliance, fewer adults with Down syndrome are remaining at home. It is not unreasonable to expect our baby to grow up, get a job, move out, and live a rewarding life of his own.

Children with Down syndrome are physically capable of love and affection, and they appreciate their families and enjoy life. Children with Down syndrome have their own personalities, talents, and thoughts.

Jan and I, like every other parent out there, had a vision of what our child would be, and that vision never included Down syndrome. I think of my baby as a toddler playing with Matchbox cars, dreaming of being on the open road, and me realizing that realistically he will never drive. I think of him playing "house" with other children and even holding a baby doll, and me realizing he will never have children. I think of him sitting by my side watching a Duke basketball game, and me realizing he will never attend college, never be a doctor, never cure cancer, never play professional sports, never solve a quadratic equation, never understand the nuances of chess, never have many of the opportunities you and I have in life.

And I realize that these are all silly dreams of a parent and we never really control what our children choose to do. I do know that he will do great things.

He will not be a surgeon doing open-heart surgery, but he will open hearts. He already has. He will not be a middle school math instructor, but he will teach something to everyone he encounters. I have been his first student. He will not bring warring nations to peace, but he will spread joy.

I have not told you my child's name. I wanted to get all of this out in the open and let you adjust to the news first. When you are ready read on. My baby's name is Kenyon Heath Purcell. He is the most wonderful, beautiful, and best baby in the world. I love him in a way words do not have the ability to express.

When you see me on the street, do not tell me you are sorry about all of this. I am not. Do not tell me a story about a child with Down syndrome who was institutionalized in the '70s or that "he'll be a baby for life" or any other story steeped in stereotype from days gone by. My child has a bright future that will be different even from children with Down syndrome born just 10 years ago.

Do not tell me it is a part of some great plan and we were chosen for this child. I do not believe that. I do believe we are lucky. Lucky to have a second child. Lucky to have each

other. Lucky to be pretty good parents with lots of potential. Lucky to have supportive family and friends.

Do tell me how happy you are to hear about my new baby. Do act as you would for any such occasion that is reason for joy. Do ask questions. Don't be afraid to mention the words "Down syndrome". We are perfectly fine talking about it and will be talking about it for many years to come.

I have included several photos below. One photo is of the first time Jan got to hold Kenyon. You'll know that photo by the look of joy on her face. There is another of Liam the first time he met Kenyon. If you didn't believe in love at first sight, you would have if you had seen Liam and Kenyon together. Liam loves his brother.

In closing, again let me say thank you and extend our love and appreciation to you all. I would also like to share a poem that has been very meaningful to me and Jan since we first discovered it more than 10 years ago. Driving alone from Hickory to Boone I pulled to the side of the road overcome with tears about everything that has transpired since Kenyon's birth. The words to this poem came to me and gave me strength. We posted it by Kenyon's bed in the hospital, where it remains today. I hope it will give him strength, too.

Invictus by William Earnest Hensley

Out of the night that covers me
Black as the pit from pole to pole,
I thank whatever gods may be
For my unconquerable soul.

In the fell clutch of circumstance
I have not winced, nor cried aloud.
Under the bludgeoning of chance
My head is bloody, but unbowed.

Beyond this place of wrath and tears
Looms but the horror of the shade.
And yet the menace of the years
Finds, and shall find me unafraid.

It matters not how straight the gate,
How charged with punishment the scroll.
I am the master of my fate,
I am the captain of my soul.

26 Closure

JIM: One day, I called Steve [Kuusisto] and walked half a mile to his apartment. He was in the middle of his graduate school experience. He wasn't looking for a job. My job was to sort of track him, basically. And because of the way Social Security pays, you get paid for all of the months that you've had contact with him. So it was important, if you had people in training that were going to get a job, to contact them whether they really needed it or not.

When I was working with Steve, most of it was on these issues he was having with the university. He wanted, for instance, the university to add more computer access, because the campus didn't have it. He wanted better access to the library, assistance getting books, assistance having a reading room in the library, those sort of things. All of those things came to pass—a place where, for instance, there could be a talking machine or cassette machine, so he didn't have to haul his all over campus. At the time, to us, it didn't seem like much he was asking for—some basic access things. The disability services office was horrid.

Basically, the goal of voc rehab was to find people jobs—getting them hooked up with training. But you got rewarded for finding people jobs. That was the real goal. And they didn't necessarily have to be good jobs.

I always kind of didn't like that at all. They called it a 26 closure, which meant you got somebody employed for over 60 days. If you did that, you got extra credit. So, day 61, you were good. The agency also gets extra money from Social Security for tracking that employment the first 60 days. If somebody's on Social Security disability, that's usually a pretty good sum of money.

I think it's more like the river of money. You do this for the money, not for the person. So what if they're vastly underemployed? Hey, they have a job. If they hate their job, that's okay. They're in a job. I was a young pup. It was my first professional job.

Some Karma to the Universe

JIM: Steve and I share several views about disability in general and some things about what are social constructions versus realities. And we've commiserated about the NFB [National Foundation for the Blind] philosophy on inconvenience.

I believe that there are enough shared inconveniences and experiences that exist to make

disability culture. And if that's going to be the case, people within that culture or considered within that culture need to intentionally shape that culture.

I don't know that Steve would go that far. We both kind of know that it's all social construction, but so are stereotypes about race or lots of things. Whether it's a homogeneous culture to be talked about as something that really exists or not, I think I'm more toward the "Yeah it exists," and he is more toward the "Well, I don't know yet," or "I don't know for sure." All of which is good for discussion.

I tend to start discussions not with "Does it exist," but with "It does exist." If general society believes it exists, then it exists, and let's see how we can use it. Because I think if you spend too much time arguing about the existence, you don't get to how is it used.

Well, [Steve] didn't graduate and left Iowa. I lost complete contact with him. It was a big disappointment. The whole thing was a disappointment for me. He left [Iowa] and I left the Department of the Blind—right in the same time period, actually. I was a good placement person. I had had a good placement record. I wasn't used to things that didn't work out for me. This wasn't good.

It is kind of funny how that has come full circle. It is strange to me. I would say it's ironic; but there is some karma to the universe.

Collecting Experiences

JIM: And the other thing I probably should mention in terms of one thing that drives my whole existence now is that I grew up really poor and what it taught me was, I don't need much. It made me look at everything different. From the time I started college, I didn't need the \$40,000 job.

By the time I was a junior in college and had worked part-time and had got scholarship money, I already had more things than I ever imagined I would ever have. Everything else since then is pretty much gravy. And that probably sounds weird, but it gave me a different perspective on the whole planet.

When I was a senior in high school, my dad got a job with the school system as a mechanic. But he had been a mechanic for a gas station and other places for very low pay. And my mom did childcare just to make ends meet.

You know you hear, "Well, we were poor, but we didn't know it." Well, that's a lie. We were poor and we knew it. It didn't make our life any more miserable. I didn't understand until I

went away to college then that all kids don't have jobs and give most of their money to their parents. I thought that's what you did.

Anyway, that has had a profound effect on my life, because I've always been a person who's tried to collect experiences rather than stuff.

Heck of Job, Brownie

It was my first time in a Super 8 Hotel. In Washington, there really wasn't another choice. There was a local motel, but I didn't want to risk a place I didn't know.

Jim offered to let me stay with him and his family. I thought that too much of an imposition. Plus, I was spending up to 10 hours a day with him and his family already. You can wear out your welcome, even with the nicest Iowans.

Each night when I came into the hotel, a group of "wide load" pace car drivers gathered in the lobby to watch the flood reports on television. Through the tinted lobby windows, their trucks looked like dark, boxy, abstract moose against the setting sun, the oversized racks of warning lights hanging over the bulky truck cabins.

I stood and watched the news come in from Cedar Rapids and Coralville: waters rising, sandbag brigades working into the night, breaches, flooding downtown, bridges washing away, power outages, a child swept away, floating propane tanks, hospital evacuations, road closings, school closings, and reports of FEMA assistance on its way.

Newscasters said this was the worst flooding in 500 years. Some of the interviewees blamed bad farming that allowed too much runoff into the rivers. Others

blamed poor city planning and short retaining walls along the river. Still others blamed sinners and spoke of a Second Coming.

One newscaster reported that the White House announced President George W. Bush would visit Iowa to tour the damage first hand. One of the drivers joked out loud, “Heck of a job, Brownie!”²⁵

River Rat

JIM: I’m a river rat. Kids from Burlington who spend a lot of time on the river have this designation of river rats. I love the river. I love the Mississippi River. My grandmother owned a little lot right on the river where we’d go camping and boating and swimming. Actually, where we were swimming, it’s not a very safe part of the river—boats and barges and currents. The current was very strong. The Mississippi River current is very strong. The undertow is very strong. But we were stupid—young and stupid.

Babies in the River

JIM: In Iowa City, by the river, there’s this place where there was not a sidewalk. Some people were hit by cars. And the saying was, “How many people have to die before you understand that it’s not the people walking on the road that are the problem? It’s the fact that there’s not a sidewalk here.”

How many people have to die? It’s not unusually bad drivers or irresponsible pedestrians that are at fault here. So your choice is to not participate and hope that after enough people get killed somebody will wake up, even though you see there’s an issue.

So your choice is—do you jump in? Do you get in?

The other issue is, as a person with a disability who’s made a conscious effort in the

²⁵ Reference to President Bush’s on camera praise of FEMA director Michael “Brownie” Brown during the Hurricane Katrina disaster.

course of your life to personally understand and create meaning to these experiences, don't you have some responsibility to help other people learn? Just as a human-to-human experience? That's the other thing I struggle with. And that comes down to the question, "If you can do something, should you do it?"

The people involved in the river of money are oftentimes people who *can* do something, but their "why" is off. They're doing it because it brings them glory and fame and recognition and money, not because they're really interested in what the meaning of disability is for the people they're serving.

It's because "I understand this technology and I can match your son or your daughter with this piece of equipment and they can function a little better and I get paid." Well, yeah for you. Did you do anything to actually change the experience of that person? No, you didn't do anything.

In fact, if you call it medical, you get paid more. And that's just, in my opinion, not good enough. If not you, who's going to take a stand? And if you believe something needs to change, if not you, who?

Even if you're the best at pulling babies out of the river, don't you have some responsibility to go up the stream and find out who's putting them in? Because at some point, you'll need more and more people to pull these babies out of the river, even if you're good at it. They should never be getting there in the first place.

Isn't that my job as part of society to go do that? If I choose not to and say, "I'm not doing that because I don't want to be part of this defective people industry," isn't that a cop out?

I'm sure your wife has experienced this. I'm sure there are administrators in the Department of Education in North Carolina who have a title as special needs something, and have no clue what that means at the classroom level. They are just part of that river of money and it's a disgusting thing.

I think sometimes these people hide behind the medical. "We're doing everything we can to help this person with their functional thing. We've provided all the equipment. We've provided all the assistive technology we can. And that's all we can do."

This disability festival stuff is a way of honestly reframing disability. Unless you're around people like me, quite frankly, for people to get used to the sense that disability can be and is beautiful, is really hard. Because people don't understand what that is. They understand, "We're having this civil rights thing;" or they understand, "We are celebrating this law." But to celebrate disability as beautiful is kind of a weird thing to people. But not to me.

River of Money

JIM: I know I talked to you about “The River of Money” before, but I have some other things I want to say about that song. First of all, that comes from dark place. Not necessarily a bad place, but a very dark sort of place.

We don’t realize how some of the systems affecting us use people as money generation streams rather than doing anything to really understand the experience of disability or moving lives toward better quality. And it is true. And to me, there’s nothing more angering.

I tried to nice up that song several times and tried a little less morose. And every time, it just never felt right. I tried to lighten it up. And finally, one morning, I said, “Okay, don’t try to make it nice. Don’t do anything to it other than the thoughts that are in your head right now. Just let it out.”

And I didn’t have the sense that once I got it out I would feel better. It has a significance and it has a certain nastiness. I think that one will always stick with me. The injustice that generated that song is a very deep, biting one.

I thought, “Let’s just give up this whole disability thing and go do something else.” But as long as I see the things that generated this song, it’s just virtually an impossibility.

I have this thing that I often say to people: “Not one more generation of this can happen.” Will one more generation of this happen? Likely, but not if I can have something to say about it.

But systems perpetuate themselves and I just get this guttural anger and I can no more deny it than I can deny that I’m sitting here. I think that’s another reason why that song never got finished, because I knew it wasn’t there yet. I knew in my heart of hearts, I knew it wasn’t nasty enough, yet. It’s pretty nasty now. It’s pretty good now.

That was a good experience for me to live through as a songwriter. It taught me that there’s a range of songwriting that I really didn’t understand. The difference, maybe, between poetry and writing rhymes, in some sense. But that was a hard one.

I don’t know if I could play that in a conference situation. I don’t know how it would resonate. It might. Where there’s a lot of service providers, it probably wouldn’t resonate too well. It doesn’t have the humorous twist that some of the songs I do.

One of my friends said, Mack, said, “There’s just no relief in it from the beginning to end. There’s no way out.” And for the people experiencing that feeling, there is no way out. There is no saving grace. So I guess that’s good.

Playing Little League

JIM: I often get the question—"If you could go back, or if there was a surgery. . ." My first response to that is, "There's not." But that's kind of an easy way out, isn't it?

I love baseball. I was able to play one year of Rookie League and did not do very well in it. Rookie League is the year before Little League. I did OK.

At that point, I would have been seven or eight. It was obvious by the next year that I couldn't see the ball well enough. Rookie League was pitched by the coach, because they didn't want little kids pitching, I guess. But by the next year, when the kids were pitching and it wasn't predictable, I got hit a couple of times during the first couple of practices and realized, and my parents realized, that this was not going to work.

Even if Jim played third base, which is the closest fielding position to the plate, it just wasn't going to work. It was just way too dangerous. And they were right. And even at that age, I knew they were right. I was clueless some of the time. And I would stand out there afraid, and that's no way to play. So, I guess, if I went back and played Little League baseball, yeah, I'd do that.

Terrifying Inconvenience

Both of Jim's children were at home during most of our interviews together. Both Cassie and Amy were patient with me and all my questions for their dad. The girls only interrupted our interviews during lunch and snack time.

Each day Jim would fix lunch. He made breakfast for lunch one day. He made pizza another. The girls had ice cream for snacks—Drumsticks and ice-cream sandwiches.

Jim and the girls rode with me back from Iowa City on Wednesday. I planted a 10-pack of fun-size M&Ms in the back seat. It was a small reward for putting up with me, but I have two kids, and I know every kid loves M&Ms.

If they said they were bored, Jim had suggestions. He not only kept up with the needs of his own kids during our lengthy interviews, but also managed to check on the neighbor's kid, too.

When too much boredom set in, he brought the kids into the interview, asking the kids questions or having Amy play the guitar or Cassie show off a toy.

As Jim took phone calls, I jotted down notes and check my tapes.

The girls smothered Jim with affection and he gave that affection back. If I learned anything about Jim, it was that these three women, his two daughters and his wife Mel were at the center of his life.

JIM: The NFB [National Foundation of the Blind] philosophy of blindness, which is that blindness is more or less just an inconvenience—I don't know whether I buy that wholeheartedly.

I think the actual physical part of blindness or vision impairment for those people who have learned adaptive skills is maybe at the level of, most of the time, only an inconvenience. I would agree with that. But the social negotiation of blindness is far more than an inconvenience.

An inconvenience, to me, is something that can be set aside. That you can have a choice to set it aside. I don't think you can set aside having to negotiate your disability. It's more formative than any inconvenience would be.

An inconvenience is you have to cook something instead of microwaving it. I think it's a way to keep people from thinking it's a tragedy. But I don't think it gives the weight to what it is in terms of culture. I don't think it's adequate. It's more than an inconvenience.

I think the intent of the statement is to say, “Look, I can still be capable.” And I believe that’s true. It’s a statement that serves a purpose for those people who have never seen their blindness in that way.

But I think it can serve to discount the negotiation, especially for people who become blind. I’ve had my vision impairment, my blindness, all my life. I think for those people who become blind, it helps them work toward a different place. I think, in that regard, it’s a very valuable tool.

It starts the negotiation in a different place. But I don’t think the negotiation ever ends there. I think there are times when my blindness is not an inconvenience at all. It has given me an avenue to learn things I would have never, ever, ever learned otherwise.

When my kids are sick, that’s not inconvenient—that’s terrifying.

Yeah, I can get a friend to take them, or if I had to get to the emergency room, I could. It’s an attempt to reframe it, but I think it is just sort of discounts it too much.

Kenyon’s Song

Jim almost always played his guitar during our interviews. Sometimes he would play a song on the CD player. If we were not listening to music, we were talking about music.

Jim wanted to know what I listened to. I realized that most of my favorite songs have some sort of emotional attachment to something in my life. When I hear those songs, they evoke memories of an event or time. Maybe it is like that for everyone.

Jim ties songs to stories all the time. Nazarath’s “Hair of the Dog” brings up thoughts of his father. “Jeremiah Was a Bullfrog” takes him back to junior high school. Any song by The Eagles takes him back to a four-band rock concert where Jim skipped

the set by The Eagles because he had never heard of them. This was just before they hit it big with “Hotel California”.

I began this chapter with the story of Kenyon’s birth. If not for Kenyon, I don’t think I would have ever met Jim, nor become interested in disability culture and advocacy. I want to end the chapter with a follow-up story I wrote about Kenyon’s progress. It is about a song. It is about my first acceptance that disability can be beautiful. I didn’t realize or vocalize it that way then. But looking back, it is clear that from the start that I had a notion that disability can be beautiful, though I don’t think that notion would have reached the level of disability advocate Greg Smith’s assertion, “Disability is a beautiful part of the natural diversity that is human life” (Caputo, 2005).

Four years after Kenyon’s birth, I find myself agreeing with Smith. The following account is of the days after Kenyon first returned from the hospital. A few days after writing this account, we would discover the fact Kenyon had hydrocephalus, which sent him back to the hospital for brain surgery.

WILLIAM: Today is Kenyon’s one-month birthday! Kenyon was in the hospital for a total of three weeks and has been at home with us for about a week and a half now. For two-and-a-half weeks after his birth, his condition did not change very much. Then Kenyon had a wonderful three-day stretch. On a Wednesday, he took off and starting eating so well that they took his feeding tube out. The following day, they took him off of oxygen. The next day, he came out of the incubator. They then said if his condition continued to improve over the weekend, we could possibly go home with him on Monday. He did improve and we did take him home Monday afternoon.

The first week at home was wonderful because we were finally together as a family under one roof. The first week was also tough because we had conveniently forgotten how tough it is to get up every two hours to feed and change, feed and change, feed and change, but we were happy to do it. Our time has been filled with doctor appointments, changing

diapers, feeding the boys, feeding us, and not much more. Kenyon is up to 5 pounds and 8 ounces, which is much more than his doctor thought he would be at this time.

Liam is adjusting great to being a big brother. The first time that Liam got to really touch and hug Kenyon was in the hospital, and it was magical. He kissed him and hugged him and, totally unprompted, Liam kissed Kenyon on the head and said, "I love you so much." It was a wonderful moment. Now Liam is getting into the jealous phase, but I hope that will pass when he realizes Kenyon is here to stay.

I really did not intend for that first e-mail to take on the life that it has. Many of you shared it with coworkers and friends and that is fine with me. I have gotten e-mail responses from people I don't even know. It was cathartic for me and was the first chance I had to really put my thoughts together.

I would like to share one more thing. Late one night while I was sitting in the car outside the hospital waiting on Janet to come out after visiting Kenyon, I was listening to a mix CD a friend made of the soundtrack from the movie *Moulin Rouge*.

A song came on that really expressed how I felt about Kenyon and especially helped me think about the many mixed feelings I was having about Down syndrome. I played it for Janet and she too thought it is the perfect song for Kenyon. It is a cover of the classic Elton John hit "Your Song."

My gift is my song . . . the sun's been kind while I wrote this song . . . it's for people like you that keep it turned on . . . anyway the thing is what I really mean, yours are the sweetest eyes I've ever seen . . . I hope you don't mind, that I put down in words, how wonderful life is now you're in the world (John & Taupin, 1970).

CHAPTER V

MIDDLE FINGER YOU

“Middle Finger You”
by Jim Whalen, 2007

Heard about the brand new store
Heard that it was fine
The latest in new products—the ultimate design
So I went downtown to check it out and
Steps, there’re only two
So there I sat right outside thinkin’
Middle finger you

Chorus—Middle finger you,
Middle finger you
For all the little things you do
Middle finger you

Talked to a man about a job
told ‘em about my skills
He only asked the interpreter to talk about my pills
I guess you know what happened after that interview
Someone else got the job
And I got middle finger you

Chorus

Went out on a winter’s day—the wind upon my brow
Discovered you have buried
My landmarks with your plow
I stood there freezing with my cane
Your cars could get right through

Underneath my icy breath screaming
Middle finger you

Chorus

Stopped in at the local pub—to have myself a beer
But skinny doors and tiny stalls said
“You’re not welcome here”
Now I sit alone at home and drink the lonely brew
Somewhere in the fuzziness growling
Middle finger you

Chorus

Finally went to congress—asked again for change
“Freedom’s what you want?” they said
“That seems kinda strange”
“Will you be on our poster? It’s red, white, and blue?”
I said, “Sure, I’ll pose giving all the
Middle finger you

Chorus

You may think our song is rude
We’d say, “We don’t care”
Physically or psychically, get your finger in the air
So many folks deserve this and we all know it’s true
Shout it from the mountain top
Middle finger you

Destined for the Shelf

Not only did Jim tell me about his writing process, he showed me. The second day I spent interviewing Jim, he sat in his creative space with his black and white electric guitar playing, tweaking, jamming, exploring—writing music.

He would reach down to adjust the volume on his Dean Markley amp, cranking it up to play riffs or turning it down to stop and tell stories.

Amy walked in and picked up her blue Fender bass guitar and ran off a lick of Pink Floyd's "Another Brick in the Wall" [Part Two], and Jim sang along, "We don't need no education. We don't need no thought control."

Jim calls himself a "rocker" and he looks the part in blue jeans, a black t-shirt, and a tortoise guitar pick pursed between his lips. Listening to him rip into Blues Traveler's "Run Around," you forget he has a bachelor's degree, a master's degree, and almost had a Ph.D.

For his dissertation, Jim wrote a series of narratives documenting the experience of students with disabilities on a college campus, but the dissertation never made it out of committee. Jim says he knows all about "being qualitative in a quantitative world." Ironically, Steve Kuusisto didn't finish his Ph.D., either. I find myself interviewing two academics that came close, but didn't acquire that title of Doctor of Philosophy. Not that it matters. Both men are successful, happy people that have changed the world of human rights and disability rights through their advocacy and artistry.

As I made notes on the details of Jim's house, I found myself looking for that proverbial bookshelf, for that dusty dissertation, for that collection of narratives of students experiencing disability in the 1970s.

What I observed instead are examples of what I think are the most important things in life: construction paper cutouts of hearts decorated with string and buttons; intricate drawings in pen, pencil and marker of dogs, horses, cats, people and rainbows; empty ice cream wrappers; framed family photographs; bowling trophies; a basket full of laundry; a handmade yellow paper sign sitting on an easel, stamped on the borders with the words "Live," "Dream," "Family," and "Laugh"—with two words in the middle, "Love" and "Whalens."

I kept the pages of my field notes describing Jim's house close at hand just because of the description of that yellow sign. Those words are not only descriptive of Jim and his family, but of how I think life should be. And those words reminded me of what was most important in my life, too. Even if my thesis becomes destined for some dusty shelf, its most important lessons will stay with me forever.

In the end, the content I create doesn't matter. What matters is the change that content creates in me. I will carry the lessons of this research with me forever, no matter where the actual pages end up.

Disrespecting the Star Spangled Banner

JIM: I suppose I'm a rocker. But most of that was rebel behavior. My father does not like music at all. Absolutely hates it, actually. He'll listen to a couple of songs, but not very loud.

But his father played music loud sometimes when he was drinking too much. And I think that had a pretty devastating effect, and rightfully. Well, I don't know rightfully so, but understandably so.

By the time I was a teenager, if I could find something I could play loud and irritate my Dad, well, that was something I was shooting for.

My first 45 was "Hair." That was the first one I bought. I think I was in 3rd or 4th grade. I don't know exactly. On Friday afternoons at my school, they would let kids play songs in a PE run around all-purpose room. Mine was disallowed. Disrespected "The Star Spangled Banner."

The Guitar Is In You

JIM: My friend Moe²⁶ told me that I was a guitar player. "Every time you chime in on your harmonica part, that's the guitar solo. That's a guitar part." I had played harmonica on some stuff he recorded 20 years ago and I played trumpet and piano a little bit.

We would talk about songs he was working on. And he would always say, "What do I need here?" And I would always play it on the keyboard and say, "This is what you need here, but you need to make it sound like this." And he goes, "That's a guitar part." He knew.

About six months before I actually bought my first guitar, he just said, "If you don't go out and buy a guitar, I'm going to bring one over here." And I said, "I can't play a guitar." And he goes, "You can play the guitar. The music is in you."

²⁶ Pseudonym.

Walking Down Here

JIM: My grandfather was a professional musician for most of his life. He played the piano. And my mom tried to get me to play the piano when I was a kid. And I didn't care for it. I didn't care for the piano teacher, quite frankly, so I wasn't keen on practicing every day. There were other things to do that seemed to me to be more important at the time.

My grandfather, who was a musician, finally just said to my mom, "Just let him be. If the music's in him, it will come out." I took another three months of piano lessons and got beat down some more.

One day, I literally picked up the harmonica and started playing. I went to a friend's house. My friend asked, "Where did you learn to do that?" I said, "Walking down here. That's where I learned to do that."

The Winner

JIM: I was a pretty decent high school wrestler, so you had to have your hair cut short. And wrestling is huge in Iowa. It's like North Carolina basketball. It's that huge. It's not a sport, it's a religion.

As a sophomore, I wrestled at 132 [pounds]. As a junior, I wrestled at 126. And as a senior, I wrestled at 119. When I went from 126 to 119, I was doing that to try to win a state title. There was no balance in my life at all. I was ultra competitive. I would be at the gym and run and run and eat. I ate fruit and meat and ran and jumped rope.

On our wrestling team, you had your own routine. So, from the time you started getting dressed, you weren't to be thinking. You were following this ritual. Your team had a ritual. We came out and ran around the mat twice and ended up in three lines of four and did this regiment of exercises and chants and these leg squats, which I could probably still do just out of muscle memory. I was one of the team captains and we had a white hooded sweatshirt with Notre Dame on the front, and part of my routine was never to take the hood off until it was time to go.

I would start doing this rope routine about two matches before mine. And in the time of two matches, I would jump rope 3,500 times, which sounds like an ungodly amount, but I was in that kind of shape. You'd do it so your opponent could see you over there.

I was 19-0-1 that year. At the state qualifying meet, I faced the kid who had eliminated me the year before. I was the only person who'd beat him during the course of the tournaments. And I'd wrestled against him every year.

I was ahead and he was trying to roll me over and he cranked it in with what was an illegal move. He dislocated one of my shoulders. I was holding with the other one—just to hold. He switched sides and did the other one, so both my shoulders were dislocated, and I still didn't roll.

I would not roll to let him score. And I won. So I'm laying here on the mat and I can't even get up. But I was the winner.

I couldn't go on with two dislocated shoulders, so he advanced even though he lost. He won the state tournament, which was cool. Oddly enough, it was some solace for me.

Go Home

JIM: I was offered a wrestling scholarship to Iowa State. Wrestling is huge there; they were the national champions. I went to two practices, then I felt a twinge. So they sent me to the doctor. And he said, "It's going to go. You're going to blow your arm. You won't ever be able to lift it above your head." I'm like, "Well, that'll be OK."

The wrestling team was my only connection at Iowa State. I didn't know anyone, just these other couple of wrestlers who lived on my floor. That was my connection to life. The coach was real good. He said, "Give it a week and see what you think." And then he goes, "I'm not going to let you wrestle, if that makes it easier for you." I said, "What if I'll take the risk?" And he said, "Go home."

It took me a couple of months to get over that. I'm just ultra-competitive. But I did realize later in life how that had shaped my high school experience. I get in this zone like I'm just going to nail it and you just better stay out of my way because I'm not going to be trifled with. It would be that far out of balance.

It alienated me from my parents. My mother actually wouldn't watch, and I didn't understand that until being a parent myself. The person across from you—their express purpose was to hurt you. She would come to the matches, but would never watch me. A couple of times, she was forced to, because I would pin somebody before she could get out of her chair.

Jim Was My Co-Pilot

I had no idea how to get to Iowa City. I knew it was north of Washington, but that was about it. Fortunately, Jim knew the way. I never had to ask for directions in Iowa. Jim always knew. As soon as we came to a vital turn or intersection, Jim would stop his story and give directions to me.

After 15 minutes on the highway, Jim knew we were almost at the exit. Even in a city, he always knew exactly where we were. Even with the pouring rain pounding the windshield, a thousand echoes on the underside of my 1996 Honda Civic, through this blur of noise, somehow Jim's sense of space and time kept us from getting lost.

He would say, "We'll be crossing a railroad track soon . . . This is where that friend of mine got his wheelchair stuck . . . Bump, there it is . . . OK, now the road will curve around and you'll want to go straight through the stoplight . . . the parking deck will be on your right and there are two entrances . . . we'll take the first one."

Some of our best interviews happened in the car driving to and from Iowa City. Riding those roads brought up stories of high school bus rides with the football, wrestling or baseball team. The highways spurred thoughts of Jim's college days.

Jim had moved a lot in his life, but only within Iowa. He was a life-long Iowan who had lived in Burlington, West Burlington, Des Moines, Pella, and now Washington.

Some Guy with a Big Overhead

JIM: At Iowa State, they would help you arrange for tests, but you were on your own to arrange note-takers, if that's what you wanted. The Department for the Blind had taught techniques on how you would go about doing this and would even pay for some of these things. They would actually get your textbooks taped, but you had to get them in months before.

The audiocassette probably had more impact on my undergraduate education than most other technologies. They were easier to duplicate. Students could get copies very quickly.

I had learned some stuff about talking to instructors about things. I had learned that you learned a lot about the subject area before you went to talk to them and then you could kind of pick through and find out where they were headed. You could learn how to figure out what teachers really wanted.

I wanted to do all the work; don't get me wrong. The magnifying readers were just coming into use, and I can only read 10 to 12 pages an hour on one of these. I don't have time to read copiously on things. I developed a technique to find out what seemed to be important, what already tied into things I already knew.

I was just voracious. I still am in terms of learning and observing, so I have a good memory. Adaptations weren't necessarily physical.

I really liked Braille, though, because I learned how to write and I could read it. I got fairly proficient at it at one time. Up to reading it at around 200 words a minute, which means your hand is just going. The person I learned it from could read about 400 words a minute. Her hands virtually were in constant motion.

I was an honors math student. Iowa State is huge and those classes were huge. My honors courses had 23 or 24 students, but the general ed requirement classes had 300 kids, so it was this completely bizarre experience at Iowa State. I spent two to three hours a day with 20 people—none of whom I particularly cared for because they had no interest in life outside of honors calculus—and then the rest of the day was with groups of 300 people I didn't know.

I had no connection with the educational experience of sitting in a lecture with some guy with a big overhead. I was like, "There is something wrong here," but I couldn't identify it. But it wasn't me.

A Clandestine Enterprise

JIM: I went to graduate school for a master's degree in rehabilitation counseling. I had thought about going for a communication major or, perhaps, law school. I even took the LSAT.

But Drake [University] had a federal grant at the time in rehab counseling, child development and child placement. It was a cohort. The cohort of only 15 students really attracted me. The other thing that was really attractive to me at the time was that you could get your master's degree in one calendar year. That meant you had to take 42 credit hours in one year, but you could get it in a year. And it was all paid for, books and everything, with the exception of part of your living expense. For a kid who didn't have much money and didn't want to get in debt, it was really attractive.

Plus, there was this disability angle that I had. My whole life goes back and forth this way. The Department of the Blind and the Commission of the Blind had this philosophy much like the independent living philosophy, and there were Commission of the Blind folks who were familiar with the program at Drake and they told me, "If you go through this program, you can get a job here."

I was too naïve to understand at the time that this was a completely clandestine enterprise. That they had known everything I had done since I was 16. Now it doesn't surprise me at all. But then I was stunned. But I was in school mode. So I did it.

Having Control

JIM: The other thing I did for money was working at radio stations. Central College had a radio station. People in my classes, several of them, worked at the radio station, and several people that lived on my floor worked at the radio station. And I loved music. So that was just a cool thing.

I moved my way up at the radio station over time. I became the student manager. I actually got some jobs in Pella and Des Moines doing disc jockey work. And I would have been happy doing that for life, except for one day, I went into one of the stations that I worked for after it had gotten bought out. There was a note—a big poster with names on either side. 'These people need to come to the office and these people just go about their regular business.' All these people I knew were given two weeks, and they were gone. They were no longer employed there. And I was one of the three who kept my job, but that was just

scary for me. I didn't know that happened a lot at radio stations. And they were going to a tape format as opposed to live DJ's. No control over what you play for a show. Having had that experience—radio was not for me in the long term.

A Gloomy Day

JIM: All I did was study. I worked part-time, ate, studied. And that was it—24 hours, seven days a week for a year. That was the reality. I wasn't in a relationship that lasted more than about a weekend. I studied. I worked. I finished in a year. And then I took a whole three days off between the end of my graduate school and my first day of work.

I worked for the Department of the Blind. I did the Independent Living Teaching thing for about a year. They hired me to do a rehab counseling job that was going to be vacated in about six months, but they didn't want me to get a job somewhere else. That was the impetus for hiring me to do the IL job.

Soon I got married and adopted my son. I had a gloomy day in '86 when it became apparent that the youngest person to ever have the next position up in the agency was 17 years older than I was and probably still quite a ways away from retirement. I realized, "I'm stuck here. I'm a regional office supervisor and I'm stuck here now. And that's where I'm going to be." That struck me as really not a good thing. And I started looking for a way out. I went back to school.

Big Margaritas

The rains stopped just in time for a family outing with the Whalens. I followed Jim, Mel, Cassie and Amy to the local Mexican restaurant. This was my first chance to put down the recorder, to set aside the notepad and to just enjoy some time with Jim and the family.

We ordered big margaritas—lime, top-shelf, and complete with the little umbrellas. Mel and the kids got a kick out of me being vegetarian, and they teased me for

it. We talked about food, kids, school, my boys, my wife Janet, but mostly they all wanted to know what North Carolina was like. Jim had a job lead in North Carolina. If offered the job, his family would move there in a couple of months.

Jim said his doctors told him he had to move further south to live because of arthritis. If he didn't move soon, he'd have to start a regimen of medications. Jim began searching for jobs in the south. He'd found an opening at a center for independent living in Winston-Salem. It is just an hour and half from my home. I asked him, why North Carolina? "That is where the job is, and it's a lot warmer than Iowa," he said.

North Carolina really didn't seem that different from Iowa. We have hog farms and farmland in the eastern part of the state. We have large cities where most of the universities are located. It's a fairly conservative state with most people living in rural areas.

Unlike Iowa, we have mountains. Our roads don't run in straight lines. You can't see the wide-open sky in the Tarheel state because of all the tall pine trees. And while we don't have the wide, strong rivers fed by snowmelt, we do have the ocean.

Between the chips and dip, the conversation veered to the weather. Mel works in Iowa City. She didn't think I'd make it back there on Friday to attend a second class with Steve and to interview some of Jim's friends. She said the water was rising and already beginning to flood some parts of the city.

The Mexican food in Iowa tasted just like North Carolina's. Jim had worked many different jobs in his life, from counselor to yard maintenance to delivery to

teaching to warehouse to director of a center for independent living to radio. Turns out he also had been a cook.

If You Can Cook

JIM: Going back to school was a strange decision. My [first] wife was a brittle diabetic. It was a great time to live in Iowa City because of the University of Iowa's hospitals and clinics. She had kidney involvement, vision issues, and heart issues. Within a year of starting my advanced degree, I found myself married to a lady who needed a kidney transplant and had a three-year-old kid. My life was completely different than it had been. And I still was working.

I had this idea that I didn't want to go in debt. That idea had been ingrained in me as a child, so I was working. I worked as a cook. I'd done that some in high school. If you can cook, you'll always have a job. I worked for a couple of years cooking for a couple of restaurants and for the university. I thought, "Well, I'm going to be in school for an extended time now."

Do What They Want

JIM: I got an Ed.S. degree and my advisor said, "Are you interested in going on for your Ph.D.?" At the time, I said "no." We had written and oral components of the Ed.S. comps and at the end of that process, the person who'd been my advisor pulled me aside and said, "You know, it would really be a shame if you didn't go ahead and try to get your Ph.D."

"The situation with my wife isn't healthy and I'm really killing myself working," I said. He goes, "Well, what if we could get you some assistantships and get you some scholarships. You might still have to work some, but what if we could do this and make sure you could take an extended period of time to do this?" And I said, "Well, can you do that?" And he goes, "Pretty much, as long as a student has a way to pay and a faculty member approves it, we can do anything we want." And I thought that was a really conceited statement.

I was in college student development, the counseling track. College student affairs,

basically, was my specialty. I spent most of the last seven years of that program working specifically with disability or career development issues.

I did that and ended up staying in grad school for a long time. And my former wife then decided that she wanted to go back to school, which was great. She got a kidney transplant and I thought life was great.

Marriage Doesn't Include Dating

JIM: And then my first wife decided that marriage included dating. And that didn't really work so well. So we went through a rough year or two. And we had a son who was then eight or nine. At some point, I just said, "We got to make a choice here." And we made the choice to not have that happen anymore.

That was a bad stretch. I had taken a job with the university with disability services. And it really slowed down my progress on my dissertation. It was a bad time in life.

It was really the first time in my life where I really felt like I wasn't directing the things I was doing, other than that little stretch at Iowa State when I really couldn't figure out why I didn't like what I was doing.

The Most Bizarre Day of My Life

JIM: I did my comps, and I was working on my dissertation and changed it from a quantitative to a qualitative one. And there had been no qualitative dissertations done in my department. I spent essentially three years teaching them qualitative design.

When people read the dissertation and during the meeting following—what was the defense—whatever it turned into—they were just raving: "Look at the depth in these stories. I understand this now." It couldn't have been any better.

I got to the end of the process—the very end—after the prospectus meeting, turned it in, and the committee didn't understand it.

It was a narrative study of the experiences of college students with disabilities. They had not seen an inductive sort of paradigm before. And so they just didn't think in that way.

They were looking at studies I'd present as "Well, this only has an *n* of 5." Well, yes, it only has an *n* of 5, but that's not the point here. The biggest part of my dissertation was to show how, by using stories as opposed to surveys, you could really understand the experiences and the meaning of those experiences for those people.

Two of the professors in there plus another still use those stories ten years later, to explain the disability experience. They understood the experience better than they'd ever understood it before by using this method. But they didn't get the point of the dissertation.

It was for me, just funny. It was probably the most bizarre day of my life, quite frankly.

Woulda-Coulda-Shoulda

JIM: I had been in graduate school for a long time. It had been seven or eight years post comps. I had one professor who didn't cooperate [approve the dissertation]. And I didn't know what to do.

My advisor suggested trying to change this person off the committee or whatever. Well, this professor, who is no longer with the university, started calling other people in the department saying, "Don't do this." And I got wind of this. It's a small world. And I was absolutely livid. I said, "I'm not going to do this anymore."

Plus, I then had another life. Amy was one-year-old. And I didn't need that kind of politics. If I was doing this so I could teach at a university, and universities allowed this kind of stuff, why would I want to be there? Why? Now, I realize it would've been a good idea maybe to finish. I'm not a big woulda-coulda-shoulda person, because I think that's just so unhealthy.

My advisor at the time, Dave Jepson, even petitioned the college to say, "Can we do something different?" He even wanted to change departments. He wanted to do something, so that this didn't just all go for naught. He just couldn't see how that could end this way. And I'm like, "You just got to let it end sometime. I'm done."

So when I found out Cassie was on the way—that was about a month after the prospectus meeting where I thought I had no other problem—life was great. And then, within a year, it was all gone. It was all different. It wasn't gone, it was just different.

Few Will Understand It

I have boxes and boxes of old newspapers. I've kept every newspaper and magazine that has my byline in it—multiple copies of each. Many of those newspapers are turning yellow. I teach an undergraduate journalism course at Appalachian State University in Boone, North Carolina. Last fall, I realized that a clip I showed of my writing was the same age as some of the students in the room.

From my working days, I've kept old brochures, marketing plans, calendars, newsletters, press releases, and printouts of PowerPoint presentations and Web pages I designed back at the turn of the century. The contents of these boxes upon boxes of my master portfolio sit in my attic, gathering dust.

As I typed my thesis, I wondered if my academic work is destined for the proverbial dusty shelf or to join the millions of PDFs in the electronic wastelands of the ETD [electronic thesis and dissertation] databases. I wondered if it is destined to join my portfolio in the attic. I remembered an exercise from *Fieldworking*, in which you write a note to yourself from your fieldwork. I wrote this before attending the SDCF and revised it for my thesis:

WILLIAM: Please remember the worst products, and indeed perhaps most products, in academia get put upon a shelf to collect dust, fade, wither and rot away as nothing more than a line at the bottom of a vita.

Ask yourself, what is going to give this product staying power? What is going to make this product stand out and really affect people's lives? If a product does not contribute to action or understanding, of what use is it?

The disability rights movement needs passionate academics to look honestly and openly at the issues not with the assumptions of incompetence many past researchers have shown, but with an openness of possibility.

Remember that most people come with assumptions you have already overcome. The readers' own prejudices must be overcome before they can begin to understand the findings. The vast majority of people in their views still see people with disabilities as poster children for telethons deserving of pity and false praise. Don't let them keep those false assumptions. They will say, "What 'they' have is good enough, why bother with more? Adequate is enough; 'they' won't even know the difference."

The traps are many: assuming people know what you're talking about; assuming they will understand the people-first language you use; assuming they care; assuming they really want things to change.

Traditionally, most people with rights don't care so much about those without rights, especially if it means those with rights might have to change.

No matter how you approach the subject, you are faced with a society operating in a "medical model" that people with disabilities are broken and should be fixed. Explaining the "societal model," that society is broken and needs to change, may be the biggest challenge of all.

In order for society to accept people with disabilities as creative beings, they first have to see them as human beings with similar wants and needs. But they will fight it. It will be uncomfortable for them.

Society doesn't want to admit the denial of housing and employment rights. Society doesn't want to admit they really don't want school classrooms to be desegregated. Society doesn't want to admit people with disability have sexual rights or much less think about the disabled mixing in love and marriage with the non-disabled. Society won't want to admit its efforts at eugenics and genocide to rid the world of the disabled.

Every idea expressed in the culture of disability through art is a weapon that can be used in the disability rights movement, and the first way to stop a civil rights movement is to deny the validity of that culture's art.

You are an advocate. Your work is important. Few will understand it.

CHAPTER VI

A LETTER TO SANTA

"A Letter to Santa"

by Jim Whalen, 2007

Layin' here one Christmas—because I could not go home
And when your body's full of Demerol—your mind, it tends to roam
So I wrote me a letter to Santa—said "I hadn't seen you in a while"
But if, you could bring me and my friends a few of these things, we sure would get a smile

Bring us some machetes—so we can cut through this red tape
And a bunch of shovels—so we can dig out and escape
Bring us some shields—oh, bedpans will do
Bring us a sling shot for phlegm
And toss in some high—powered catheter nozzles—so we can piss back on them

They used to call this a rest home
The staff, they sure know how to rest
I get no whiskey or friends in here
And the shrink wonders why I'm depressed

Santa, could ya keep the bible beaters away?
They keep askin' my family for checks
And could ya bring in a sleigh load of hookers?
O'Lordy, do I miss sex
Can ya fill up the stockings hung with care
With something yummy to eat?
And leave behind a couple elves for PAs

I'd like to get back on the street
Take our current food swill up to Capitol Hill
And make 'em eat it till they choke
And Santa, by next Christmas
Can ya make this nursing home go broke

Peace on earth, good will toward men
It's what the angel has said
But if I have to spend another Christmas in here
I think I'd rather be dead

(fade to humming) Wrote me a letter to Santa

The Story of My Life

Jim told his life to me in small stories. It is not until you take the whole of the stories together that you appreciate the life Jim has led.

I thought it appropriate and important to share some the small stories of my life. Not to compete with Jim's story, but to show how I came to this point in life: the point where I'm negotiating my role in disability culture; the point where I'm defining my role as a disability rights advocate and as an artist; the point where I'm reframing my past experience with disability.

In part, I include the following section because Jim forced me to re-examine my life in terms of disability, and to understand my re-examination requires background. First, I told Jim that Kenyon's birth brought about my interest in disability. By forcing me to tell my stories, Jim allowed me to come to the conclusion that disability has always been a part of my life. My mother experiences disability as manic depression. My grandmother experienced disability as violent paranoid schizophrenia. Disability has impacted my life in ways I'm only beginning to understand.

As a fieldworker, I look for artifacts. I collected many artifacts during my fieldwork in Iowa, including a CD of Jim's songs, lists of song lyrics, a resume and vita, newspapers, brochures, class handouts, and a book of poetry from Steve Kuusisto.

I don't have many artifacts that represent my own life. I have photos, but few tangible things from childhood. But I do have memories, which I have been putting down on paper since college. What follows is the one artifact that represents my childhood.

What follows is part of my “life story” that I’ve been keeping and adding to for the past 20 years. This life story is a well. I go to it when I need inspiration to write. I go to it when I need ideas.

I went to that well to gather material for my admissions essay for my graduate program. I went to the well for various classes that required me to reflect on my life. I will go back to the well now to share parts my life story. I told Jim parts of this story in person. Other parts he read in an e-mail I sent him before my arrival in Iowa. The story is not complete, nor will it ever be. It is something I will continue to write and reflect upon.

Aristocrat

WILLIAM: A few moments of my life stand out for the sheer physical nature of the experience. I climbed out of the crib and tumbled head first onto the cold wooden floor at two years of age. At four, a mare kicked me, breaking bones and spilling blood. I was beaten with a garden hose at six for not watching my toddler brother who walked out into the road in front of our house. A half-drunk family friend resuscitated my limp eight-year-old body after pulling me from the bottom of a pool. At age 10, I watched terrifying R-rated movies in a cockroach filled apartment while my mother smoked marijuana and drank Aristocrat vodka in a back room. It was the start of my first experience with her disability—a disability experience that would end in a hellish descent that would eventually cost her her marriage, her children, her home and her mind. But there were good childhood moments, too.

Mayonnaise Sandwiches

WILLIAM: Bill Miles ran a greasy corner store at the intersection of Lake Brandt Road and Highway 150, just a short mile and a quarter walk for my brother and me. I asked him for a job. If we picked every downed limb out of his oak-tree-filled yard, he said we could have

any two things in his store. It took us two afternoons from the time we got off the elementary school bus until dark to finish. Mr. Miles led us to the candy stand and smiled.

I walked away from the candy shelf and over to the freezer and took out the largest pack of bologna and a gallon of milk. Mr. Miles looked confused. He had said any two things in the store. My brother and I had been eating mayonnaise sandwiches all week while my mother was on another drinking binge.

My Brother's Keeper

WILLIAM: The divorce court judge gave custody of us two boys to my mother. It didn't last for long. Mom worked second shift at Maid-Rite Foods slapping pimento cheese between triangle-shaped bread, sandwich after sandwich, hour after hour through the night. I raised my brother. I cooked frozen Salisbury steaks and canned biscuits. I sliced thin the blocks of government cheese. I split wood and kept the stove fired.

Clinging tight to each other during midnight thunderstorms with no power, we dared not open our eyes during the flashes of light for fear of what monsters might be lurking.

Sometimes Mom would forget to leave money for things at school. I learned to steal from her, squirreling away change to pay for fees, pencils, field trips and occasional ice cream treats. I learned to forge her name, treat a cold, write a check, fix a toilet, and to mask my fear because I was my brother's keeper.

Meet Grandma Daisy

WILLIAM: I liked to walk down to my maternal grandmother's house. One day, she didn't answer the locked door. I tipped over a five-gallon bucket, climbed up, and saw her on the floor. I wanted to break the windowpane, but feared getting in trouble. Instead, I ran to get a neighbor. I was too late. In her obituary, I learned she was my mother's "foster" mother. My real grandmother soon moved in with us.

Grandma Daisy was a violent paranoid schizophrenic who had lost her baby girl after throwing her down a set of steps. But in her early 60s, looking more like her late 80s, she was rather tame with the series of pills she took.

I hated her. Mother made me clip her toenails. She spit snuff in a Styrofoam cup all day. Swinging a flyswatter at me in violent fits of rage, I understood little of what she said, save the swearing. She only moved from her pee-stained chair to eat and sleep. I kept my brother away from her. The summer of hell she lived with us ended with a 10-hour round trip in a 1965 red AMC Rambler, hauling her to a nursing home in Wayne, N.C., where she died a month later.

Black Santa

WILLIAM: For a short while, we moved to Charlotte, where I went from being one white kid among hundreds at Summerfield Elementary to the only white kid in the entire third grade. My bike was stolen. Our car got stripped and put up on blocks. I learned to take a beating and I learned to fight back.

Fun at the apartment complex meant jumping on old mattresses in the woods, playing pinball, crawling through drainpipes, or finding things to toss over the fence into the gangrene-green pool.

The News 3 helicopter landed at our school for Christmas, on a baseball field full of hundreds of black children cheering, and me, too. I stood in shock to see black Santa step out, but I took the candy cane. I learned about black Jesus, too. Race didn't seem to matter much to us kids because we all had poor in common. Two years later, we were back living in Greensboro.

Redneck Crop Circles

WILLIAM: We stayed at home alone a lot while my mom worked second shift. Alone one night, I held my little brother tight and watched the silhouette of a man take off the screen to our bedroom window. The dog woke up and jumped at the window, and the man ran away.

The decision had been made weeks earlier for my brother to go live with my father starting the next month. I didn't look forward to nights alone. My Aunt Elaine and Uncle David offered to take me in, but I had to be the one to tell my mother. I was twelve.

That night, I called my mom at Maid-Rite, squeezing my younger brother for strength. In

tears, I told her I was moving out. I didn't have much to pack. Some clothes, a Nerf football, a bike.

In a few short years, my mother lost her marriage and her children, and would eventually lose her home, her sanity, her pride, and any sense of self. People who knew me then and know me now ask me how I turned out the way I did.

I should have been trailer trash locked up in jail or Butner Mental Hospital with three kids by three different mothers, living life from 12-pack to 40 ounce, smoking Winstons, eating pork skins and Little Debbies, cheering Dale Jr. while fighting with my neighbors over my chained-up pit bull that barks all night and leaves redneck crop circles in the overgrown crabgrass outside my single-wide.

Rolls-Royce

WILLIAM: As a child, I had untold acres of woods to escape to and explore all day long, where I saw a 10-point buck, newly born fawns, skunks, giant carp, salamanders, giant hornet hives, streaking red sunsets, and sleeping hunters in deer stands. I ate from fields full of wild blackberries, built rock dams in streams, fished illegally on Old Man Richardson's lake, drank from natural springs, threw rocks at water moccasins, picked up turtles, and ran from mean dogs.

To my mom, cheap babysitting meant dropping me off for the day at the library, where I fell in love with books and clean toilets that didn't run out of paper. Down the road, Advoca Arabians hired me to sweep the stables and shovel horseshit from the stalls, but they also taught me to ride a horse, drive a tractor, and once let me ride in the owner's Rolls-Royce.

First Beer

WILLIAM: Approaching a police checkpoint on Lake Brandt Road, my mother handed me a Mason jar full of clear liquor. "Throw it out," she barked. My cousins took me to a party where middle schoolers drank beer from a keg and hit acid. I hid in the kudzu with my cousin, trying to hold his best friend down from the piercing lights of a dozen cop cars busting the party. He's on a trip. Thinks it's a scene from *Red Dawn*. I hold him down until it's safe. He pukes on me.

Why didn't I become an alcoholic or a drug addict? Two of my three best childhood friends did. George Benfield's²⁷ father caught us with a beer from his fridge. We were eleven. He didn't get mad. He cooked us chili and made us drink the beer, while explaining the nuances of food and alcohol. The beer was terrible and the chili not much better. "Choose to drink for the right reason or don't drink at all," he said. His three-story house had an art studio, a formal dining area, 5 bedrooms, a sunroom, and a room just for listening to vinyl albums. Early on, I learned to carefully choose which examples to follow and which to ignore.

Flyswatter

WILLIAM: Outside the Whitsett Country Club, complete with Confederate Flag on the side, the boys took turns playing a game called "death match" or just plain old slugging it out, while our single parents drank and line danced inside before pairing off, driving half-drunk back to their trailers.

Being beaten with hands, belts, switches and garden hoses nurtures an intense desire to be free from violence. It took me years to articulate, but from violence, I found a desire for peace, vowing to be the parent I never had. Being beaten with a flyswatter by my mother one day, I rose up, took it, and tied its thin metal handle in a knot. Injustice nurtures a desire to fight for what is right.

Christmas in a Parking Lot

WILLIAM: When I was in fourth grade, Mom told me she accidentally stepped on the abandoned kitten that I was bottle-feeding back to health. She was lying. She really dumped it down a dirt road. Twenty years later, she still lies to me, and I still want to believe.

Sneaking into the neighbors' vast wooded lands, we cut cedar trees each year for Christmas. At 16, with my mother on the verge of another nervous breakdown, I took the car and my brother and left her home to spend Christmas night in a grocery store parking lot. I didn't sleep much. I didn't see Santa, but that night remains a perfect example of much of my childhood and teen years—a lot of time to think, wonder, wander, question,

²⁷ Pseudonym.

dream, plan, and envision a new way.

My rich friends' parents laughed at our lawnmower. I had to hit the crankcase with a two-by-four before it would start. I laughed, too. Often they stopped to drop off an extra pizza, a shirt they bought the wrong size, or to see if I wanted to spend the night at their house.

He Knew How to Live

WILLIAM: My cousin Sue²⁸ dated Randy²⁹ who put me in the backseat of his 1973 Mustang Mach One hit 120 miles per hour on a long stretch of Pleasant Ridge Road. No seatbelts. Didn't care. At the short track in Winston, we got rubber in our teeth while cheering. He taught me to drive in the snow and took me to Krispy Kreme Doughnuts at 4 a.m. I regretted she didn't marry him. He really knew how to live.

Moving in with my aunt and uncle saved me. They bought me clothes without holes and shoes that fit, cooked real meals, and even took me to Sears to pick out a record player and my first album, *Purple Rain*. It took me a while to get used to not being alone at night. When they said they would be home for dinner at 5:30 p.m. they were. They told me "no." They took my brother and me fishing. They never had kids of their own, but I think they came to love me in that same way.

Like the Rest of Us

WILLIAM: When I showed people my acceptance letter to Appalachian State University, they responded, "You . . . why?" I made one visit to Appalachian with a friend whose sister was a freshman. We got kicked out of her all-girl dorm and had to spend the night in the car. But we danced, hiked, attended a football game and picked up some brochures, and I fell in love with the red sugar maple leaf, the security of the mountains, the cold air stinging your lungs and the thought of freedom. Before I left for Appalachian I overheard one of my uncles tell my grandmother, "He'll end up in Cone Mills like the rest of us."

²⁸ Pseudonym.

²⁹ Pseudonym.

Take on the World

WILLIAM: My first two years of college could not have been any better: making the Dean's list, getting involved with organizations, becoming a peer leader, discovering a love of the mountains, becoming a camp counselor, discovering journalism, writing for the college newspaper, and being selected from 2,000 freshmen as one of 20 to join the English honors program.

I decided never to go home again and spent my summers working, traveling, and studying. I backpacked Europe with the English Department. I explored New England with the History Department. I learned to kayak, climb, and rappel, and to teach others to do the same. I became president of the advertising club, and became vice-president of my fraternity, directed the jazz music programming at the college radio station, became business manager of the student newspaper, participated in marching band and pep band—I took on the world. I worked two and three jobs a semester, too.

Black Eye

WILLIAM: My first week as a counselor at Camp Cheerio, the director called me to the mess hall to meet a camper arriving two days late. Tall, skinny, tangled red hair, hiding the fact he had been crying: Eleven-years-old, with two black trash bags full of his stuff, one black eye; seven years between our ages, and only destiny between what fate dealt each of us. Four years later, as the lead counselor working with the most difficult cabin containing the oldest kids at camp, I witnessed kid after kid after kid dealt much worse than I ever was.

Scrapping Hope

WILLIAM: While I was at college, a sheriff's deputy knocked on my apartment door one night. He told me my mother was in Butner Mental Hospital. I drove two hours to Greensboro. I became her legal guardian. No bills had been paid in months. With walls covered in her crazy crayon drawings, the house was piled with clothes, debris, old food and bugs, the yard waist-high in weeds.

I got my mother's life back on track. I saved the house. I struggled to graduate while trying to hold my life and hers together. I scrapped hopes of a double major, settling for a degree in English and a minor in communication. I graduated and took a job as a journalist.

Cherish Each Day

WILLIAM: Racing through thick rain in the night to a murder I heard over the police scanner, I found myself the third person on the scene. The sheriff kneeling over a teenage boy told me to cut tape. I did. I stepped in blood. I remember putting a tube on the IV and holding it, handing scissors, cutting more tape, but nothing any of us did helped. The boy died right there.

I saw dozens more dead people during my time as a journalist: a grandmother who shot her preacher for impregnating her 16-year-old granddaughter and then setting up his teenage son to marry the girl, a Marine who shot himself after killing a jailer who fathered a child with the Marine's stripper girlfriend, many murder-suicides, a lot of robberies gone bad, some just in the wrong place at the wrong time. I've walked through the smoldering remains of a home where three young children died in a fire. I've gone on undercover drug raids, joined search parties in the Linville Gorge, bungee jumped from a crane, chased tornadoes, have been yelled at, threatened, run-off, thrown out, chastised, patronized, and humiliated, all in the quest to tell a story.

I've covered speeches by Bill Gates, rallies by Jesse Helms and Harvey Gantt, stock market crashes, school board battles, budget crunches, angry neighbors, people who have lost everything, lottery winners, addicts, victims, spelling bee winners, cheating lawyers, pageant winners, state softball champs, title-run losers, music makers, dying artists, cancer survivors; a long and often lurid menagerie of the human experience that, above all, has taught me to cherish each day.

Extraordinary Stories

WILLIAM: I'm a father, a brother, a son, a husband. I'm a stay-at-home father by day and adjunct instructor at night. I'm an advocate for people experiencing disability. I'm a writer and a poet. I'm a web designer. I know how to sail a boat. I can Eskimo roll. I'm optimistic. I'm open. I'm forgiving. I'm Southern. I'm self-made, self-motivated and self-educated. I can juggle. I've skinny dipped in the Mediterranean, watched a sunset from the Eiffel

Tower, and slipped inside a sarcophagus at the Louvre while no one was looking. I was robbed and tear-gassed while in France. I've eaten octopus. I love jokes. On my iPod, you'll find Copland, Bernstein, Nickel Creek, Notorious B.I.G., They Might Be Giants, and Amy Grant. Since 1994, I've kept a written mission statement, and it has evolved into this today: to create and share extraordinary stories. I try to live that mission every day with my students, my children, my conversations, and my writings.

Screw the Status Quo

WILLIAM: In teaching journalism students at Appalachian State University, I don't think outside the box—I get out of the box and compost it. Emphasizing a healthy dose of “learn by doing,” I get my students out on the streets interviewing real people.

To start class I might put up yellow police tape around the chalk outline of a body. I might hurl a cinder block onto a table. I might pass out Play-Doh. We leave the classroom to find better learning places like the basketball game, the diversity festival, the street corner, downtown or the duck pond.

I take inspirations, stories, concepts and ideas from my work and life both past and present as a journalist, a public relations professional, a volunteer, a board president for a local non-profit group, a camp counselor, a father, an advocate for people experiencing disability, a husband, a freelance writer, a natural birth educator and a poet, and I weave these experiences together to help me become a learner guiding learners. My personal goal is to make each class extraordinary. Sounds simple. Sometimes I fail. I think most times I succeed.

I see many students like I was: first in their family to go to college, working two or three jobs to pay their own way, burdened by family responsibilities, and full of potential. I take personal interest in these students trying to be the mentor I didn't have. I teach the way I approach my work and my life—screw the status quo; what works best?

Another Stained Glass Shard

WILLIAM: Fighting discrimination, advocating for my own son's inclusion in school and society, and promoting natural birth and breastfeeding, I take up causes others seem to

leave by the wayside. Staying the course or maintaining the status quo, to me, is moving backwards. To borrow from Augustus Caesar, "If I inherit a brick, I want to leave it marble."

When you boil my life down to the core, I believe I am three things: a thinker, a teacher and a creator. I hope that every day of my life is another stained glass shard in the mosaic that is my life. Some of the shards are darker, some lighter; but taken as a whole, I hope the end product is a beautiful thing.

Protecting my Sons

WILLIAM: I continue to help my mother, but as she ages her manic-depression has become more difficult to manage. We tried letting her live with us for almost five years, but after the birth of our first child, we asked her to leave. Living with us did not help her condition and perhaps put more stress on her to live in a way she never had before. Our negotiation of her disability was very different than her personal negotiation of it. We attempted to get her to reframe—to see a new way to live. It didn't work.

As she continues to struggle to manage her disability, my guilt sometimes swells for not being able to solve it. After my parents' divorce, I believe I began to fill a parenting role for my mother—a role that continues today. Since then, our relationship has always been one of me playing the responsible parent and her playing the child in need. I would send money. I would take time off work to kick a "boyfriend" out of her trailer. I would complete her disability paperwork. I filed her taxes. I fixed toilets, doors and cars. I tried to send gifts, photos, letters that would keep her in good spirits. I would chastise her for drinking or using drugs or skipping medication. I belittled the "bad" crowd with whom she liked to hang out. Often, I was an enabler.

Her last mental breakdown culminated with her decision to leave our town and move back to her hometown where she had spent her entire life, save the years she spent living with and near us.

I have come to a point in my life where I am choosing between her needs and my children's needs. I don't want my children to grow up with the experience of disability that I grew up with. I don't want my sons to know a "Grandma Daisy." That may mean they don't get to see their grandmother very often.

When looking at my son Kenyon, it is very easy to see disability as beautiful. When dealing with bill collectors searching for my Mom, destroying marijuana she bought without me getting busted with it, moving her belongings when she gets evicted, speaking with doctors as her guardian, or scrubbing her crayon drawings off her living room walls, it is very hard

to see disability as beautiful. It is hard to reframe that experience.

Yes, disability is my culture, and has been for a long time. You don't have to have a disability to experience disability. Jim says each of us must negotiate our experience with disability. In regards to my mother and grandmother, I have a lot of negotiating left to do. I have a lot of reframing to do, too.

CHAPTER VII

AT THE INSTITUTION TONIGHT

“At the Institution Tonight”

by Jim Whalen, 2008

(To the tune of Eric Clapton’s “Wonderful Tonight”)

It’s six and we’re eatin’
They’re layin’ out our clothes to wear
At seven there’s TV time
They come get me, if I’m not there

They give me my meds now
So I don’t put up a fight
Oh darlin’—we’re in the institution tonight

It’s eight in the morning
They’re loadin’ me in the van
I was lookin’ for fun but
I had my annual prostate exam

At 5:30 they lock all the doors
At nine they turn out the lights
Oh, darling, we’re in the institution tonight

Bridge

Tonight I’m plannin’ a breakout
I’m gonna go really far
If they try to find me
They’ll have to search every bar
This institution
Takes away all my rights
But it’s ok
Cuz this is my last night

Inspiration

After the first couple of days with Jim in Iowa, we began to share more intimate stories with each other. Our most intimate conversations were conducted sitting on barstools at a large laminate-topped island in Jim's home. Jim sat on the kitchen side and I sat on the dining room side.

Jim and I had talked about my mother and her battles with manic depression. He listened to my stories of her hospitalizations and the times she spent in institutions. I told him about my grandmother, too, and her battles with violent paranoid schizophrenia.

One morning after my cold Danish and cold coffee at Washington's only chain hotel, The Super 8, I drove through the steady rain to Jim's house. I found him composing in his creative nook.

"I want to play you a song," he told me. "Some of the things we were talking about yesterday [my mother and grandmother] were running around in my head and this came to me."

He then played "At the Institution Tonight." He had been trying to write a new song all week and now he had it. As I listened to the lyrics and music "run around and catch up with each other," I thought of my mother and the half-dozen institutions I had visited her in. I thought of my grandmother and the institution she died in. I thought of the institution less than one mile from my home that houses adults diagnosed with severe mental retardation or so-called severe handicaps. I wondered why I had never visited that institution. I have to drive by it every time I leave and return home. The sign out front has

a slogan; “In every face a possibility.” Now, after hearing Jim’s haunting lyrics, I always think about the particular time of day and wonder what is happening at the institution tonight? I wonder if a sheriff’s deputy is going to pull up to my house, knock, and tell me my mother has been committed again. I wonder if, in her face, there is a possibility of anything different than the cyclical life dictated to her by the highs and lows of manic depression.

Musical Gymnastics

JIM: The songwriting part is difficult in that there are times when it’s just not there. You can’t come up with another word. You can’t figure out another tune.

Many days, I wake up about 5:30, come down and have a glass of water or something or some Alleve, and go here and that’s where I am. And often at night, that’s where I am. And often during the day, that’s where I am.

I have to do something and then let it sit in my head. I use a cooking metaphor. I have to cook it and then see. I finish it and it’s done. And I can’t change it, then.

My talent is more in taking a concept and doing some musical gymnastics with it. Making people stop and think about that. I’ve been known all my life as a speed bump.

Phrase Hunting

JIM: I always have the idea first. I’m not inspired by the tune first. I do what I call phrase hunting. I don’t know if that’s a technical term or not, but it’s what I do. Think of a phrase that seems to catch, and build songs from that. Sometimes it’s far easier and sometimes it takes a long time. Some things like “The River of Money” are just accumulated life experiences—seeing this happen over and over and over.

“At the Institution Tonight” is nearly done now. And probably the things that need to be worked on are the chords, since there’s going to be two guitar players. Is there going to be any embellishment, or how we’re going to duet it?

The Blind Guy Saw it Coming

JIM: I ride bikes because my peripheral vision allows it, I don’t ride too fast. People say “How do you ride bikes?”, and I say, “I just don’t ride faster than I can see.”

A year ago, I was riding down the sidewalk. A car came out of a parking lot and had to pass two lanes of traffic to get on a relatively busy street in Iowa City. There’s heavy traffic in Iowa City because everyone has to drive two cars to get there.

But this car was coming out of this lot and I was coming down the sidewalk, and I realized that the car was probably looking at the traffic to see if he could beat the traffic to get across these two lanes. I thought it would probably stop. Well, then all of a sudden I hear the engine of this car rev, and I’m like, “This car is going to try it.”

When I was telling Mel the story, I said, “I saw it coming.” My wife says, “Well, the blind guy saw it coming.” And she just revels in my use of—“I saw this coming.”

The blind man saw it coming. Unfortunately—there’s nothing I could have done—I put on my brakes at the driveway and there was a little curb that jutted out in a triangular shaped thing. And the front of the bike hit that curb.

The car went speeding past and hit the curb and went over the front of the bike. As I was in the air, I realized that I was going to come down head first. In my head I was thinking, “You’re going to hit your head. Get your hands down.”

I hit both hands and basically shattered my elbow. I had broken it in three very slight fractures, but I’d also broken the back of the elbow socket and they didn’t X-ray it up that far. I had a cast for four weeks, then when I couldn’t put my arm flat, they got another X-ray up higher. There were four more breaks in there. They did a full arm cast.

The very next day, the doctor called because they had sent the stuff off to an orthopedist. And they said, “You need to come get that cast off.”

Medieval

JIM: “There has been a mistake,” the doctor said. “These bones are already fusing in that position and your elbow’s not going to work at all pretty soon. We’re going to have to re-break it.” I was not happy. And they just broke it. It’s medieval. They just put your arm in this clamp and just take this big weight thing and virtually just smack it. They just hit you.

I said, “Can I play the guitar?” And she said, “You can do anything you can tolerate. You can’t go lifting 50 pounds with your arm. You won’t be able to anyway. I was really happy because I could play the guitar now. As long as I can play the guitar, I’m good.

The blind man saw it coming. My wife just revels in saying that because she knows. My kids just give me crap all the time about it. It’s really funny because every time I tell them to do something—“be safe”—they say, “What do you mean, like hitting a curb?” I mean, they take my big negotiation point and ram it down my throat all the time. It’s funny.

Shut up and Follow Me

I find myself forgetting that Jim is blind. Maybe that is the point. However, as a journalist, public relations writer, freelancer and student, I’ve interviewed thousands of people over the past 20 years with only half a dozen of those interviewees experiencing vision impairment or blindness. During those interviews, I never forgot that any of them were blind, save Jim. In fact, I was overly conscious of the blindness: giving plenty of verbal feedback instead of nodding, using my voice to provide verbal cues for movement, and always articulating what I was doing.

During the SDCF, I found myself at the end of an interview with a young woman who experienced blindness due to microphthalmia, or, as she put it, “I was born with small eyes.” She told me about an art exhibit featuring sculptures and paintings created to

be touched: blocks of wood punctured with metal spikes; oil paintings with the figures rising out of the canvas; stone carvings of masks with textured surfaces alternating from smooth to jagged; intricate weavings of silk, rope, and taffeta; and a giant sheet of plywood music with putty notes lifting off the wooden staff, a treble clef floating on a metal pin, and an ceramic fermata slapped on top. “That’s perfect for my research,” I told her, and not thinking before speaking, I continued, “I wish you could show it to me.” She immediately stood up, her lips pursed, her eyebrows clinched together, she grabbed her white cane, turned toward the door, and with a defiant heart, she said, “Just shut up and follow me.” She then smiled. And I followed.

People Experiencing Disability

JIM: I’ve started, on many occasions, moving from the term “people with disabilities” to “people experiencing disability.” It’s a more inclusive term. It also allows you to think in terms of your family who experience that disability as well.

Using the word “experiencing” connotes that it has a meaning within the life of a person. That disability has a meaning that we have to pay attention to. And maybe that the meaning for an individual or the surrounding society is far greater—that’s a far more valuable thing to understand than the medical part of disability.

It is more important for you or my kids or for anybody to understand the meaning of my disability than to understand the physical nature of it. What it means is part of the experience of it.

The medical model would say, “Jim has a disability.” My vision is this and what I can’t do is this. What I can’t do is drive a car. What I can’t do is see. I can’t read normal print. Normal print, whatever that is. Don’t know what it is, but I can’t read it. If you can’t read normal print, then you don’t have normal vision, you understand. If normal print was 24 point type, then I could probably read normal print. Maybe not. Not being able to read normal print is such a little part of the life experience in general.

I really believe that the idea of forcing a different kind of thought process regarding disability is the key to much of what disability in our society is hung up on. Disability is beautiful. If beauty is among the range of thoughts that you need to connect with disability, more power to it. I think any concept that broadens the spectrum of your thinking about labels is good.

We have a zero sum idea. In order for me to be more powerful, I've got to beat somebody else. The way I decide that I'm more like a man is to be less like a woman. Those sorts of ideas, they just don't cut it. Or in order for me to have more, I've got to take some of yours. You have to have less. They're so limiting and destructive in terms of having everyone reach some sort of potential. I just find it disgusting. But I didn't used to. Remember yesterday, I was talking about that wrestling thing? For me to win, I've got to make you lose. That's how it worked.

Disability is beautiful. I think also it says something about the negotiation of self. The t-shirt invited you to think of that as a beautiful thing, not something to be negotiated away from. That disability should be embraced. Keep "should" and "coulds" and those sorts of things out of it. I think it's something that you will embrace, if it's something you experience.

You're going to have to negotiate it, so why not negotiate it as something that's a positive, creative thing? In a sense, a thing you can be proud of, or at least not be ashamed of.

It's also part of a larger discussion in terms of disability culture. Is there a culture of disability? I've got quite a lot to talk about in terms of that, so if you want to hear it, I can start.

Sister Mary Gregory

JIM: Before I started high school, one of the nuns, Sister Mary Gregory, came to me. She knew I was intelligent. She also knew that it was even more important in high school that the classmates helped each other. There was sort of a ranking in that the smarter students had more contact with other students because they were a resource. In the summer before my freshman year, Sister Mary Gregory said, "You're going to learn the whole first year of algebra, so that right away the students will be coming to you for help." And she knew that would change my role from someone who needed help to someone who was giving help.

Of course, she didn't explain that to me. She knew it and she took an hour or two a week and gave me homework and had tapes. And now when I look back on it, it was a really

kind of cool developmental thing that she was doing. But at that time, it was, "Geez, I have to do school in the summer?" But it was still kind of cool.

What You Hear About Nuns

JIM: She would do some of these lessons in the convent. No males were ever in the convent, for God's sake. And so it was kind of like I had a special knowledge of something. "What's that like inside?", everyone wanted to know. In the Catholic school where she lived, it was cloistered environment. "What's it like in there? Is it just all bedrooms?" I would say, "I don't know. I wasn't in the bedroom part."

Between my family and my school, it changed the dynamic of how I thought about the world. I think it probably changed my philosophy about disability because there was never a "lesser than" feeling for me. A little bit sometimes, but hardly ever, because this was just the matter-of-factness of it. I had a very matter-of-fact existence.

Of course there was some pity and some other things, but not on the part of my educators. That was just not in their constitution. And all the stereotypes you hear about mean nuns, they're all true. Every one of them is true. Psychotic, but they had a resolve.

Jim Knows Algebra

JIM: Home teachers came out to start teaching me Braille when I was in high school, but I wasn't good enough to really read it until I went to the adult orientation center after that. And they had books on tape, but not very many for my school.

They had *The Grapes of Wrath*. The classics were available on records. They had big stacks of them. And I used quite a few of those in high school. I really ate that stuff up when it was available. That was cool because I could do that by myself.

But there were some large print books, and they were not only large books, they were huge books. That's not a real inclusive thing, to have a huge book like this. A lot of the teachers in my classes, even if there was a large print book, would spend time taking the essentials of it and just writing it up for me in a notebook or reading it. Sometimes my mom would do that at night.

I was a wrestler. I played some high school football. I had some high school newspaper experience. I had very little time for work. I had to be pretty efficient all the time. So, yeah, I did have some accommodations in high school, but very few. Not very many. But it really didn't seem like you needed it.

And once it was known that Jim knows algebra, I never had any problem. If we had homework, I'd just sit down and somebody would come up and read the problem. They'd be more than happy to read or write out the problem if I could tell them how to start to work on it.

Our study hall was a room with blackboards all around. That was the one freedom spot in the school. But it wasn't run by a nun. Different people took turns proctoring it. So it was kind of this open learning lab. So a lot of my accommodations came as a result of fellow students, quite frankly.

Jumping Trains

JIM: Burlington's a big train town. We would sometimes jump the train. Don't listen, Amy. West Burlington has a big hill and the trains would have to slow way down. So we would jump the train and ride it downtown.

We didn't do this until we were ten. The train would have to be going two or three miles per hour. If it were a big coal train, for instance, 600 cars was not unusual. Huge long trains. When they get to the river, they have to make two 90-degree turns. So they'd have to slow way, way down again. There were lots of places downtown where you could jump off. So we would jump the train and ride downtown. It was a mass transit kind of thing.

Burlington, I always say it was a good town to grow up in. I would say it was a good town to grow up in because there was enough to do. Some kids complain that there wasn't enough to do. Not me. That wasn't an issue.

Entrenched in the Medical Model

About six months into Kenyon's life, after the initial shock of his early birth, his diagnosis of Down syndrome, and his diagnosis of hydrocephalus and subsequent brain

surgery, I began to try to frame, or reframe, our life and his life. Life is different after the birth of any child, but this was a particularly different kind of birth.

There were so many friends, family and coworkers to keep updated on our family's progress. Everyone wanted to help, and wanted to know how we were doing.

I took to writing e-mails to keep everyone up to date. It was the only way. Telling the stories individually would just take too much time and too much energy.

Though I could not have articulated it at the time, I had a growing uneasiness with the medical model of disability that was entrenching itself into Kenyon's care. Through my communication with my friends and family, I began to reframe issues of disability—not only for myself, but in order to change the notions of the people in our lives. Looking back, I can see how entrenched we were in the medical model of disability. I can also see that we were looking for a new negotiation of disability. And we were already reframing. I wrote this e-mail near Kenyon's first birthday:

WILLIAM: If you thought we kicked you off our Christmas card list, you were wrong. We just haven't sent them yet. We've been waiting in hopes of sending out the final word on Kenyon's health issues and especially on his second brain surgery.

You might remember that we were supposed to have final word on whether or not Kenyon would need a second brain surgery by Nov. 17. That date got moved to December. Then that date got moved to January. More tests, more waiting, more tests, more waiting. We thought we'd send out a New Year's card, then a Valentine's Card, and, until Monday, had our hopes set on a St. Patrick's Day card. If we do send out a card, I think it will say "To be continued!"

A short recap: Kenyon Heath Purcell was born two months early on July 26, 2004. In September, he underwent brain surgery to attempt putting a hole between the two lateral ventricles in his brain. The left ventricle had a tremendous amount of fluid in it and was squishing Kenyon's brain. The neurosurgeon couldn't make the hole, so he put in a shunt

that drains the fluid through a tube from Kenyon's brain, behind his ear, down his neck and down into his abdomen, where it is released and reabsorbed into his body.

The Sept. 17 surgery went well, Kenyon recovered, and at a follow-up CATscan in November, the doctors noticed his right ventricle now appeared larger. They were not concerned, but wanted to conduct more tests and monitor it.

On Monday, we went back to Wake Forest Medical Center in Winston for an MRI. There were supposed to be only two results: either Kenyon's right ventricle was the same size as in November, and no surgery would be required, or it was bigger and he would have to undergo a second brain surgery. We found out Monday there was a third option.

The comparison of the November CATscan and Monday's MRI revealed that his right ventricle was 2 millimeters larger. Put your finger and thumb together and try to get them as close as possible without touching and you have an idea of about 2mm.

The neurosurgeon said this could be just an error in measurement, because while comparing a CATscan and an MRI usually is sufficient, in this case it was not because of such a small change. Or it could be that his right ventricle is getting larger, but at a very slow rate.

The bottom line is that we have to wait three more months to do another MRI so that we are comparing "apples to apples." In June, we'll go through this again: either his ventricle is the same size and that should mean no surgery, or his ventricle will be larger and we'll be facing sending him back in for a brain surgery again.

If he does have another brain surgery, it will be different from the first. They will go in with a computer-guided "needle" that will use a GPS-type technology, where they literally put dots on Kenyon's head so that the computer can calculate the exact trajectory to cut in a straight line through his brain until it reaches the right ventricle, where it will make a hole leading to his third lower ventricle. The idea is to make a new hole to allow the fluid to drain more and stop the right ventricle from growing. The thought is that, for some reason, not enough fluid can escape the right ventricle and therefore a tiny bit is building up each day. It is sort of like drops of water dripping into a sink with a slow drain. Eventually, if the drain is not cleared, the sink is going to overflow; or in Kenyon's case, his fluid will build and squish his brain, resulting in brain damage and eventually death.

We are not looking forward to the idea of surgery. We've come to accept his shunt and first surgery because without it, Kenyon would not be alive. And it the same situation this time. It is just frustrating that there is nothing we can do—no therapy, no diet, no pills, not anything that can be done except wait and see.

Neurosurgeons don't have much of a sense of humor. A good thing I guess. I asked him how much brain tissue Kenyon would lose due to the surgery. He said an extremely small

amount. Think of it like a straight needle-size hole. The area of the brain that controls your thumb is about the size of a nickel, so imagine a straight needle going through nickel. I asked if he could try to hit the part of the brain that is responsible for the rebellious teen. He didn't laugh.

He was pretty blunt. If the surgery is required, there would be a one percent chance Kenyon would die in surgery. Sounds like pretty good odds, but then again, our chances of having a child with Down syndrome were one in 675, and our chances of having a child with hydrocephalus was one in 1,000, and the odds of having a child with both unrelated conditions plus being two months early (also unrelated to Down syndrome and hydrocephalus) were astronomical, so you have one baby that is pretty adept at hitting the odds. I think we should plan a trip to Vegas and let Kenyon pick the numbers.

There is also a chance of damaging brain matter during the surgery. But overall, for Kenyon's age, his chances were 60 percent of being a totally successful surgery with no complications. Sometimes I think he's just making numbers up as he goes. The percentages really don't matter because it is again a situation where, if we did nothing, the doctors say the ventricle would continue to enlarge until it killed him.

I sometimes wonder why we put so much faith in what the medical community says. Our faith in the medical system has been challenged over and over through this entire seven-month ordeal. While there have been shining moments of greatness and extremely talented people and kind workers, we have also seen mistakes, wrong medications, a nurse who took Liam's vital signs while he was sleeping instead of Kenyon's, and conflicting opinions between the neurosurgeon in Charlotte and the one in Winston and then what I call the best mistake of all.

At our December meeting with the neurosurgeon, he showed us areas of Kenyon's brain described as "permanent" brain damage. His exact words while pointing to the dark areas on the outer edges of Kenyon's brain were "These areas will NEVER grow back."

In February, Kenyon had his first fever and began spitting up. Two major signs of his shunt malfunctioning. It was Superbowl Sunday. At kickoff, we were in Watauga Medical Center. Kenyon had blood tests, a chest X-ray, a CATscan, and every other test you could imagine. Turned out to be a stomach virus, but they had to rule out the shunt malfunction because that would mean immediate surgery. However, in the radiologist's office while looking at the films of Kenyon's CATscans, he said, "Look at this, his brain has grown back around the edges here were it was damaged."

On Monday, our neurosurgeon confirmed that Kenyon's brain had grown back in that area of "permanent" brain damage, and seemed baffled by it.

The biggest reason we don't want to have to do another surgery is that Kenyon is doing so well! He has taken off, especially since the holidays. He is babbling, especially to Liam; he

is playing with faces; he is bright-eyed and loves to look at faces and smile at people; he has strong hands that love to grab glasses; he can turn the pages of his favorite book *The Velveteen Rabbit*; he loves to hear you sing or whistle; and more than anything, he loves to look at, babble at, touch, and be with his brother. And Liam loves to kiss, hug, hold, and help with Kenyon. I could not imagine them loving each other more. They are both so physical with their love to each other.

On Christmas Eve, Liam walked up to Janet and said, “Can we have another baby just like Kenyon?”

If we did, it would be wonderful. I think Liam sees Kenyon more clearly than anyone. He has no preconceived notion of Down syndrome or hydrocephalus or anything. To Liam, Kenyon is the most perfect brother in the world. I wish we all could see Kenyon through Liam’s eyes.

Kenyon is such a joy and I think every person that meets him leaves with part of that joy.

Down syndrome has not really been an issue. We have been so focused on getting his hydrocephalus taken care of that we just haven’t had much time to give it much thought.

Kenyon is evaluated each month by the Child Development Services Agency (CDSA) and sees an occupational therapist and a physical therapist for his developmental issues. So far, he has been meeting the milestones at a “low average” level, which means he would be on the low end of development for a typically developing child his adjusted age. It gets complicated. When medical professionals look at Kenyon they don’t see a seven-month-old, they see a five-month-old. For the first two years of his life, they will continue to subtract the two months he was born early as they calculate what he should be doing when.

We are very glad that he is meeting milestones. But we have come to the conclusion that it really doesn’t matter to us that much when he crawls, when he walks, when he talks. Milestones are for people to brag at the playground. We’re just glad to have Kenyon alive and in our lives, no matter what milestone he does or does not reach.

At the same time, we’re doing everything the professionals tell us to do to help him develop. But I think the most important things we can do are the same things we did for Liam—give him lots of love, lots of attention, lots of holding, lots of reading, lots of talking to and singing to, lots of laughs, lots of time to just hang out and be silly, and lots of good family and friends to help love him.

Another thing is that our time is more limited than ever, with seeing the pediatrician twice a month, the OT, the PT, the CDSA representative, the neurosurgeon, the developmental pediatrician, the pediatric ophthalmologist, the cardiologist, the FIPP representative, and dealing with the seemingly endless paperwork that has accompanied this whole journey.

Kenyon's medical bills have now eclipsed a quarter of a million dollars. We were very lucky that before, Kenyon was born, we opted for the best insurance policy Blue Cross Blue Shield offered. We debated if a \$400-a-month policy for me and the two boys was worth it; but it has certainly paid for itself over and over. Our share of that \$250,000 has been just about \$10,000, which isn't too bad for everything he has been through. We're still questioning charges, asking for itemized statements, and disputing charges in a seemingly endless cycle of statements, phone conversations, and letters. Sometimes I think the paperwork is worse than the time in the hospital.

About a year ago we decided that we were tired of seeing cesarean section rates skyrocket, drug use becoming routine during labor, and the joy of birth being taken away from mothers and fathers. We had to do something about it. We wanted to be more than advocates for natural birth. We decided to go through training to become natural birth educators in the Bradley Method of Natural Birth. Both our babies were Bradley Method babies and we want to share that gift with others. Bradley training has not been available in Boone for more than two years now. But now it is. We've completed all of our training and are halfway through our first class. We have three wonderful couples who are committed to learning how to give birth naturally. It is a small thing, but it is a start in making the world a better place.

Friday the 13th

News of the floods began to dominate the media. Newspapers featured big, bold headlines. The notable absence of music on the radio was replaced by listeners' call-in reports and disc jockeys' readings of historical accounts of past floods. The local television anchors began to show stubble and baggy eyes.

Hundreds of roads were closed across the region including, for a time, Interstate 80. Major bridges in Waterloo and Cedar Rapids were closed. The same was predicted for Iowa City. Despite heavy box cars parked atop a railroad bridge to hold it down, the rising waters between Mason City and Nora Springs destroyed the bridge, taking the

railroad cars with it. With Amtrak service down, many passengers were being put on buses to drive hours out of the way along intricate detours to avoid the rising rivers.

Coralville Lake crested at a record of 717 feet and burst from the spillway, causing the Iowa River to rise faster. Officials called for evacuations of thousands of people living inside the river's 500-year floodplain.

Local television news station KWWL went off the air after losing power.

The waters crested in Vinton on Wednesday at 24 feet, knocking out power and flooding 15 blocks downtown. All of the town of Palo's 890 residents were evacuated and the city became completely marooned by the flooding.

The flooding was worst in Cedar Rapids, where thousands of residents were evacuated from the 1,300 downtown blocks that were flooded by the rising river.

Those in Iowa City saw the devastation from Coralville to Cedar Rapids and knew that all that water had to come downstream eventually.

The University of Iowa called for volunteers to help sandbag and move the library's collections to the top floors. I wanted to help, but Thursday would be my last full day to interview Jim. I knew I was heading back to Iowa City on Friday to meet with Steve Kuusisto again. On Friday, I would sit in on another class with Steve and then meet a friend of Jim's for an interview over lunch. Maybe then I could volunteer.

Forecasters predicted the river to crest at a record 33 feet in Iowa City on Friday—Friday the 13th.

CHAPTER VIII

GOIN' RIGHT HERE ON THE FLOOR

"Goin' Right Here on the Floor"

by Jim Whalen, 2008

(To the tune of "Knockin' on Heaven's Door")

Someone find a stall for me
I can't hold it anymore
I've got to find a place to pee
Feels like I might be goin' right here on the floor

Chorus—Go, go, goin' right here on the floor
Mother Nature's mighty roar
Pressure's to great to ignore
Go, go, goin' right here on the floor

Some people say hey, hey there pal
Why are you in such a rush?
Because every guy and every gal
Deserves to have a place to flush

Chorus

They say this is the land of the free
Liberty and justice for us all
I wonder how this can really be
Until everyone fits in the stall

Chorus

Now some folks don't like this song
But I'm just tellin' it like it is
We have waited far too long
Just have a place to whiz

Chorus

One Bad-Ass Mother Fucker

The skies cleared on Wednesday night, just in time for the movies. Washington has an old downtown movie theater that looks more equipped for vaudeville acts than movies.

Jim wanted to treat me to a movie, so I met him and his daughters at the movie theater for the 7 p.m. showing of *Indiana Jones and the Kingdom of the Crystal Skull*. It was free popcorn night, so we got our red-striped bags of buttered popcorn and settled in for the show.

The change from light to the darkened theater always troubles me. Jim says it's terrible for him, too. He used Amy's arm to guide him into the darkened theater.

It might seem strange that Jim enjoys the movies. However, the wide screen allows him to use his peripheral vision to see the movie, he says. Jim also says the sound at the movies is always a big part of the experience for him.

We sat a third of the way back from the screen, munching popcorn and just enjoying the show. Jim said he'd seen all the Indiana Jones movies. I meant to sneak peeks at Jim throughout the movie, but I, too, became engrossed in the action the Indiana Jones clichés of flesh-eating bugs, snake pits, and crazed treasure-seeking Nazis.

Everything seemed so normal with Jim, though I hate that word—normal. I spent all my time in Iowa palling around with Jim's so-called "blind guys." Yet it all felt so normal. It's a feeling I don't often have at home.

I still have yet to become totally comfortable with the gawkers who watch Kenyon and me as we walk into a restaurant or through an amusement park or down the hall at school. I watch their eyes focus on Kenyon and his stuttered gait. I watch their expressions as Kenyon blurts out one of his excited screams at the top of his lungs.

Sometimes the people frown and look away. Sometimes they smile and nod. Sometimes they turn and whisper. But they always look at us. No one did this with me and my eldest son. But they always do it with Kenyon. We always command attention wherever we go, whether we want that attention or not.

Jim and Steve both exhibit such confidence: they go, they speak, they enjoy, they laugh, and they always seem to have the bull by the horns. I am only four years into experiencing disability with my son, and I have yet to gain anywhere close to that level of comfort and confidence. I'm always acutely aware of the staring masses. I'm always listening to the whispers as we pass. I'm always uncomfortable with the well-meaning words of strangers calling Kenyon cute, special or sweet. They'll say, "He's so sweet . . . he's so cute . . . he's such a special little boy." I always want to say, "No, he's one bad-ass mother fucker and you better watch out before he reaches up and bitch-slaps you." I really do think that, sometimes. I whisper that sentence to my wife sometimes in public and it makes her laugh.

The painful truth is that he *is* cute and sweet; he's not a bad-ass yet. But he is not *special* in the way they mean it.

Sometimes when I see an older child or adult with Down syndrome at a grocery store or department store, I stalk them. I'll watch from afar. I'll pretend to look at jeans or

a box of cereal, but I'm really watching to see what Kenyon might be like one day. We live in a very small community and very rarely see another person experiencing Down syndrome. I guess I'm guilty of gawking, too. But my reasons are different.

As we left the movie theater, I looked for people noticing us and Jim and his blindness, but no one paid us any special attention. But as we left, the rain began to fall again.

This is Normal for Me

JIM: This is something I told my mom when I was 14. We had just had a fight about something. I don't remember the genesis of that now, but I suppose I was battling with my father, which was almost a five year constant. Quite frankly, I don't really know how, as a family unit, we survived my battles with my father. I didn't agree [with him]. My mom said, "Maybe it would be best if you went to the school for the blind, in Vinton."

Vinton was a residential program for blind kids. She obviously didn't understand. She was trying to draw some parallel. I said, "You don't understand this." I was getting in a lot of fights at school because between my 6th and 7th grade years, I grew from 3 foot 9 inches tall to 5 feet tall, which was a considerable jump in size. Well, I thought, "It's payback time."

I went from one of the smaller kids in my class to average size or even fairly large for some of them. And it was time, if people gave me crap about almost anything, to get in a fight about it. And so I did. And she said, "Why are you doing this?" Well, because kids teased me and I got mad. That was one of the reasons.

And she said to me, "Well, I feel bad that you are not a normal kid; this is not normal." And the thought that struck me—and I can remember the exact place I was standing and the exact stance I was standing in. I just said it, "This is normal for me."

That constitutes normal. This is normal for me. I'm perfectly okay with this. It's normal for me. That had a profound effect on me from that day on. So I didn't go through this whole thing about how I'm not going to be able to drive. I'm not going to be able to drive. Of course, that was inconvenient. But this is not what makes me odd or different from my classmates. This is normal for me.

But along with that, I said [to my mother], “And you can’t understand it,” which was a really harsh thing to say to your mom. “You can’t get it. It’s perfectly normal for me and you can’t understand it.” That’s a parent-crusher there. I realize that now. That wasn’t my intent.

Coming to a new understanding of blindness, this inconvenience—you can come to a new understanding or change the meaning of blindness or the expectation of what it means to be blind.

So the thing with Kenyon, bear in mind that, over time, this is normal for him. This is not uncomfortable. Of course, sometimes it will be, but not necessarily for the reasons you would supplant on the expectation. I’ve come to that over years.

He’s not at an age where he can make that negotiation. He can’t drive that negotiation. And he may or may not ever do that. He will, actually; there’s probably little doubt in that. Whether or not we’re smart enough to recognize that he’s driving it, that’s a whole other thing on us.

Urine Trips

JIM: Being at the end of the line isn’t going to be the place to educate people about disabilities. Now, I have never accepted, for instance, a free ticket for someone to be a traveling companion with me. That’s one of those things that assume that I couldn’t do this by myself. I won’t do that. But economically, it would be great. But that’s a thing that I won’t do. That’s part of the negotiation as well.

But the other part of it is the internal negotiation that I was talking about. I guess this “Goin’ on the Floor” thing is part of that. The person in the wheelchair, Ron Kevins³⁰, just to give you a story about the way he chooses to negotiate his disability.

We went on a staff picnic at a campground. The restroom facility was accessible, but not the main shelter area. It was posted as accessible, but it’s really wasn’t, especially for people who use an electric chair.

Someone drove him around to a whole other facility. And we all wanted to write a complaint. But he absolutely didn’t want to do that. Instead of making a fuss about that, for him personally, he would rather not. Well, we asked if it would be okay if we did it and he said that no, that wasn’t okay.

³⁰ Pseudonym.

And so that caused consternation within the staff. But Ron did not think that it was up to the level of conflict, because he would be in the middle of that conflict and he didn't want that. Well, he was choosing to negotiate it differently.

He ended up getting to go to the bathroom on that day at that time, and that was enough for him. He was satisfied enough. And it wouldn't have been the way I would have chosen to negotiate it. But, if you believe in a choice model, people take responsibility for it. And so, I wonder how many times and places Ron plans his urine trip with regards to where he knows there will be a place to urinate.

To me, that's an unacceptable way of negotiating life. But a song was born.

Pep Rallies

JIM: I worked in this transition group with the schools, special ed teachers from early grades to high school, and the administrators at the schools. Some would say, "Other schools aren't going to do this *this way*."

"So what?", I said. I often throw athletics in their face. Do you treat your athletes different? I said to an administrator, "Have you ever had a pep rally for one of your BD [behavior disability] kids who finally got 10 out 15 on their spelling test?" And he said, "What?" And I repeated the question. And he just got so red-faced.

And I said, "Think about that. Here's a kid who has worked all semester to be able to sit in their seat and do these things and only got this grade. Where's his or her reward? Where's everybody in the school that stands up and cheers for that? It's likely these kids have put in just as many hours and it's just as meaningful and the teachers worked just as hard as a coach, maybe harder. Where's the assembly for that? I want to know."

"Well, it's different," he said. "To who?", I said. "Who's it different to? To you, maybe. Can you imagine going through town and seeing a big sign saying 'Go John' instead of 'Go Panthers'? No, you can't. Well, that has a meaning to it, whether you want to admit it or not."

Think about that. Just for a minute, think about what that means. Athletic teams have places to practice within their schools. Do the parents of kids with disabilities, get a key to the library so that, at seven at night, when they need to help one of their kids through something, they get to go do that? Not likely. Does that make people like me angry? Yeah, it does. It really does.

I didn't have that kind of experience at all. My parents didn't have to go beg the school to make sure their kid was going to learn as much as everybody else, because every kid was going to learn as much as everybody else. So I didn't live that experience. For me, it goes from whatever experience that kid is in now to one sort of like mine. This is one reason why I think inclusion is really important.

I have this thing that I share as a teacher that I truly believe goes beyond the classroom, quite frankly. Whenever there's more than one of us in a room, there's the chance I'm not the expert on something. And I think that's really true. I don't just say that because it's cute. It's probably true. There's something I can learn. And consequently, I've learned much. Some of it I didn't like to learn, because I figured out the way I'd been doing it up until now was wrong.

Everyone Doesn't Need CPR

JIM: When we talk about disability and these transformative experiences, in terms of changing attitudes or changing the world or whatever, we often think that we change it in these little tiny increments of trying. And we do change the world sometimes that way, but oftentimes, it's the moment at which you just decide, "We're going to flip this thing. We're going to flip the expectation."

It's not that "this kid can't read, so we're not going to teach him." I don't care if it fails or succeeds: we're going to try this and not assume he can't. And that becomes a transformative moment. It's not a bunch of little tries. It's a complete different reprint. It's a flipping of the paradigm. That changes the whole thing. It doesn't happen over years and years. It happens in a moment. And it completely changes everything for that kid in terms of from what sources of information they now have to learn the rest of what they need to learn.

The impact that will have on the path of his life just because of that one moment is huge. The whole thing changed that day. And it wasn't the sudden building up over time that finally broke through this barrier. It was that one moment that changed it.

And I think we often look at compromises that way. "Well, we're going to get this much more; but if we fight hard, we're going to get that much more and that's okay." And I would argue that, most of the time, in my personal experience, it's not that building up of little bits over time that changes it. It's that one moment where, from that moment on, everything gets redefined.

I often think in an inclusion situation, there's more chance of that peer learning. There's more chance that all of a sudden, it clicks. "I get this part." There are more opportunities. More scaffolding gets built. More opportunities. More lines to catch onto.

Inclusion is fair. People say some kids don't get equal time. I often equate it to someone having a heart attack, which makes people wonder. Well, if you see somebody on the street having a heart attack and you know how to do CPR, do you think, "Well, since I'm not going to give everybody CPR, it wouldn't be fair to give this person CPR?" That makes no sense at all. And that's what I equate it with. That's a silly argument. Sure, fair means everybody gets a shot.

I think your intent can be fair and equal, but the application of it isn't ever going to be that way. That's not how this works. That's not how human beings work, anyway.

Velour Shirts

JIM: My mom, she's one of these, "If we buy one of our children something, if we give one of our children something, then everybody has to get the same thing." This is a trait taught through her family. Every Christmas, one of the grandchildren would need something, and really need it. And so grandmother would buy nine of those, whatever it happened to be, whether you needed one or not.

Well, this creates this dynamic at Christmas because when the first person opens their gift, well, everybody else knows what they're getting. The surprise is now over. And that was fine. Christmas was not about the presents, so much.

One year, my cousin had started league bowling and, of course, everybody got a bowling ball for Christmas. Well, that was just a huge joke. Yeah, sure, everybody got a bowling ball with their name on it.

But as we got older, at one point, the drinking age was 18 in Iowa. When I was younger, there were eight of us who were then 18 or older. And we all got this same shirt for Christmas. This same velour purple: same color, same everything. All eight of us decided to go around town in these purple velour shirts to the bars.

We all knew a lot of these same songs. This was the day after Christmas. And we'd go into each of these bars and sing a song, have a drink, and walk out basically just to see what the reaction was. And it created a great memory, of course; but by that point, we had just all come to accept the fact that this was just the way everything was with Grandma. So one

person would get what they needed. But the rest of us, we had everything we needed, anyway.

Want a Ride?

JIM: Disability has some functional component to it. By the medical definition of disability, you have this idea of falling outside some normal range of what's considered physically or cognitively or behaviorally. Even here in this medical model, in my view, there's room for negotiation.

Who gets to decide? Who gets to decide what is a normal IQ? If the task at hand was to pound a stake into the ground—one task that was the purpose of your life—and your intelligence was enough to figure out how to do that, then why should you be considered abnormal next to the person who has a 50-point higher IQ but is doing the same pounding of a stake into the ground? To me, that's negotiated—a learned thing. There's no empirical proof that one person is normal and one is not. It's a social negotiation of what's normal.

You're going to experience being treated differently and have to make decisions about how you're going to react, respond, or try to educate. You're going to have to decide where you're going to place responsibility for that differential treatment. This is where all kinds of negotiation takes place.

And if you have an outwardly noticeable disability, or even other disabilities, in order to function in society, you have to negotiate this. You have to negotiate how that's going to affect your family role, how that's going to affect your work role, how that's going to affect your friendships.

As a college student, instead of going to the professor right away on the first day of class and saying, "I can't read this book. I'm legally blind." Even though they knew I was because most of the time it's obvious. I didn't go to them right away. I wanted to change the negotiation. I wanted to see the essence of the class. I wanted to ask some questions, fairly intelligent questions, if I could. I wanted to change that negotiation right away.

Instead of saying, "I'm going to need help with this task," I would change it. When I went to professors I would say, "How are you going to make this class accessible for me? Here are some ways that will probably work." And that's a different negotiation. I'm not convinced that most people with disabilities do this negotiation over the broad spectrum of their life.

I have a friend—we've been friends for 20 years now—who would always get frustrated because he would be driving and he'd pull over to see if I wanted a ride. And I said, "Well,

no, I don't want a ride. I'm going to take the bus."

One day, he confronted me. He said, "Why won't you take a ride from me?" I said, "I didn't want you to see me primarily as a person who needs a ride—I can take care of myself and I'm more than that." I was pretty sure at the beginning of our friendship, if he saw someone who needed a ride, that's how he would characterize me in a bigger chunk. But after I got to know him as a student, or as a peer, or in the classroom, then one day I took a ride because by then he really knew me.

In the negotiation of our relationship, this was something I was conscious of: that if his first inclination was to help me—that I had this disability and I needed help to do this—that is not the negotiation I wanted. Are there costs in that? Sure. There were days I got home tired and wet because it was raining. Was that a smart thing not to take a ride from him? I don't know, but I knew what I was doing. I controlled that negotiation.

In my personal negotiations, what I generally try is to say, "Here are the things I can do." Even in the course of asking for an accommodation, start the discussion with, "Here are the things I can do without; here are the things that are no problem whatsoever." If you can start the negotiation there, it becomes a different negotiation than, "Here is the diagnosis; here's the disability."

Something They Barely Let Out

JIM: One of the things that seems to be successful for me is to start talking about something that seems to throw folks off guard. For instance, I will say something like, "When I was reading such and such," or "When I was listening to this week's TIME magazine," or something that everybody does. So, you might say, "When Kenyon was playing with his Hot Wheels, he learned to do this." All of a sudden Kenyon, or any person with a disability, doesn't look like something they barely let out of the hospital to force into these situations.

It is baggage in a way. Baggage you and Kenyon are going to have to haul, in order to get to the quintessential learning part for the other person. I've found stories about the activities that I do, or if I'm working with a student who needs an accommodation, are excellent ways to start. So start with, "Kenyon seems to learn these things this way," so the expectation is that Kenyon learns instead of not *if* he learns, but *how* he learns. It's not *if* he can read it's *how* can we teach him to read. You have to learn to negotiate.

Some people with disabilities just let folks help because they don't want to confront that. And that's okay if they're comfortable with it—except it's not really okay with me. And it's

not okay with me because it allows that stereotypical thinking. It allows them to transfer that onto me, and then when I do something different than that stereotype, that creates even more dissonance.

Sometimes you wonder what's really driving the negotiations. Sometimes I've avoided situations where I figured the only way I'm going to get past this part of the situation is to ask for help and I didn't want to ask for help in that situation.

I didn't eat at a restaurant because I didn't know what they served and I didn't want to ask a waitress for help that day. Now, I don't do that anymore, but I have done that. Is that selling out? Yeah, it is, a little bit.

Negotiation

JIM: We have to be negotiators: kids, parents, and teachers. I think it's time, high time, we faced that. Figure out strategies to negotiate as opposed to hoping that you're not going to have to, because the truth is—you are. You're going to have to negotiate.

Part of what my music is about—probably most of what my music is about—is that negotiation, quite frankly. It's about looking at things different. Starting the negotiation at a different spot. Understanding the meaning versus this functional thing.

The other side is sort of the sociopolitical side. Some people call it the social-cultural side. What disability means within a society. I tend to like the sociopolitical thing, because I think much of what we assume about disability is learned and based on learned behavior. But it's also the personal negotiation. You will have to come up with some personal meaning, some personal negotiation of your disability within yourself. So maybe it's the self-negotiation model or something. But it goes beyond the physical or functional aspects. It goes far beyond that, quite frankly. I think most every person with a disability experiences, at times, that personal self-negotiation. I think they do. I think we do. I think people do.

I think it involves three functions. I think it involves a consideration of the function. Jim, you can't see very well. So somebody says, "We're not going to let you do this because you don't see very well." It does no good to deny that I don't see very well. That's a physical sort of reality.

Now, there is a negotiation about what it does require. Do you absolutely have to be able to see to do this activity? Then I think it involves two other factors. One is—what others' assumptions are about the meaning of your disability or the function of your disability. But the person experiencing the disability has to have a sense of what the other people in the

environment are bringing to it. Just like anyone's self-concept seems to have something to do with what other people think of them: that's the parallel.

And then I think there's the function of the person experiencing the disability saying, "Here's how I'm going to present the meaning of it. This is what I believe it is for me and this is how I'm going to present it." And as part of that presentation at that point, I think you make a decision of, "I'm taking a responsibility for how I'm presenting it to the outside as well."

If I'm assuming these people are having this attitude toward me because of a disability, I'm giving them responsibility for that. I'm taking responsibility for presenting my meaning of it to them. So it's a joint thing. It's a joint negotiation. It's a joint self-negotiation.

But I have to take responsibility for how I'm presenting it to them as well. I can't opt out. I can't say, "You know, I can do this and this and this," and then come back to them and say, "Pity me because I couldn't do that." You can't have it both ways.

People experiencing disabilities choose to present that "self" in some fairly archetypical story lines. One of those lines is "I'm the overcoming hero. So I'm going to explain my experience as, These people were discriminating against me and I fought and fought and I'm going to overcome that and some experiences are like that.

I think some other folks only go as far as, "This didn't happen, because I was oppressed." And some folks, like Ron, say "I am to be helped to some extent, always. And that's okay." None of these things are pure in terms of explaining who I am, but I do think people with disabilities kick into those sorts of presentations.

Iowa 80

After my last long interview session with Jim on Thursday morning, I left Washington for a field trip.

In my class An Anthropologist on Mars, we read a field study project about the world's largest truck stop—Iowa 80. I wanted to visit the fieldwork site and see firsthand what I had read.

As I drove north of Iowa City to pick up Interstate 80, I passed many flooded fields near streams and rivers that feed the Iowa River. I took I-80 east toward Walcott, and just outside of Coralville, I could see the flood waters of the Iowa River reaching up toward the interstate. It appeared I was crossing a huge lake rather than a river.

The radio news reports continued to list road closings, mandatory evacuations, school closings, flooded bridges, and power outages.

In an hour and half, I arrived at Iowa 80. As promised, the truck stop lived up to the description in the field study, from the smoke-filled air to the cowboy hats to the hard-scrabble truckers moving to and fro inside the giant tourist trap. There were things I didn't expect but could have predicted, from blue-haired ladies buying souvenir magnets, to road-weary yuppies buying cheap machine-made cappuccino, to wild kids running to vent the energy from hours cooped up in the family car.

I wanted to find some of my favorite trucker icons of the open highway, and I did—from a \$19.99 Yosemite Sam “Back Off” mud flap, to the sitting silver lady decal for \$9.99, to the Peterbuilt “379” logo cap for \$12.99.

I wanted to eat apple pie at the counter with the truckers, but couldn't bring myself to belly up to the bar through the thick cigarette smoke. So I settled for a machine-made cappuccino and hit the road back to Iowa City with my set of commemorative Iowa magnets.

Cherish the Grand Adventure

JIM: There are people who stick by a civil rights model of disability. I would probably count myself in those. Although sometimes, I get in that civil rights thing, so I can find fellow travelers through an issue.

But I've met some folks who view disability as just part of a grand adventure. That's part of this "I don't want to be normal, if I've got to be like you" mentality for me. It's part of a grand adventure. And so I think people who experience disability as a grand adventure take on this—well, they almost cherish it. I've met folks with dyslexia or information-processing functional things who would look at a sign and think it said one thing, then later came back and realized that that wasn't what it said at all. But the thing that they thought it said somehow seemed much more interesting to them.

And that seems to be part of a grand adventure. Instead of being mad that they didn't read it correctly the first time, or being angry that the person with the sign didn't make it clear enough, they have just decided that this is an adventure and that they will see things differently.

And they will hear things differently. I have known people who use sign language who enjoy the fact that they can communicate in a way that not many other people can. And I think that's more of a grand adventure sort of thing. Does that change the negotiation? Sure, it does.

I've had my disability all my life, okay; but I think from probably the last 20 or almost 30 years—it's weird when I think about it that way—my idea about it has changed.

And I think you have to come to a place where you're willing to accept that you have an active role in that social negotiation and responsibility. If you expect people to learn that they need to examine their assumptions about the experience of disability, then you have to be willing on the other hand to do it yourself. I guess that term "people experiencing disability" fits right into that whole thing. That's where I am, and I'm comfortable here.

Forks and Spoons

JIM: I enjoy the fact that, because I use my hearing for so many things, so many learning experiences, that the range of sounds I recognize is tremendous. I think that's a cool thing.

Is it important that I can recognize the sound of a handful of spoons versus a handful of forks? No. I'm never going to make a million dollars saying, "Here, rattle those. I can tell you what's in there." No; but is it cool? In a way, that's cool. The thing I have to do now is to transfer that into situations where I'm helping other folks learn.

I don't know Kenyon from anyone, but I would think that Kenyon has learned to do certain things in ways we don't understand. But if we can learn those ways, then we can use those ways as teaching tools. I've learned the sound that my dry vacuum makes when it gets full versus the sound when it's not full. I don't have to check to see if it's full. I've learned that strictly by the pitch of the sound. I only learned it because I thought of paying attention to it.

It's that kind of divergent thinking that allows all kinds of creativity and learning to take place. But if the only method to find out whether the dry vac is full is to open it up and look in the hole, then we've really limited what is possible.

Music and Lyrics Run Around

JIM: I'm writing a song about burnout. About 70% of my songs are written with a process that my friend Buddy³¹ calls "the tune and the lyrics run around until they catch up with each other." The next two lines of this song are: *I know it's just a game, but I don't want to play, it doesn't matter what I say, but it matters how I say it.* The chorus: *I'm burning out, don't want to think, tonight I'm going to drink, but when I sit on my knees and say amen, when the morning comes we'll do it again.*

For advocates, the task at hand is sort of never ending. But there's this shared thing among advocates that it's inescapable, although you do burn out. So, it's sort of a song for those people—parents and those people who will be doing this basically all their lives.

There are some stock rhymes and verses that I can come up with almost instantly. But then there are the ones that really mean something. And what I'm trying to get at is—this advocacy thing—not only is it about who you are, it's about your purpose, your purpose on the planet. So there's no way to avoid it. There's no escaping it. You can walk away. You can put your head in the sand. You can do all kinds of things. But it goes beyond a role.

It's about your abject purpose for the universe. And that's a heavy message in a "burnout" song. And I'm trying to get there from here. And can I do that? Eventually.

And so I was looking for sort of a happy tune to carry it. A faster, happier tune — because,

³¹ Pseudonym.

developmentally—and this is going to sound like, “Man, he gets real deep.” And I do I think sometimes—developmentally, I think those people who are sort of just getting used to this advocate experience. Yes, some days I get burnt out. Those people who have done advocacy for a long time sometimes really get toasted.

And it’s more for us to know you have allies who understand the meaning of that experience. But also, in this song, somewhere I’ve also got to figure out a way to talk about celebrating that instead of just begrudging it.

I’m very sure that the time to write this song for me is close. It has to do with my life circumstance, sure, but it also has to do with thoughts I’ve been cooking a long time and people I’ve observed and the need for a song about burnout. A message that people can understand—that can help—and also a message that some service providers can then understand their colleagues who are service providers like them.

So that song is close. Now, how close? I don’t know. Three weeks? A month? Tomorrow morning? It’s close. In my head, it’s close. And so I’m toying with different tunes to get there. That tune I like just to play to lighten up my head a little bit. You can’t play “The River of Money” all morning long. You just can’t.

If you’re going to use these kinds of media, these kinds of songs to understand disability culture, I think you have to honor the experience. I can guarantee you that there have been days that you’ve had to get up and put on your armor. That’s not necessarily what this song is about, but it is partially. Sometimes you have to do it every day for a lot of days in a row. And does it take a toll? It does.

I think, in order to understand disability as part of a social phenomenon; you have to look at all of those angles. My mom today still feels guilty that she has this kid with a disability. Now, to me, at this point in my life, that is just sad. This is now starting to touch me. I see in my daughters their absolute differences. Do I compare them to each other? What does that do to me by comparing them to each other? What gets imposed upon your family if you have a kid with a disability? Most of the time, it’s no big deal. It’s just normal for that family. But you do have to deal with the way others look at you. And, for goodness sake, there has to be some sort of emotive expression that an artist has to bring to that phenomenon. I share this experience with other families through song.

You may have noticed when I play, and when I perform especially, I take my watch off, because time doesn’t exist. I’m all-encompassed in that envelope of that idea that catches me. It’s not just a big bolt of lightning that comes down. It’s getting cooked. I do have the sense that I’m getting close.

I'm a Crip

JIM: Language is important. I've gone to a place where language wasn't so important. "I am who I am—I'm a gimp, I'm a crip." I still sometimes do that stuff, but then does that become a power term?

"I'm a crip and you're not." Well, if that's what it is, which to me, that's what it is—then you better darn well understand that's how you're using it. Language has power. Period. And there's no other way around it. Language has power. The language you use. The images you create with it. It makes a difference.

How I Survived

JIM: We moved into a neighborhood that had all younger kids than us. So we played whiffle ball there, too, but I was a bigger kid. So I never got called names. We had a rule within our family that we were not supposed to fight with each other. I should qualify that in a great way. We were not allowed to fight. But if someone was picking on one of us—I wouldn't say we were allowed, I would say it would be closer to *encouraged* to fight.

One of the brothers of this family got in a fight with my younger brother. A little neighborhood spat ensued. And after that, I think all three of my brothers and I got involved. I guess we were victorious. I don't remember too many of the details, but I guess we were victorious, because that ended that.

I think being one of the older kids in that neighborhood made a difference because you were bigger and stronger, and I was a pretty good whiffle ball player. And whiffle ball had a standing there. I was a good hitter. If I could see the ball, I could hit it. I've always been smarter than better. I've always been a smarter player of the games than a better technician of the games. So that was always part of how I survived the school yard, so to speak.

Scoops of Sand

I spent a rainy Thursday evening with Dr. Bonnie Sunstein and her family at her home in Iowa City. Dr. Sunstein co-wrote *Fieldworking* with Dr. Chiseri-Strater. Dr. Sunstein is also good friends with Steve Kuusisto.

She treated me to dinner and time with her family and a good bit of advice on my fieldwork project. It was a nice break from my week of work interviewing. I left Dr. Sunstein's house and headed down toward the Iowa River. The quickest way back to Washington was to take any of the bridges near the university and pick up Highway 218.

As I approached the flats leading up to the river, I saw the blue, yellow and red flashing lights from an array of fire trucks, police cars, and other emergency vehicles. The roads along the river were closed. Teams of poncho-draped sandbaggers worked around every small business, stacking the white bags ever higher. Tractors and backhoes plowed through the standing water with giant scoops of sand.

It seemed every road I chose ended with a "Road Closed" sign or a barricade. I worked my way through a series of right and left turns, moving toward the campus of the University of Iowa and the Burlington Street bridge. I made my way across and back to Washington wondering if by the morning the bridge would be underwater.

Back at the hotel, the 11 o'clock news anchors reported a hospital evacuation near the river. I checked the University of Iowa web site, which said classes were still on for Friday. So after reviewing my fieldnotes, I went to bed in anticipation of another day of class with Steve Kuusisto on Friday.

CHAPTER IX

THE ASSISTIVE TECHNOLOGY LAMENT

“The AT Lament”

by Jim Whalen, 2008

(To the tune of Last Kiss)

I was out on a date in my power chair
We we're rollin' round everywhere
We had a few laughs
She had a smile on her face
She even invited me back to her place
I'll never forget how I cried and cried
I was almost there when my battery died

Chorus—Oh, AT
Why have you abandoned me?
I trusted you, and man that stunk
I've got to get rid of some electronic junk

I was takin' an exam with my modified PC
I'd studied so hard I was gonna get B
Typing so fast I was almost losing track
That's when it happened, the screen went black
The hard drive had gone to an early grave
And wouldn't you know it, I'd forgotten to save

Chorus

I was making a call on my TTY
I'd finally hooked up with some really cute guy
We were hittin' it off when the lightning struck
Fried both our phones now we were out of luck

Chorus

Now these pretty little wires and microchips
Convenience of life at your fingertips
But the mess up your school work
And foul up you dates
One one person to blame
We hate you Bill Gates

Chorus

Repeat Chorus

AT (Assistive Technology)

JIM: I think people with disabilities who use technology develop this relationship—every American develops this relationship—with technology, with their computer, or telephone, or some device. It's something we didn't used to do. I think some people developed that relationship with their car, but I don't think there was this string of technologies that we have now. This song is about what happens when those things fail you.

I don't think there's been a lot of research done on that psychological relationship between independence and technology and what the relationship is for people with disabilities—when they have a device that they've really gotten to be quite independent with, and then it fails them. And also the relationships between how other individuals believe that it makes the person independent—that it's not just a tool for independence. That's the AT song. And it's a pretty popular one in terms of the ones that I do. But it's also a short, happy tune.

Meeting Atlas

After Steve Kuusisto's film class on Wednesday, I followed Steve and Nira to a downtown restaurant called Atlas. Steve wanted to make sure that the vegetarian interviewer got some decent food while in Iowa City.

I had the Veggie Heaven sandwich, which lived up to its name with its sautéed bell peppers, onions, eggplant, zucchini, tomatoes, couscous, and pesto. However, I had the chef hold the goat cheese.

Jim had described a dichotomy in Steve that he calls "Serious Steve" and "Fun Steve." I certainly got to meet "Serious Steve" that morning: Steve the award-winning author of three books, including his *New York Times* "Notable Book of the Year" *Planet of the Blind*; Steve the graduate professor; Steve the poet; Steve the Director of Disability Studies; Steve the blogger; Steve the Writer's Workshop graduate; Steve the essayist

whose work has appeared in *Harper's*, *The New York Times Magazine*, and *The Washington Post Magazine*; Steve the speaker who has appeared on *Dateline NBC*, *The BBC*, *NPR*, *Animal Planet*, *A&E*, and *The Oprah Winfrey Show*; and Steve the Fulbright Scholar.

On our 15-minute walk to lunch I began to hear “Fun Steve” opening up to complain about technology and poke fun at me being vegetarian; but as we began our interview about disability, disability culture, human rights, and politics, “Serious Steve” reemerged.

Most of the time, an interviewer maintains control of the interview with a carefully constructed guide of topics and schedule of questions. Not so with Steve Kuusisto. Steve was always in control. Steve guided. Steve didn't waste time. He answered very thoughtfully and quickly inserted questions of his own for the interviewer. Like Jim, Steve seemed as interested in my thoughts and philosophies on human rights and disability as he was in sharing his own.

Steve opened my eyes to a new way of viewing disability rights in terms of the fight for human rights. In a moment of self-reflection at the end of our interview, Steve wondered aloud about “the sea being so vast” and if he was really making a difference in the fight for human rights or for disability rights.

Almost two hours had passed as we ate, talked, and enjoyed coffee at Atlas. I noticed the restaurant's blue logo of the continents and how there was much more blue sea than white land. I thought of Ayn Rand's classic novel *Atlas Shrugged* and the book's title line where Francisco d'Anconia suggests that the Atlases of the world shrug. Unlike

d'Anconia, I see the true titans of the world as people like Steve and Jim, and maybe even me. Through our collective efforts we become Atlas holding up our own version of the world, hoping enough people will help support this ideal of human rights that includes people experiencing disability.

In Iowa, I found my lost enclave of like-minded thinkers. And the cause is too important to shrug, no matter how vast the sea.

Universally Screwed

STEVE: You know, I would be a Macintosh person, except my good friend Steve Jobs at Apple has managed to make Macintosh completely blind unfriendly. They keep saying they're going to retrofit it and they come out with various versions that are supposed to be [blind-friendly]. This is a subject about which, if you get me started on it, I will foam at the mouth: Macintosh, cell phones, the world of electronics, everything that's disability-inaccessible. Even though it's supposed to be accessible, nobody enforces it. Cell phones are inaccessible. You can buy third party software to make a cell phone accessible, but it's really expensive. The blind are pretty much universally screwed.

Pursuit of Happiness

STEVE: The world of disability in arts, disability in culture, disability in scholarship—these things are evolving, but a lot of it is still in its infancy. So there are film festivals having to do with disability. But that's a comparatively recent phenomenon over the last decade. Arts festivals having to do with disability, again, really taking off over the last decade. And that makes sense, if you think about how the Americans with Disabilities Act is a kind of civil rights legislation.

Often following civil rights, there's a sort of 10-year lag time as people organize at the grassroots level . . . culture comes together around that sense of difference. Self-reflection is involved. Slowly, but surely, things evolve, right?

I think I first heard the phrase ["Disability is beautiful"] in the early 1980s. I was talking at that time to a group of students with disabilities at a university and they were talking about the need for the disability rights movement. It came out of a sense that the African-American civil rights had been using the phrase "Black is beautiful" and there was this sense of needing to have that affirmative and positive sense of difference on the model of that movement—the African-American civil rights movement. And so that's about the first time I remember hearing the phrase.

I think I thought, as a sentiment, it's good. And I felt that there was a very strong, substantial, uphill struggle associated with that. And I still think there is. To accept disability as a form of beauty is a complex uphill struggle, because there are so many social, cultural, and historical formations, and the power of advertising and media that get in the way.

It depends on whether or not you define culture as having a language. If you think that language is essential to the articulation of a culture, then I'm not sure there is a "disability culture" outside of the deaf community. There is a disability interest group, a disability neighborhood, a disability community. But the difference between community and culture is an academic question, and I'm not sure how important that question is.

It comes down to what you think about human rights. I don't believe that I have to have the same ethnic, spiritual, linguistic, musical, or literary heritage as the people I ride the bus with. What I do believe is that everybody riding that bus should have access to the bus, should have equal opportunity to use the bus. In other words, our sense of community should be around our shared opportunity to achieve what Thomas Jefferson called "the pursuit of happiness." So, I do think from a human rights perspective and not so much from a selected identity group perspective.

No; in fact, I see disability rights as being at the core of human rights. The right to health care, the right to equal opportunity and accommodations, the right to partake of everything at the table of culture equally. Those are things we want for everyone.

Human Rights is My Culture

STEVE: I'm thinking of this from a complex position, okay? You're using the word "culture" the way it has come to be used in our contemporary American usage. Like pop culture. You're using the term to denote a kind of shared fascination. I don't think that's what culture is. I don't think that, because 50,000 people go to see the New York Mets play baseball, they have a culture. See, they have a shared fascination. They have a shared interest in seeing the team win. They may like the team's mascot or the theme music. But

there isn't a unifying language.

Now, on the other hand, it's possible for human beings to come together and agree that they have shared—a shared ethos, as the Greeks would say. Ethos is a set of standards and values to which everyone tacitly agrees. Typically, that is also tied to language, but I could concede that it's possible that you could make a culture around a document, like the United States Constitution. So you could say, "We hold these truths to be self-evident, that all men are created equal," and you set out a form of governance designed to make sure everybody is equal. And everybody subscribes to this. That becomes a culture. And your separate linguistic heritage, your separate physiological or ethnic heritage, while those things are of interest, you don't need them to join this new culture. So, what I'm aiming at is it's possible to create a disability culture that is not tied to heritage, ethnic history—I think it's possible to do that. Have we done it yet? No. Is it in the making? Quite possible.

The grander culture based on everyone being equal and the disabled haven't attained it amongst themselves, much less in relation to the larger society they live in. Sure, I'd wear that t-shirt. But I would also argue that disability is a component of human rights. So I would prefer a t-shirt that says "Human rights is my culture."

Abject and Suffering

STEVE: Don't forget that disability can be created by the military industrial complex. And part of the military industrial complex mission is to render enemy peoples disabled and then to abandon them, to leave them helpless. There are two million disabled Iraqis right now who are getting no medical care, health care, rehabilitation care, or treatment. They're not being talked about on the *NBC* evening news or the *Today* show. You're not hearing about them in your local newspaper. They're not part of the presidential campaign. Disabled people who have been created by warfare, by efforts of genocide, by political opportunism, exist all over the world.

I see that creation of impoverished and helpless people as the same engineering that creates starvation, that creates massacres of women and children in Darfur, that unleashes pestilence and disease, that leads to the political uses of hunger and terror. I see them as being interconnected.

I worry about that. Not just for people with disabilities, but for African-American people, Latina people, Chinese-American people, that we've created a Balkanization, to borrow that metaphor from the First World War. We've Balkanized identity in an effort to celebrate and bring up the morale of people who have been historically marginalized. We tend to look at experience within the singular lens of that isolated cultural experience, and as a

result, we lose the larger picture. That all of these marginalized identities, which remain abject and suffering, share that abject and suffering because of bigger human rights issues. I worry about that a lot.

More Than One Way to be Disabled

STEVE: One of the problems with identity politics is that it can very quickly, if divorced from a larger vision of human rights, become intolerant. So, for instance, we see the recent protests at Gallaudet University in Washington where one group of deaf people didn't like another group of deaf people and their internecine argument became vicious and intolerant at a very high level.

I don't know if you're familiar with that story. They selected a new president of Gallaudet University who was a deaf woman. But a particular group of deaf people thought that her sign language wasn't really fluent. She'd learned it along the way and they argued that she wasn't sufficiently deaf enough to be president of the university. And the argument became ugly. And it led to, I think, some very unacceptable behavior on the part of the warring factions.

The idea that there's only one way to be disabled is a very destructive one. There are two different groups in the blindness community that advocate for the blind. There's an organization called the American Council of the Blind—ACB—and they're a Washington-based organization with chapters around the country. They're a lobbying and education group. There's a rival group called the National Federation of the Blind located in Baltimore with state chapters.

These two groups are opposed to each other. They argue with each other bitterly. So the ACB says, "Gee, installing talking traffic signs—that's good for the blind." And the NFB says, "Oh, if you're really a blind person, you don't need that." They oppose each other. And the truth is, the more varied the accommodations, the better, you see. So these narrow identifications with a particular way to have a disability and experience a disability are destructive. If you put in talking traffic signs, it turns out they help children who aren't blind. They help the elderly. They help everybody, but it's not about which way to be blind. So this is how I come at these things from a more universal design perspective.

Because marginalized groups historically marginalize groups, all have suffered from a lack of political power. The word they use in literature departments is "agency." To lack agency is to lack effect and power. In that climate, the disenfranchised and the disempowered will inevitably crawl over each other to gain advantage.

What are You Doing with Him?

STEVE: I think gay and lesbian people suffer terribly. African-American people have suffered terribly, and continue to do so in disproportionate ways. I think people with disabilities suffer terribly. There are unifying principles to all that suffering. But the closer you look at it, the unifying principles have everything to do with human rights and less to do with the identity. I think the differences are less interesting or powerful than unification principles.

But look. If you're disabled, you're told all your life, "You don't belong, you're not part of the mainstream—you are a problem." Even today, if you have an intellectual disability, as your son does, you're barely admitted into the room.

I've been told at various stages, "You don't belong here." And I've had to fight my way in. I'm luckier than your son in that I don't have a neurological or learning impairment. And I have a keen intellect and I'm able to talk persuasively. So I can bulldoze my way in. But that doesn't mean I don't feel conditional all the time.

You walk into some space as a blind person, and everybody looks at you. And it's this sort of awkwardness. "What's he doing here?" My wife and I have been out to dinner on more than one occasion—she's not blind or overtly disabled—and she's caught men looking at her—and looking at me—and then looking at her. They do this little thing—"Well, what are you doing with him?"

Clint Eastwood is a Horrible Human Being

STEVE: I wouldn't say that coming together around celebrating disability is a bad thing at all. I don't pooh-pooh it. I don't look down my snoot on it. I think it's incredibly important. It's just that I look at these issues from lots of different angles.

In *Only Bread, Only Light*, there's a poem in there called *Guiding Eyes* and it's dedicated to my first guide dog. His name was Corky. And it describes Corky and I walking together around New York City. And what I'm trying to do is take the reader inside what it feels like to be us—man and dog navigating their way through a complicated, crowded, difficult, sometimes dangerous city, feeling a sense of independence and bonding. So I try to take the reader inside the mind of the man—dog combo. And there's an effort there on the part of the poet to describe something intimate and beautiful. But it's also a political gesture, isn't it? Saying to those who may not be familiar with this kind of difference, "Look, it's not

what you would suppose.” In other words, what the poem is saying is, “Yeah, blindness is beautiful. There is a beauty to it.” Yeah, and look, your son’s world is beautiful in its own richly diverse, complex, hard-to-understand way for other people. Well, and then there are people like Clint Eastwood, who think if you’re disabled, then you might as well kill yourself.

Clint Eastwood is a horrible human being. Do you know the disability rights organization Not Dead Yet³²? I admire them. In the whole issue of the Terri Schiavo case those being loudly debated, first in the courts and then on Capitol Hill, that moment was interesting, revealing—not interesting, revealing to me because it forced me into an unusual sense of relationship.

I wound up agreeing with President Bush and conservative Republicans who, historically, I do not like. But I really, honestly felt like Terri Schiavo should have the right to live. I do not believe that forced euthanasia is something we should delegate to governments. I have very complicated feelings about this. And I was very angry at a number of Democrats in that debate. Useless eaters. Where does that stop? Where does it stop and who gets to say?

I don’t want to give you the wrong impression. I think that to seize a positive definition—to seize a positive definition and identification around disability is very important particularly in a culture that would do everything it could to marginalize and categorize and rank you. So these are very important things. And we both know in terms of epistemology—ways of thinking—that disabled people have beautiful alternative ways of thinking. We know that. We are coming to understand it more and more.

So the work of a disability culture festival, using the arts to promote a sense of disability as an aesthetically, intellectually, culturally beautiful thing is really important. It’s part of human rights.

Beethoven Was Fucking Great

STEVE: Is Stevie Wonder a good musician or a great musician and songwriter/composer/performer because he’s blind? Or is he just plain flat-out a great musician/songwriter/composer? I think the latter may be more true, than the former.

³² Not Dead Yet organized protests of Clint Eastwood’s film *Million Dollar Baby*, in which Eastwood’s character kills a disabled boxer so that she will not have to live life as a paraplegic. Eastwood was also sued as owner of a hotel because of its lack of accessibility for those experiencing disability. Eastwood lobbied congress to weaken the Americans with Disabilities Act, according to Not Dead Yet (Not Dead Yet).

Paul McCartney, if he was blind, would still be Paul McCartney. And we sometimes get confused. We say, "Look," this is the Tiresias metaphor—we say, "Oh look, Stevie Wonder has got this compensatory gift from the gods. The blind genius musician." And in a way, that demeans his extraordinary musicianship, which isn't to say that blindness is demeaning. It's just that he's got some compensatory gift.

I happen to just think he's a flat out great, brilliant musician. And here's my analogy. Before Beethoven went deaf, he was fucking great. I know you're taping me. After he went deaf, he was fucking great. It's the same greatness. I happen to think it's remarkable that he persisted and found alternative ways to work once he couldn't hear. Good for him. God bless him. And aren't we all lucky that he did? But it wasn't the deafness that made him a musical genius. And they now think that Mozart had Tourette's syndrome.

How many stories have we heard of poets or artists who began their careers and were terrible alcoholics but then got sober and, lo and behold, they continued to be great artists? You can be happy and be an artist. There's this romantic idea that you've got to be a suffering wretch.

The Sea is So Vast

STEVE: The response to *Planet of the Blind* was much greater than I thought it would be. The book got a lot of attention, it got a lot of critical acclaim, and it got a lot of media attention. And then it's been translated now into 10 languages. And that exceeded any of my expectations. I thought, like most creative writers, "Well, my five friends will read it, and it will sell 20 copies."

I mean, do you ever just go home at the end of the day, and you just kind of think, "Man, the sea is so vast, and the boat is so small." I like to think that, in the small ways that I can, I'm helping particularly younger people with disabilities born in my generation to see possibilities. That's really important. And to the extent that I can do that, then I think I'm making a difference.

The Tyranny of a Normal Body

STEVE: Think about the tyranny of living in a normal body. If you think disability is bad, think of having to ride that pony. “May my body always be perfect. May the children of my family always be perfect. May my relatives always be perfect. May we never have affliction. May we never have to adapt.” That is an imprisonment of a very high order to live in that cage. If disability rights were fully adopted, and if human rights were fully adopted, it wouldn’t make any difference if you had a disability or not. There would be no fear factor.

Want Some Fire Scarecrow?

After lunch, Steve led me to the mall to meet Jim. Along the way, he pointed out some of the landmarks on the campus of the University of Iowa, including the gold-domed Old Capital Museum which served as the first Iowa State Capital.

I certainly felt privileged to ask questions to Steve during our interviews, but I felt equally privileged to get a glimpse of “Fun Steve” as Jim and Steve interacted in the mall. Like any two old friends, the two hammed it up and spent more time laughing than on serious matters.

As the two chatted about scuttlebutt surrounding local politics, disability issues and recent fundraisers, Steve called out one of my favorite movie quotes in a perfect imitation of the witch in *The Wizard of Oz*: “Want some fire scarecrow?”

The two laughed hard. I felt out of place. They had a more than 20-year history together. They shared a similar disability. They both play guitar. They were good friends and I sat down and just listened.

Tie Their Tales Together

STEVE: Man, you look more like Cary Grant every time I see you. Damn.

JIM: I know, getting better looking every time.

STEVE: What did you do with the kids?

JIM: They are at the pet store. Between seeing guys Dad knows and the pet store, we don't have a chance.

STEVE: Do they have pets now?

JIM: Cats. You may be a cat liker, I don't know, but I don't like cats. I can barely touch them.

STEVE: I have had one cat in my life that was fantastic—lowa farm cat that I adopted. He was great: independent, affectionate—you know, like, if you were reading a book, he'd want to come up and sit next to you and purr. But most of the time he wanted to go out and kill things. He was a good cat.

JIM: Ours aren't. We have two. I said, "We should just tie their tails together and see who wins." Then we'd only have one. Maybe they'd both die.

A Blind Professor Teaches Me to See a Movie

STEVE: What do you think of that class?

JIM: Oh, I think it's going to be a super fun thing to experience. And with the way you leave it open for their expression, I think it's going to be great to see what they do with it. How they deal with it.

STEVE: That's exactly what I'm hoping for.

JIM: I think that's really cool.

STEVE: You never know when you go into a room like that how many people have any idea about disability, or culture, or the theory. Film Studies 101—of course, with the irony

that I can't even see the fricking thing anymore. "Then there was the blind professor who taught me how to see a movie."

JIM: I think that's part of the cool part.

STEVE: I had to wonder, when I walked in the room, how many of those students knew I was visually impaired versus the ones that had no clue, because some of them had to have no clue. I walk in with the dog. "That's when the judge walked in with the Seeing Eye Dog."

Now That's Fucked Up

STEVE: I used to tell this friend of mine that I wanted to start this consulting organization called "Now That's Fucked Up." You'd come into a place that was only working marginally, and we'd really fuck it up.

JIM: Exactly. You think you've had it.

STEVE: And then they'd be so grateful for how things worked before we got there . . . and that would be our slogan, "Now, that's fucked up."

JIM: There you go.

A Beer for the Dog

STEVE: This is the only reason to have a guide dog. It's not that they give you any kind of edge in traffic, though that might be true, it's that you can suddenly say to people, "Oh, I have to take the dog out."

JIM: Hey, good move. I never thought of that one.

STEVE: When you want to get the fuck out of a room . . . and they ducked into the sanctuary and had a beer. My dog needs a drink. Maybe two. Got this thing for Guinness.

CHAPTER X

POSTER CHILD

"Poster Child"

by Jim Whalen, 2007

This whole thing started when I was 2 or three
I noticed those white-coats staring at me
Yeah, I am certain that is when it began
If they needed a star boy—I'll be your man

My aunts & my uncles, they looked at me strange
But I'd talk 'em out of all their loose change
I'd kinda feel sorry for most girls and boys
They'd often get nothin' when I'd get new toys

Chorus—Don't worry 'bout justice or pa-ri-ty
Just keep sending checks to my charity
We're gonna find a cure —and then we'll go wild
Yeah, I wanna be your poster child
Lord, I wanna be your poster child

When I started school I knew I'd pass
My teachers said I inspired their class
I always wondered if I made the grade
But some of my friends said,
"Ssshhh, you've got it made"

In Junior high some called me a freak
But I always sat behind the bigwig when they'd speak
When some guys started worryin'
About getting chicks in bed
I only had to worry 'bout gettin' pats on the head

Chorus

Don't worry 'bout my ego or that parity
They might find a cure for me and then we'll all go wild
Boy I got what it takes to be your poster child.
Man I'm gonna make it as a poster child.

Now every now and then we went down to the big city
They rolled me on the stage and told me "smile pretty"
Soon I was like the B movie star
Made the tote board rise, I was gonna go far

Well, the national folks, they noticed this you know
So Jerry calls me up "n" says,
"You made the Big Show"
I sat by corporate heads and I answered the phone
And after Jerry sang, I knew I'd never walk alone

Chorus

Don't worry 'bout justice man, that's not my trip
I'm at the top, No. 1 super crip
Send in your checks and we'll all go wild
Look, everybody, I'm the poster child—I knew I would
Make it as the poster child

At the end of the show a new record had been done
I asked what I'd get, and of course, I'd get none
They'll send some docs some millions
To study some chimps
And they'd scour the country for a fresh crop of gimps

Suddenly I realized I was cute no more
So I got me an apartment near the liquor store
I got SSI — sold food stamps to stay high
And some other cute gimp is makin' 'em cry

Chorus

Sabotage

Early intervention programs in North Carolina are delivered through an agency called the Children’s Developmental Service Agency [CDSA]. Our experience with the CDSA consisted of an endless string of meetings that resulted in a nonstop parade of weekly visits from occupational therapists, physical therapists, speech therapists, and, eventually, a technology therapist.

The technology therapist brought a large, round, red, electronic button on her first visit. It was like the Staples “That was easy” button, only you could record a few seconds of your own audio that would replay when you hit it.

They wanted us to start sabotage therapy. We were instructed to record a praising phrase into the button—something like “Yeah” or “Good job.” We then would withhold food from Kenyon until he pressed the button. When he pressed the button, he would get food. If he didn’t press the button, he wouldn’t get food.

They explained, in the coldest of terms, that this would teach him cause and effect. This would teach him to manipulate his environment. This would teach him to follow instructions.

We didn’t do sabotage therapy. That technology therapist never returned to our home. It was the final straw. We soon quit all therapies. For almost three years, we had been following, somewhat reluctantly, the orders of therapists who were trying to “fix” Kenyon. They were trying to shape Kenyon into a “normal” child. They were trying to

assess Kenyon to show us how far below “normal” he was on all the tests. They were defining Kenyon as broken and in need of fixing.

Through the absurdity of sabotage therapy, we finally realized that these pity merchants from the river of money sought only to keep Kenyon labeled, scheduled, and billed for services rendered.

No one told us Kenyon was perfect. No one told us Kenyon was just right. No one told us that this was normal for Kenyon.

They told us we should put Kenyon in a segregated pre-school with other kids with disabilities. We said, “No.” I stayed at home to raise Liam and I would do the same for Kenyon. Kenyon didn’t need segregation. Kenyon needed to be right where he belonged—at home.

Pushing a Stroller

JIM: What I do have a problem with is that, somehow, to prove that you should have a right to do something, you have to prove you meet some qualification as deficient—and then that protects your civil rights. That is bizarre.

I think that’s part of the trouble with disability culture. A lot of times you want to be considered part of the regular crowd. And so to identify yourself as part of disability culture is choosing to be segregated.

That doesn’t mean I don’t want to be included in the major activities of society—just because I have this part of me that I’m going to celebrate in some way.

How you define a person with a disability as opposed to normal. You might as well say as opposed to nondisabled, whatever that is. And that also leads to [the question], are there times in that person’s life when they’re not experiencing disability? Well, absolutely.

But family members, they are also experiencing disability. I think lots and lots of people are. Every time you push a stroller up a curb cut, you're experiencing disability. Because that curb cut wasn't put there for you to push a stroller.

Twelve Steps with No Problem

JIM: Society is moving in a far better direction [toward accommodation, modification and universal design] faster, in part, because of cheap technology. Modifications are cheaper and easier. It doesn't cost very much to produce an audio book³³ or to put a sensor in a crosswalk³⁴. With the baby boomer generation aging, there's going to be all kinds of physical and cognitive modifications because this population of folks is getting older.

You're going to see everything available in all formats, and not just audio books and large print. You're going to see furniture that is easier to get in and out of. You're going to see these things because Baby Boomers have money and they will need these things to function. Universal design is going to explode.

I have a theory—it is only responsible design if everybody can use it.

I've been experiencing arthritis. There are 17 steps to the top floor of my house and there are days when I can make 12 steps with no problem, but those last five steps are just horrible. I am going to go to bed and I can only make it up to the landing.

Even if you had put a stack of 1,000 one-dollar bills on the top of those steps, I could not have gotten up there. My legs wouldn't do it because of the arthritis. They just wouldn't.

So that concept of universal design is a good thing. Not that all houses have to be one story, but the idea that most houses are designed with at least some bedrooms on the bottom floor is really attractive to me. And that is a universal design that everybody can use. This idea that everybody can use it is very important.

It becomes a question not of if we should do this or not, but how? How can we make this work? How does this work for everyone, or at least for more people?

³³ An audio book is a modification that not only provides an alternative to Braille books or text readers for those experiencing disability as blindness, it is also a modification that benefits the temporarily able-bodied.

³⁴ Crosswalk modifications for those experiencing disability as blindness range from motion sensors to audio signals—and these modifications also benefit others such as small children and people on cell phones who don't pay attention while crossing the street.

He Speaks with an Accent

JIM: Maybe I'm "ye of little faith." I was told that if you have a disability the only way you are going to get a good job is to work with people with disabilities. That is the type of message I heard when I was a kid. I don't want my kids to be saddled with those kinds of thoughts about disability. I want my generation to be the last one that experiences disability the way I did.

As I watch and listen to the way that my kids talk about the kids in their school that experience disability, it's decidedly different, which is hopeful to me. A kid in my daughter's class has a cleft palate. He has some speaking differences. My kids don't see the difference as disability. They say that he talks with an accent. It's not a disability. They don't call him retarded. He's not the special ed kid. He just talks with an accent, that's all.

I want to say that I'm a proud dad. I got my kids aware of disability, but all the kids in their class think that way. Maybe it is changing. I hope so.

Blind Drunk

JIM: I have three uncles on my mom's side. The oldest one is an advocate. My grandmother was probably the best of all advocates in my life and was a great example of advocacy in general for me. Not necessarily for me, but for injustice. When she saw something she didn't think was fair, she was on it, always, just vigilant about it. This eldest uncle of mine follows in her footsteps in that regard.

One time, when I was working with the Department for the Blind and I no longer wanted to work for that agency, we were sitting around actually talking about the terminology and the conversation came around to this word "blind" and what it means and how people use it.

The Department of the Blind has this term called "blind guys," which is sort of the code for "I belong to this minority group, and we're 'blind guys,' and if you are a blind guy then you are a part of this philosophy and part of this thing."

And my older uncle says, "I'll be real truthful with you. I don't think of you as blind. Maybe legally blind is the more honest way to get to the function part of it, but I don't know what illegally blind is. What does that mean? How do you deal with that?"

And I go, "You know, I often say 'illegally blind' or 'legally blind' just so people get a sense

for what that is. And then I talk about what the range of blind might be.”

So, my youngest uncle was real uncomfortable with the whole conversation. It went on until finally Uncle Louis³⁵ was so uncomfortable he said to Uncle John³⁶, “Well, look, he is who he is. We know who he is.”

I said, “None of this particularly bothers me. You talk about me however you feel comfortable. If somebody says to you, ‘Isn’t that your blind nephew?’, don’t feel uncomfortable. If you want to say something about it, fine; but if you don’t, fine. That’s your choice.” Uncle John goes, “Well, the other day, Ronnie³⁷ said, ‘We should go pick up Jim and all go get blind drunk,’ and John says to Ronnie, ‘Well, Jim has an advantage. He’s already halfway there.’”

Just the fact that we could have this conversation is huge. Otherwise, that’s all below the surface. That uncomfortable situation already existed for them. “How do we talk about Jim?”

A Cry is a Cry

JIM: Because my uncles could sit around my grandmother’s kitchen table and talk about my blindness, my cousins had no problem with it. You can help create those situations by saying, “It’s okay to talk about disability.” And then, if somebody chooses not to talk, well, then they chose not to. I think art allows people a different way to express the term.

I think that’s one reason why the disability culture festivals are so important. It brings a whole new set of language that you can use, a whole new set of tools. Poetry brings a whole new language to disability. Dance and movement bring yet another language.

We don’t have to choose the traditional definition of disability. Disability can be something I can sing about. I don’t have to be defined by a medical or educational assessment. I can say, “I need to explore my feelings by writing this poem, or I can do this or by dancing with this rhythm.”

The medical model wants you to have that which is normal, that which falls in the normal range, that which looks like the normal average, and then that which does not. There are those things that we can cure or treat to move to normal level, and then those things we cannot.

³⁵ Pseudonym.

³⁶ Pseudonym.

³⁷ Pseudonym.

Experiencing disability isn't an individual phenomenon. Is disability like a fingerprint? Is there a human experience of having a fingerprint that's shared? Yeah, there is. I do think disability is a shared phenomenon. We function as people on the basis of shared meanings. A smile in almost every society means a smile. In almost every culture means a smile means happy. A cry is a cry.

She Can't Even Brush Her Teeth

JIM: You can create a meaning that both sides understand. You can talk in language that both sides can understand. As an advocate, you'll need to function in situations where both sides are playing themselves out. This is where the self-negotiation of disability experience comes in.

When I go to see Dr. Booth³⁸, who is the low vision specialist at the University of Iowa, I understand that he comes from the medical model of disability. He is a great guy, but he comes from a medical model, a functional model of disability. If you talk to him about disability civil rights, well, that's not his experience of disability. I'll throw in some terms, but do I expect him to have an "Aha" experience just because I'm not going to talk disability in terms of the medical model? No, I don't.

But if I say, "I don't want to use that device because even though functionally I can see a street sign with it, the reason for seeing the street sign is to get some place. I don't want to have 12 people on the street stopping me and saying, 'Hey, what is that huge thing on your head?'" My function is to get somewhere, not to stand to talk about the device on my head. For the most part, he's stuck on, "Well, it will allow you to see the sign." Yes, it would. But it won't allow me to get to the place I want to go in the time I want to go there. That's my relationship with him.

If I'm talking with a parent who's solely been engulfed in that medical model, I'll say, "Show me something that Johnny is good at. There are lots of things he can't do, I'm sure. But there's lot of things everybody can't do. Show me something he's good at. Tell me how he learned to do that."

One of my favorites is brushing teeth. I once sat with the parent of a 13-year-old girl in a meeting about planning a transition goal—by the time she's 18, to transition to a place where she can live on her own or in an assisted living kind of situation. And the argument was, "Well, she can't do that because she can't even brush her teeth."

³⁸ Pseudonym.

To decide one's living situation based on whether she can brush her teeth or not, for one thing, throws me. But this is the one thing they were talking about: "Well, she can't even brush her teeth."

And I asked, "Well, have you tried to teach her?" They said, "Yeah, we've tried to teach her to brush her teeth all these times." I said, "Well, have you tried teaching parts of it?"

"Well, yeah, once. Well, she can brush her teeth, but what she really can't do is get the toothpaste on the brush. We've tried putting the brush in the stand." And I asked, "Have you ever thought about having her squirt the toothpaste in her mouth? The key is to get the toothpaste in the mouth. All you have to do is have her own toothpaste, not the communal toothpaste. The key is getting it in her mouth so she can brush, right?"

They had never thought about that. They were stuck on that everybody brushes their teeth this one way. And they were making decisions about where she was going to go to school, what kind of plan she was going to have, based on the fact that she couldn't brush her teeth. "How was she going to do this if she couldn't even brush her teeth?" Well, come on.

But society works that way. And it works that way a lot. They say, "Can't tie her shoes; not normal." Well, try Velcro. If you have a broken hip, ever tried to tie your shoe? Are you automatically sent to the back of the bus because you can't? Where is your thinking there?

"Can't live alone because she can't cook?" Well, I know a lot of people who can't cook. It's the whole definition issue. I won't accept that that's the case. But this medical model thing, it provides a language for some people to understand and bring meaning to your disability. And some will try to bring that meaning in the social discrimination model. I think, in the end, it's how you personally negotiate it. And how you share it. How you create that shared meaning. How you communicate it. And how you own it. How you own those choices.

Expert Understanding

JIM: It's all about choices. In the end, if we're to expect responsibility, we have to have choice. Otherwise, it's all just dictated. If there's no free will, then it's just molecules. I refuse to take that stance. And I also refuse to say that the person experiencing the disability isn't the expert. My life experience has taught me that the person experiencing disability, be that the family member—they are the experts. They understand how the kid learns. They've seen it. They've been the teacher. They understand how the person with the disability understands what it means to be called "retarded."

I do believe that we, as a society, have a shared meaning that we create for disability in general—and we are still medical-model dominant in that meaning. From where the meaning is created in society, what people have been taught in society is so medically oriented. So overtly medical that the only way to combat that is to start driving hard the other way.

They Can't Be Equal

JIM: Discrimination is the parties of the negotiation choosing not to learn anymore. It's a power issue. There's a certain amount of people in society or a certain group of people in society that have a stake in not learning or changing. Whether they're willing to admit that stake or not, is not the point. The point is that we have a stake. People feel a compunction to help others.

That's not a bad thing. But where it becomes dubious is when an entire class of people become people that are supposed to be helped. Then that turns into, "Those people need help." And then it goes full circle. "Because those people need help, they can't be equal to me, because I don't need help."

When it becomes that this is a whole class of people who need help, then you have a situation where discrimination can be rampant. We should make everybody aware, and then they wouldn't have to worry about this zero sum power thing. That in order for me to feel good, I've got to find somebody who feels bad to help out. I don't think that's going to happen. I think that's also just part of human nature. But I think you can come into it more aware.

More Than One Reality

JIM: I think, going full circle to the beginning of our conversation, this is where you throw in a statement like "Disability is beautiful." I'm no longer a person with a disability. I'm not a hero. And you're not my savior. This is the beautiful thing. Now where does that fit? It changes the negotiation. It changes the whole dynamic. It gives a third meaning, and maybe a fourth meaning and a fifth meaning, instead of one of these dichotomous relationships. The reality is, you either learn our way—the way of the schools—or you're labeled special. What if there were multiple ways of learning? There are.

This freaks out lots of people, but I'm going to say it anyway. I was talking with my son one day about "Whether I really believe in god and heaven." And I said, "Well, yes, I do." Throughout life, there's just so much evidence in that regard. I think I believe in it pretty strongly. But I said, "Consider this. What if there is a heaven for people that believe in it, but not for those who don't? That there are two different realities out there. It's not either. It's not or."

He looked at me and he said, "I don't even know how to think about that." I said, "When you learn to think about that, come back and talk to me. When you learn to think about that, then we can start."

So what if there's a normal? And what if there's a range of activities and behaviors that every individual takes part in because that's the way they create meaning for themselves and try to create meaning for others to understand? But what if the differences between people are far greater than between group differences? Then how do scientists study that? How do people label people, if that's the case? What if the variety of ways that people bring meaning to their life are far greater than we think? That creates problems for people who want to put labels on folks. It wouldn't be a bad society. It would just create some problems.

Dark Days

Kenyon put up with his therapists for a long time. His speech therapist insisted that we put him in a chair with a Velcro strap, so he couldn't escape her 30-minute sessions of show and repeat, show and repeat, show and repeat. His occupational therapist insisted on him putting his fingers into gooey concoctions of dough or pudding or other texture-filled bowls, although, just like his older brother, Kenyon hates to get messy.

Kenyon came to dread the physical therapist the most. She worked him hard for 30 minutes a week: step up, step down, reach, grab, pull, push, crawl, roll, stand, whew! Kenyon typically rebelled against all therapy. In the beginning, with his physical

therapist, he would arch and stiffen his back. Then, one day, he learned to go limp. Just like a ragdoll, he quit all motion and refused to tense any muscle in his body for her, so that therapy was impossible.

Her reaction was to blame him. “Kenyon, you just don’t want to work today,” she said. Her passive-aggressive language always put the blame on Kenyon: “He can do it. He just won’t.”

Those were dark days. We didn’t have mentors. We didn’t know about disability rights. We’d never heard that disability is natural, much less that disability is beautiful. We just were stuck in the disability services machine—signing forms, paying co-pays, and scheduling appointments—all instead of just enjoying life with our son.

Tennis Balls and Shredders

JIM: I almost got into this huge harangue with an occupational therapist about tennis balls. “Well, he can’t grip enough tennis balls and put them into these canisters, so he can’t go on to the next thing.” Well, I just gave her the phone book and said, “Show me all these employers in the phone book that require on the job application the ability to put a green tennis ball into a canister.”

The next task was ripping up paper and putting it in a bowl. This kid was 16 and I just went over to OT’s office, and I took the shredder off her desk and put it over the bowl and said, “Jeremy³⁹, can you show me how to use this?” And he put the paper in the shredder. “Well, there’s a whole bowl full of paper. Let’s go on to the next task.”

They said he had a behavior problem because he wouldn’t do these things with tennis balls and paper in bowls. He didn’t want to do them because he didn’t see any sense in doing them. It had nothing to do with his ability. But he then had a behavior problem because he’d chosen not to do that. It’s so sad. And as a parent, you don’t know.

³⁹ Pseudonym.

Especially at first, you don't know. You've never been down this path. And you trust that these people are actually experts.

Most of the battle is getting the educators to understand that Kenyon and you are the experts on how Kenyon experiences disability. You are there 24/7. That's, unfortunately, the battle. That's where the battle takes place. And now I'm using battle terminology, because that's what it is. It's often a battle. It's you having to teach them, "This is *how*, not *if*," because don't ever move the battle to "if."

The battle is lost if you to move to "if." Move to "how." *How* can this work? Not *if* this can work. At some point, you may come to an *if*, but that's not where it started. That's a little bit of my advocacy coming through, I'm sure. *How* are we going to make this work? *How* are we going to do this?

Sometimes you're going to have to take the lead and show them how. You're going to have to go above and beyond, because they haven't experienced that before.

It Had a Label

JIM: I grew up on sports teams in the schools I went to, and when you made the team, you weren't a special person. You were just another person on the team. I was a competition junkie. I don't like competitions where everybody gets a medal. I'm not for that. If, during the competition, you did your personal best time, you should get a medal. Otherwise, no.

But my argument would be, if you're trying to develop ways to share the meaning of your life, then don't create something that's virtually meaningless for everybody else just to have some meaning in your life. Okay, you got a medal. For everybody else, that means they did their best or did better than everybody else. But for you, everybody gets one, so they can immediately discount your experience. And that's not right. That's not helpful.

It's important to understand that most kids don't make the team. Most kids aren't the starters. And you don't have to attribute it to Down syndrome or to blindness. Most kids just don't make the team. It's not so much what happens as it is making the meaning from it.

I was one of two people who were voted Outstanding High School Blind Student of the Year or something. In Iowa, there is something called the Palmer Award, and it's given to the outstanding blind high school student in Iowa. I didn't even want the award because I was a pretty good high school student, period. I wasn't so keen about the whole award thing because it had a label. I don't like false competitions.

Buttons

JIM: My college GPA when I finished was 3.42. Pretty decent. I never made the Dean's list once. The Dean's list is 3.5, right? That will tell you that I always knew where it was, but never really cared too much to make it. I consciously only took three courses per term. They were these intensive courses and they were great. I loved them. But I would always pick one where I said, "This is the one I'm not going to pay attention to. If I get a B, so what?" And most of the time, that "so what" meant I was getting a B. That's part of that negotiating.

Like Kenyon's situation, someone may at some point ask him to do something or say something and it's not going to matter to him. And it has nothing to do with disability. He just doesn't care about it. It's unimportant.

Like that button—the sabotage button. In no other experience had pushing a button meant food. So was it now his fault that he didn't get food? That he did or didn't get food? Push a button. Did you guys all sit around the supper table or wherever you eat, push a button, and then food came? No. What the heck is that all about really? Knowing that Kenyon is looking and saying, "In no other situation do I see pushing a button bringing food. Why should I learn that?"

It may be that for Kenyon or people like Kenyon, whoever they are, learning to walk is important because it opens up so much more territory. It may be that he would be able to function with a wheelchair and go anywhere. I don't know. But if you're in a society where walking and using a wheelchair were parallel in terms of it's just a way to get somewhere, then the whole issue of all of that goes away. But it's not there yet.

But maybe, I don't know. If we worked on it, it could be. I've been thinking about trying to write a song about this Olympic runner who uses the carbon leg—the jack rabbit. So, the song would be about "That's unfair because," or, "That's perfectly fair because."

Why don't we have people with wheelchairs run marathons? Many people who are wheelchair athletes are much faster than typical runners. I want to see some of these guys who can finish the marathon in an hour and thirty minutes. See how then this disability is such a pitiable thing. You get three people up there on the stand, all of which use chairs, and then that pity thing's going to go away in a hurry. Because I've experienced the competition thing, and there's no pity to be had.

For the Olympic runner with the carbon leg, it's normal for him. It's how he competes. How can we have a world-class athlete who looks like that? How can we? This is the Olympics. It's for only the best and the brightest. How can someone like that be part of that? I don't know. How can you? How can you not?

From If to How

JIM: As an adult with a disability, it's my responsibility to bring my meaning of my disability to the table. As parents of someone with a disability, who have the best way of communicating with their kid, it's their responsibility to bring that meaning, what that means, before the educational system supplants their definition for you. You'll get things like, "This kid can't communicate."

And the parent will say, "Well, yes they [the child] can. This is how they do it. They don't want milk. They're not being obstinate or angry. They're saying, 'I don't want milk, move it away.'" So when the school psychologist says this person [the child] can't communicate, the parent thinks, "What do you mean they *can't*?"

To start the negotiation with, "This is how Kenyon" or "This is how Jim learns best. This is how he does this," that gives the parent an enormous advantage in the negotiation of all things, but it also says to the people whose job it is to provide that education, "Look, you need to look for the ways of *how* this can happen, not *if* it can happen."

Changing the negotiation from "if" to "how" is huge. And sometimes, I've just come into a situation and said, "This isn't about *if*. This isn't about *if* I can take this class. It's about *how* I can." It's not about *if* he belongs here; it's *how*. How do we do this?

CHAPTER XI

THE BALLAD OF LUKEMIA BOB

“The Advocate’s Proclamation: The Ballad of Leukemia Bob”

by Jim Whalen, 2007

We were havin’ a discussion
We were doing our job
We were talking about disparity

That’s when it came forth
From Leukemia Bob
It rang out with crystal clarity

It came from blissful narcotic concentration
And it henceforth became the advocate’s proclamation

Chorus—Life Sucks
But I’m feeling good about it
And I’m gonna stand and shout it
And leave no doubt about it
There’s one thing you can trust
As long as it’s unjust
Life sucks

The medical evangelist stands there perplexed
Wonders why his white coat never tricks us
He smiles politely but wonders inside
When we don’t just beg him to fix us

We are his failures and you can be sure
Under his breath he has cursed us
He’ll take research money and search for our cure
But will never work for justice

And certainly he won’t turn down the large donation
So I think it’s time for the advocate’s proclamation

Chorus

The third party pirates—some called caregivers
They come in quite a splendid variety
The managed care mob sponge up the cash
And clothe themselves in faux piety

It’s the era of apathy and attitude pollution
If you’re not part of the problem
Can you be part of the solution?
High time has come to channel your frustration
By calling out the advocate’s proclamation

Chorus

And there are many things
An advocate may never know
I’m going to mention several in a row—like . . .

How much wood can a woodchuck chuck?
How much extra work does it take to make good luck?
How many strings can a banjo player pluck?
What makes a mallard an extraordinary duck?
How many cowboys fit in a pick-up truck?
And how the hell’s a hockey player ever see the puck
And who really, really, really gives a whoah, whoah

But one thing the advocate knows
From our heads down to our toes
There’s one thing you can trust
As long as it’s unjust
Life sucks.

Jim Did All the Talking

Before I left Iowa, I drove the streets of Jim's hometowns of Burlington and West Burlington. The towns look just like he described. The sidewalk-lined neighborhoods had large trees along the roads, creating a canopy for the bike-riders, rope-jumpers, and ball-throwers who all scattered as my car came through.

Baseball and softball teams practiced behind the brick buildings of the private Catholic schools. The long rectangle-shaped blocks chock full of homes built during the 1950s and 1960s seemed endless as I moved from stop sign to stop sign to stop sign.

Around the central hub of homes and schools in West Burlington, modern strip malls have sprung up. But it still felt like Jim had described it.

I could envision Jim as a child, sitting in an apple tree, getting ready to chunk some fruit at the kids coming down the street. I could picture him playing whiffle ball in the yards. I could see Jim as a six-year-old in Rookie League, standing at home plate, ready to bat.

During my final day interviewing Jim, he spent a lot of time reflecting on the stories he had already told me. He stumbled through the stories roughly, adding in things he had forgotten. He seemed to be questioning some of his long-held beliefs about those stories, too. I didn't speak much on that final day. Jim did all the talking.

People Like You

JIM: I got straight A's my last six quarters in high school because the person who ended up being class valedictorian had made some remark about "people like you"—not disabled people, but that I was not part of the "smart" people—and that "You could never [make good grades]." I wonder how much of my behavior in high school was driven by that kind of thing.

This happened in the hallway one day, pretty much out of spite. It was actually a girl. Her locker was two down from mine. And the locker next to mine was a person you would call a stoner, I suspect. He wasn't a great student, but he was good in math. He had said, "Jim could get straight A's, too, if that's what he wanted to do."

She was making some slur about our behavior. We were just being foolish, but we were 16. Actually, we were making some comments about someone else altogether. The person with the locker next to me had made some comment, "But you've always got your nose in a book," or something like that. I think her exact words were, "People like you, you could never get straight A's." And I guess, right then and there, I decided, "Look, I can do this." And I did it.

I Really Loved to Hit People

JIM: My first year at Notre Dame was the first year that they had varsity football. The coach coached at a public high school for years. He was a 50-year football coach, if that tells you anything. He coached my dad. And so, I said, "I want to go out for football."

Coach knew I couldn't see, but he wanted everybody out because it was the first year. We had to put together some sort of team. I was a freshman, and I wasn't very big. He said, "Well, come on for the first two weeks and do the calisthenics and we'll see how it works out." And after the first week or so, we put some pads on, and I was so determined that I learned every play and every technique and could execute anything.

Well, one thing I could do was punt the football. Coach figured since this was our high school's first year in football, we'd be punting quite a lot. Since we'd be punting quite a lot, I had some value on the varsity team. And that came true. We had 30-some kids on our team—and so the irony of ironies was that every kid had to learn two or three positions because somebody is going to get hurt. He said, "Well, what else do you want to play?"

I told him, “I run fast, but I can’t catch the ball because I can’t see it very well—maybe a fullback or a running back.” And he said, “We need somebody to play offensive line who can tell what the defense is and call out the signals.” And I go, “You know I weigh 130 pounds. That’s not really lineman material, exactly.”

So I started off being a guard. When I got to be a sophomore, I punted for the varsity and played for the sophomore team. They did put me as a running back. My position was punter. I didn’t really get into any of the games at all. I’d get in a play or two, but I was the punter. Get in there and kick it and run back. My sophomore year, I was a running back on the JV team and still the punter on the varsity team. But on the sophomore team, we had a position—a lot of teams have this position—kind of a rover defensive back, linebacker position. I really loved to hit people. I really loved it. And so they put me as that the last half of the season. I really enjoyed that.

You Can Do Anything

JIM: About three weeks into my junior year, I injured my ankle and couldn’t play the rest of the year. But I really wanted to go out for football again my senior year. And I worked real hard all summer on wrestling stuff and got my weight down. When football season started at the beginning of my senior year, soaking wet, I weighed about 123. So here I was—a skinny little kid who couldn’t see.

We had a new coach. And I came out for the first day of practice. I came trotting out in my stuff and go into practice with the backs. We had this drill where a person stood in the middle of the circle and you’d call out somebody and they’d run to the middle and see if they could get through the tackler guy in the middle. Coach said, “Put Jim in the middle and just start calling out people.” And of course, I tackle every one pretty ferociously.

It’s probably a circle of 15 people. You’re in the middle. Actually, you have to be lying down on your back. They call out a name. So it could be somebody behind you or in front of you. You have to get up, locate them, and get them down to the ground. Well, I was really good at getting people down to the ground. I’d get up on my feet immediately and use my peripheral vision. I would catch the motion, and once I got it, I was really quick.

Teachers hadn’t really encouraged me to apply for college. But this coach was semi-amazed how I did in this drill. He said, “If you can do this, you can do anything.” He was blown away. But he was also blown away by the way the rest of the team just accepted me as just another player.

No Problem with Notre Dame

JIM: I ran the ball some. I did okay. I gained four or five hundred yards on the ground. We were a ground team. But I really got into the defense thing. We had, for what was a small school in Iowa, a huge defensive line. It was six foot something and weighed 200-something. I would just walk up behind them and hide. And that's what I would do, too. And then just come out. It was really fun.

My last three years of football, we made the state playoffs. We lost every year. But we made it. So it was a big improvement. We played a team, Hamilton High School, who were undefeated before we played them. And as we went down—it was about 40 miles or so on the school bus—on that town's radio station they said, "Hamilton High School, 7-0, rated second in the state, should have no problem with Notre Dame." We beat them 43-7 or something. I can't remember the exact score. It was very motivating.

Super Motivator

JIM: I was the super motivator teammate. I always kept on people. I was keeping people in the game. Always all over them: "Keep watch for this, keep watch for that. This is your deal. This is your job." I really was that kind of guy.

When wrestling season ended for me, the basketball coach asked if I would come with the basketball team and sit on the bench and talk with these guys. I had that kind of relationship with most of the kids in my high school. And he knew I did. And he knew the kids knew I would get in their face. And it worked out well.

It was a good thing, because I would keep people focused. But I had this ability to learn plays and techniques and pay attention to those things and really get on people about concentration.

Of course, I was over-competitive. I could get other kids to focus. Sometimes I had to yell at them. At the midpoint of my senior year, they had this pep rally. I think it was close to homecoming, and they had the cheerleaders have this thing where they got dressed up as football players and imitated certain players who had habits. Of course, I got imitated.

They had somebody come out there and get in a couple people's faces and just scream. Of course it was me. There was no doubt who it was. I just laughed. Of course that's me. That's exactly how I behave. And I was equally as crazy when something good happened.

I got to thinking about my whole sports experience. I got to wondering if, in some ways I was using that as . . . I didn't have that big of a social life in high school . . . so I was wondering if that was my compensation for being afraid of trying to get dates. I mean, I had a few dates.

It kicked off something in my head. At the time, that didn't go through my head. Was it a way to be—I wouldn't say a big fish in a small pond, because we had a lot of good athletes there. But was it a way to at least be *one* of those fish in the pond? I started thinking about it, about as a kid, of course I'm much more self-aware now than I was then, was that a way for me. . . . I think a lot of it was a way for me to get away from my dad, but maybe not. I started thinking about that in terms of the overcompensation kind of thing.

Nike Award

JIM: I wonder how many of the other things I did were compensatory or to somehow . . . when I'm thinking back, I wonder, if that wasn't something . . . I can't say for sure. But thinking back . . . I think I did do that . . . it's got me thinking. When I go back to Burlington, what teacher can I look up to ask, "Was I overcompensating? Did I do these things?"

I'd like to get some insight on that. But that was 30 years ago, so I'm not all that concerned. It did spark that thing in my head. Did I do these things mostly because . . . did I do them because I couldn't play baseball?

And I think that's partially true. And that really sounds odd, too. Baseball has always been my favorite sport, and the reason I say that is, during the summer of my junior year in high school and partially after my senior year I went to every baseball game and . . . I was invited to stand behind the dugout. Not in the dugout, *behind* the dugout, and talk it up with the players. That year, the team went to the state tournament, and I was invited to go with the team, ride the bus, and be on the bench during that experience. And so that was obviously my role in the school.

Why I adopted that role now is striking me odd after talking about it yesterday. I was kind of a "spark plug" student. "You can do this." Like a cheerleader, almost.

In a sense that role was . . . how do I put this? That role was not so important for the play on the field, whatever that was. I guess there always have to be people on the team who do that. I even got an award on the football team. It's called the Nike Award, for that particular role.

The Greek Goddess of Victory

At the front of Jim's old high school is a statue of Mary encased in plexiglass. She sports the school colors of blue, white, and gold as she stands there with arms wide open.

School may have been out for the summer, but students were on the ball fields, practicing. The campus stretches for several blocks encompassing the high school, middle school, and elementary. I had hoped to get inside the school and roam the halls where Jim once went to school, but the building was locked.

My first job as a newspaper reporter was covering high school sports for *The Alleghany News* in Sparta, North Carolina. It was a one high-school town. I spent a lot of time with the football team, the wrestling team, the baseball team, and the school's state-championship softball team. That experience covering high school sports helped me envision what life was like for Jim during his days at Notre Dame High School. I have spent time in a sweaty, smelly wrestling practice room. I have watched the pageantry of a high school wrestling match. I have stood on the sidelines with the players during a football playoff run.

As a reporter covering Alleghany High in 1994, I was doing the same thing that I'm doing now in Iowa with Jim—telling other people's stories.

JIM: I got to thinking too much last night. Okay, did the coaches form me into that inspirational role because they thought my story was an overcoming story? I would like to talk to them and ask, "What the heck were you thinking?" But none are around anymore. I need to track one of them down, just to get that information somehow. The fact that it made me think about it that way, I think it is important to share.

I think probably, given the other parts of my personality, it sure made it convenient if the coaches were looking at me in that role. I never heard a coach say, “Look, if Jim’s out there doing that . . .” I never heard a coach say that. But I don’t know. I certainly wouldn’t have put it beyond any of those coaches to grab some player aside and say that. I certainly wouldn’t. But it got me thinking. It got me thinking about that yesterday.

Just a stray thought, I suppose. But I wonder about that in terms of the roles kids with disabilities have on sports teams. You know, being the manager, what that really is all about. I don’t know. I just thought I had to throw that out because it was spinning in my head yesterday.

That was my senior year on the football team, so it would have been 1976. I felt good about it [Nike Award for sportsmanship]. There was a fall sports banquet. That’s where those things were handed out. One of my friends said, “Of course you’re going to win that.”

It was for the player on the team that made contributions that weren’t necessarily on the field. And I remembered—that “not necessarily on the field” thing—that’s what kind of struck me as maybe that’s what the coaches wanted all along.

And it’s not a blame thing. Don’t get me wrong. I was happy to be involved. But it’s been kind of grinding on me. I may never be able to talk to anybody about how that came about.

My senior year, I probably mostly played that bench role more than anything. When I stop and think about it, although I got in games, I wasn’t a starter at that time. We had a kid come from the Netherlands or one of the Scandinavian countries—a foreign exchange student—who could kick. Who could really kick. And I was fine with all of that. But I hadn’t really thought about it in terms of the disability thing. But now, I kind of am. I don’t know, really.

We were the Notre Dame Nikes. The shoe Nike, which is named after the Greek goddess of victory—before Nikes were Nikes, we were the Nikes.

CHAPTER XII

FREEDOM TRAIN

"Freedom Train"

by Jim Whalen, 2006

You promised me you'd right your wrong
Now I have waited way too long
You tossed me a penny and tried to buy my soul
Handed me a shovel when my life was in a hole
Pennies for my soul, life in a hole, pennies for my soul
You take holistic lives and define them as wrecks
You never rock the boat 'cuz it brings you the chicks
Throw out all our dreams like last Friday's trash
In God you may not trust, but no doubt you'll always take the cash
Dreams in the trash, always take the cash, dreams in the trash

Chorus—Have I had it with your bull—Hell Yes!
Am I gonna take control—Hell Yes!
The time to sell my soul is passed
And if you don't like it you can kiss my ass-perin won't cure the headache I'm about to bring
And let freedom ring

No more pools of pity 'cuz you leave us here to drown
No more livin' in the ugly boxes on the edge of town
I think it's time you look us in the eye
We want our slice of the American Pie
Look us in the eye, we want our pie, look us in the eye
A warning to all you bureaucratic hacks
You've spilled our blood upon the tracks
We're comin' with a red-tape axe
You'll probably have to get some whacks
Comin' with the axe, gonna get some whacks, comin' with the axe

Silence us? Oh, I'm sure you'll have a plan
But I look at our warriors—I don't think you can
You will try to push our spirit in the morgue
But resistance is not futile and we won't be assimilated into your Borg
No spirits in the morgue, not part of your Borg, no spirits in the morgue
It's time for "Be it sunshine, be it rain"
If you bring more prejudice, your forecast will be pain
Injustice is the shackle and it's time to break the chain
It's time to ride the new freedom train
Time to break the chain, new Freedom Train, time to break the chain

Stuck

I checked out of the Super 8 on Friday morning. It took me an extra hour to get through the detours in Iowa City and to find an open bridge to cross to campus. I had not heard that classes were canceled at the University of Iowa, but even if I had, I would have probably come to the river's edge.

Though I haven't been a true newspaper reporter since leaving journalism for public relations back in 1999, I still act like one. There is something in me that makes me want to drive into the storm. I always loved that part of the job. When there was a tornado, you drove toward it. When there was a standoff with a gunman, you got as close as possible. When there was a fire, you raced to it. When crowds gather, you stand on the edges and watch. When the police scanner beeps, your ears perk up.

So I found myself outside Steve's building watching the river. The sandbags stacked on Wednesday had already given way to the water. You could smell the water inside the building. People were filing out of the building with boxes, computers, monitors, lamps, plants, books, and stacks of papers.

I could see the Burlington Street bridge being reduced from four lanes to two. All the other bridges were already closed. Major parts of Iowa City were underwater. Interstate 80 was closed, and traffic detoured hours north to avoid the flood.

If I didn't make it back across that bridge, I would be forced to drive toward Chicago to get back home. If I didn't get back across that bridge, I wouldn't see Jim

again to say goodbye. If I didn't get back across that bridge, I wouldn't get to explore Jim's hometowns of Burlington and West Burlington.

I left the water's edge, got in my Honda, and crossed the bridge. Turning left onto Riverside Drive, I saw the water coming across the road. I stopped.

Several trucks rolled through the water with no problem. But I was in a Honda Civic. I was low to the ground. I revved the engine, got up speed, and plowed through.

I made it halfway across the flooded road before the car started floating. The engine raced. The tachometer spiked into the red zone as the rear of the car turned toward the river. As the front of the car sank back into the water, the wheels struck ground, gripped, and pulled forward. Again the car floated for a moment. Then the wheels touched ground again briefly. Each time the front wheels struck the ground, the car lurched forward, but was also then sent floating. The rear end of the car had come completely around toward the river. The front wheels again gripped pavement, this time permanently. The wheels pulled forward and the rear hit pavement again. I steered back into my lane and onward.

No hoot, no yell, I flat out *screamed* from the excitement. I beat the steering wheel. I could feel my heart pounding. I love that feeling—being there. It is that feeling that drives a journalist. I don't think I'll ever lose the desire to feel that way.

Riverside Drive was flooded in two more places, but I used parking lots as detours around the water. Soon, I was back onto Highway 218, heading south to say goodbye to Jim.

Smart-aleck

JIM: I remember rarely being a self-advocate in high school. There was one occasion I handwrote a paper. My handwriting is atrocious, so I usually typed papers, but I didn't have time for this one.

The teacher made some comment that she couldn't read it. I grabbed it and told her, "I'll hand it in later in a readable fashion." I went home, took my slate and stylus, and Brailled it out. I handed in the whole paper in Braille. I said, "Here, this is perfect. It's perfectly legible now."

She couldn't read Braille. But she handed it back and said, "Okay, you read it." And it was fine. I don't know if that was an advocacy moment as much as a smart-aleck moment.

Roller Skating Lessons

JIM: Lately, I've been thinking about high school. Did I have crushes? And if I did, did I do anything about them? I remember at least one. I remember my older brother having three or four girlfriends when he was in high school. Why not me? Did I just not expect it? Why didn't I expect it? It probably had to do with my vision. I didn't date much.

At my 10-year reunion, I talked to one old girlfriend. I asked her about this other girl that turned me down for a homecoming date. I wanted to know if it was the driving thing. I couldn't drive, so she would have had to drive us to homecoming. But then this other female chimed in and said, "Honestly, Jim, it was your personality that kept you from having more dates."

Apparently, when I was a freshman in high school, there were two of the "socialite girls" who were interested in me. Our class went roller skating. They wanted to teach me how to roller skate. I didn't know them. I didn't want to learn. I didn't want anything to do with them.

And that kind of wrecked my first couple of years of social life in high school. They were mad at me. And I was a smart aleck. Not was—I still am—but I was even worse then than I am now. These were fairly influential girls in the realm of social things. I was point-blank told, "They blackballed you."

I had a date my sophomore year and I fell asleep. It was after an athletic event, and I was

really tired. Maybe that's why I don't sleep now. I don't want to miss out.

I guess that was it, except for this girl who wouldn't go to homecoming with me. That was during my senior year, and after that, I kind of felt excluded.

Personality for Birth Control

JIM: Back to that high school thing about dating. Some people said, "Your personality was the problem." In high school, we did have a class period on birth control. I still believe that in my school, you weren't supposed to know anything about sex until you were married and had two kids. But we did have this one class. I happened to be going with somebody at the time, and Sister Mary Catherine⁴⁰ asked me about birth control and what I thought about premarital sex and birth control. Before I could answer, my girlfriend spoke right up: "You can pretty much count on your personality for birth control."

I wonder about eye contact—not being able to pick up on others' eye contact. Maybe it's a bigger loss than I think. I think those people who are part of my life don't probably think about it twice. Maybe they do. Maybe it doesn't change their behavior at all. Maybe they still make the same eye contact and they just, in that second, realize, "Oh, he doesn't get it." I guess I just know it exists. All in all, over time, I've become comfortable with the whole physical part of the vision thing.

I will say this. I have one of the better memories of anybody I know. And it's the vision thing. Because of the annoyance or the energy it would take to go look up a number again. Knowing where things are, the location of something. To remember where it is so much better than for me to have to look it up. I tell my kids, "The way to look for things you can't find is to think. Look by thinking first."

No Such Thing as a Good Divorce

JIM: I dated quite a bit after high school and I wasn't very good at it then, either. My first wife was actually a rehab client of one of the other counselors in our office. This was after I got my master's degree. I don't even know how to analyze that. I think I was more in love with the idea of being married than being married to her.

⁴⁰ Pseudonym.

She had her faults, too. We won't go down that list. You don't have another week. I was married the first time for nine years. To my knowledge, she had three affairs. But we had Joe⁴¹, my adopted son. And I didn't know what to do.

But it got it to the point when we both realized that this isn't how life is going to be. There's no such thing as a good divorce. There just isn't.

Fish on Friday

JIM: We would go to Mass every Sunday, come home and watch University of Notre Dame football highlights on the TV. "Catholics." We were your stereotypical blue-collar Catholic family. And our whole neighborhood was that way.

At school, the nuns were disciplinarians. If you did something really bad, it was hands down, smack on the back of the hand with those little metal-edge rulers. If you really got smacked hard, there was blood. I can laugh now, but it was strict, very strict.

We were really union Catholics—fish every Friday. In fact, I had fish every Friday until I was 18 years old. Even in college at a Dutch Reformed Protestant school, there was a group of us who would go down to Mass, then come back and go to the library and start studying the stuff we should have been studying all weekend.

Peace Out

When I arrived at Jim's house, he wasn't there. The house was full of the neighborhood girls, some playing Littlest Pet Shop Animals and the older ones lip-syncing to Hannah Montana. Jim's older daughter gave me directions to the convenience store where I could find him.

⁴¹ Pseudonym

As I pulled into the parking lot, Jim was coming out with two bottles of Diet Coke. I told him about the morning's adventures in the river and about not getting to interview Steve or any of Jim's other friends because of the flooding in Iowa City.

Jim gave me rough directions to his hometown hangouts in Burlington. We made plans to touch base later the next week. We shook hands and said goodbye.

Jim's bicycle had an infant carrier with wheels hooked to the back tire. He put his Diet Cokes into the seat, hopped on the red bike, and rode off toward home.

I watched him ride away. Just before he left the parking lot, he made a peace sign with his fingers, put it to his lips, and then lifted his hand into the air, shaking the peace sign back and forth.

I had 24 hours of audio tape, stacks of yellow notepads, and a 14-hour trip home. I pulled out of the parking lot and headed home.

Why Did God Give Me This?

JIM: In church, I would hear "Everybody has burdens to bear," and that kind of thinking got to me. I don't see my disability as a particular burden. There are some burdened characteristics to it, but I don't think that God said, "You're going to be smart and you're not, and you're going to be this, and you're going to be that, and I'm going to make you blind because you need a challenge."

But I heard "Everybody has a cross to bear" and "God has a reason." Hearing that over and over drove me crazy. Three of my best friends from college have passed away in the last year and people say, "That's all part of God's plan." But that seems of little solace. Show me the plan. Show me the page that is on.

I did, curiously enough, sometimes ask, "Why can't I get that miracle? Why can't lightning strike me and make me see? Why not me?" I also think, quite frankly, of all the times

where I've almost stepped in front of a car, but didn't. I give thanks for that.

When Cassie was born we were having a lot of family stress. Joe, my oldest, was having difficulties. And then Cassie was sick with a high temperature. I was at home with her. And I couldn't read the thermometer . . . I couldn't . . . and just—I couldn't. And I said, "I'm not sure, dear Lord, I'm not sure . . . I can't handle this . . . give me a way."

I was thinking I was going to have to take her to the hospital. Her temperature was so high, and I couldn't see the thermometer. And I said out loud, "Why God? Why did you give me this?"

What the Hell She Did

JIM: My mom sometimes wondered out loud if my blindness was a punishment from God for something she did. I want to know what the hell she did. That's what I want to know.

She feels far more guilty about this, still to this day. And I sometimes blame the church for that. It's part of that guilt thing. I've tried, and there's nothing else I can say or do to relieve that guilt. I've gone through trying to convince her that she shouldn't be guilty. And I've gone through chiding her for that sentiment. I've come to the conclusion that there's nothing I can do about it. And I feel sad about it.

When my teachers were not able to write things out for me really large so that I could read it, or when they couldn't read aloud to me, my mom would do those things for me. She was sort of a teacher's assistant for me. But I would never adopt this helpless kind of attitude that I think that she expected.

I'll tell you how my younger brother puts it, and I think he's hit the nail right on the head. I never acted helpless. I never allowed other people to pity me. And even sometimes when the help that would have come with that pity would have been okay, I just never allowed it. And my mom was included in that.

I think that's always been a spot of contention. I think my mom expected to get pity—"You have this kid who is blind and you're doing these special things for him." My mom wasn't allowed to get the story that she was helping this kid overcome. I cheated her out of that experience. I think Mom never was allowed the social support and the social congratulations for helping her kid overcome this thing, because it just didn't play itself out that way. And given the time when she grew up, she semi-expected to get some credit. More credit, probably. And it's not that I haven't given her credit for helping. It's not that at all.

She didn't gain great admiration from her brothers and sisters, for instance, or from some of her friends. She wasn't allowed to be pitied for having this terrible burden because I didn't turn into this terrible burden. I can understand that now. I never could then, but I can understand that now.

Nazareth

JIM: I love my father now. I probably always have. But we didn't see eye-to-eye on many things, and we still don't. I wouldn't want to say that his children were a labor force, but we kind of were. And everybody needed to pull their weight. And he would teach his kids things and then expect them to be able to do it. He was very matter-of-fact about it.

I think, all his work life, he wouldn't have been capable of treating anybody different. That was just how he went through—that was his view of the world. "If I teach you how to do something, you should pay attention, and you should know how to do it then and do it. Don't come begging me."

I was 10, and we were just expected to help. "Here's how you break out the drywall. Here's how you mud a wall. You're big enough. You're strong enough. Do it. That's the world. That's how it works, kids. There you go."

Tile a floor, for instance. He would say, "Here, you do this and you do this." And he would show you, and he would watch you do about three, and he would say, "See that floor? Here you go." I would respond, "Well, Dad, it's going to take all week." He would say, "Well, you better start now."

Everybody had work to do always. And he got us up every day at 6:45, Sunday through Sunday. There were no days off. And of course, once I got to be a teenager, that was also part of why I hated my dad.

But I think the main thing between my father and I was the music thing. He just absolutely hated it, and I just absolutely loved it. He didn't like to hear it at all. You couldn't play it in the house when he was there.

His father was an alcoholic, so I don't know if he was abused as a kid, and when the music got loud, he got hit. I don't know. And when we could buy music with our own money that became the source of contention. Whatever we made, 90% went into the general family till. But when we would spend our 10% for records or something, I'm sure that just had to eat him up.

I do know that I did buy something a little louder when I had the opportunity. When I was about 14, I distinctly remember buying some Bob Seger that I could play really loud, and some Boston and Kiss. I distinctly remember buying those bands, not because I liked them so much, but because I could play them loud and really irritate my dad.

The band Nazareth—probably when I was 16 or 17, and right before I moved out of the house—had this song, “Hair of the Dog,” which has that “son of a bitch” lyric in it. And I distinctly remember buying it that for that reason, and then shaking the house with it.

The guys I went to high school with would get together and play cards every weekend—poker. Mostly because of my mathematics skills, I was a really good poker player. And would often win 40, 50, 60 bucks in just a game. I remember one weekend, I won 230-some dollars, which was just huge money. It’s still good money, but it was big, big money. One of the people owed me, like, \$70, and he had a stereo that he gave me instead of paying me the money. I bought the biggest speakers that I could buy and came home and put that record on. That was probably the biggest fight I had with my dad. I am pretty sure I brought it on.

We would say hello and be somewhat polite to each other after that for about 10 years. But if I called home, it really didn’t matter if I talked to Dad.

The Church is in Me

JIM: By the time I was 15 or 16, I had sort of worked my way through that whole “Was this a punishment from God?” I’ve had a few “Why me?” moments since then, but not many.

I consider myself a very spiritual person, but I would say more have moved away from the traditional every Sunday kind of thing. I’m more of, “The church is in you” sort of person. It’s more of what you do, than how many times you read the Bible a week. I think I’ve moved more in that direction.

I’ve also become a lot less conceited in terms of, I’m not so sure that what any individual does has that great of a cause and effect relationship on the universe. And I’m not so sure that any human being can really dictate what’s in the thoughts of God. What the intent of God is, either. In fact, I’ve become a lot less conceited on that point over time.

People who come and direct you and say, “This is what was intended.” Or, “This is all part of your burden to bear.” I think that’s pretty conceited. How do you know how this is? Do you have a pipeline? I would still say definitely I’m a Christian. I would say, “What would

Christ do?” And I do say that to myself consciously. “How do you think that would be? What kind of guidance can you get that way?”

I guess I’m not completely devoid of the thought that there is a reason, maybe not for everything. But I am big on free will. There’s a choice. You make choices, and you’ve got to be responsible for those choices. And that’s something I learned from the Catholic faith quite strongly. I don’t know of any other place where I would have got that.

That’s My Why

JIM: Everyone has a “why” as a human being. Everyone has a “why,” a purpose. And I know this is sounding like a Zen speech, but that’s okay, because it’s what I really believe. I think everyone has a “why.” Everyone has a purpose. Everyone has a function within the universe.

And we have an obligation to try and understand each other’s “why” as we’re trying to understand our own. And if we don’t, shame on us, because I think we’re throwing something valuable away.

It’s like the Gestalt thing. How do you see the two faces versus the vase thing? How do you change that? That’s one of my skills. That’s one of my gifts from the universe—to get people to reframe.

That’s what I do. It doesn’t matter so much how I’m doing it, but that’s something I’ve been given the gift to do, so that’s something I’ll do. That’s my “why.”

To reframe—it’s my function. Now, I find that, personally, it sometimes is not very comfortable, because people aren’t always comfortable with me doing it. That’s my “why,” so get over yourself. That’s just who I am. And I’m not going to change.

Does He Love Me?

I teach a class at Appalachian State University called Interviewing Techniques.

One of the main techniques I teach involves moving through three levels during

interviews. The first level involves basic information that the interviewee is completely comfortable disclosing because it is not personal. The second level involves delving into more personal information about beliefs, feelings, motives, and thoughts. If you are lucky, you can get to the third level of an interview, which involves disclosing intimate information with each other. It's a two way street. The interviewee is only likely to disclose as much information as the interviewer also discloses.

My first day with Jim focused on level one questions. The next two days focused on level two questions that probed deeper. When you reach level three you really don't have to ask too many questions. At that point, either you've built enough trust to share intimate information or you haven't.

On Thursday, after a few hours of sitting across from him at the table, Jim really opened up in a way that honored me. We both shared intimate stories with each other.

There was one moment at the very end. It wasn't a moment of insight or a nugget of truth to use as an advocate. It was a moment of sharing between fathers, as one friend speaking to another friend, as one human being sharing an intimate moment with another human being.

There was no disability, no thesis, no advocating for rights. It was just us, just this moment. After this moment, Jim made a joke and brought the conversation back around to disability rights. But that one moment of connection, to me, was what the entire ethnography is about.

We share a belief that disability is beautiful. We share a belief that disability is a culture and that we are both part of that culture. Part of being in disability culture is negotiating and reframing.

My negotiation and reframing of disability have mostly been about letting go of false expectations. Most of the time, it is about letting go of superficial things. It is likely that Kenyon won't get a driver's license, won't go to college, and won't have children. He will have to work much harder than most typical students to graduate high school, find a good job, and live independently. We will have to fight for his inclusion in school. We will have to deal with a society that often mocks those with disabilities more than it accepts them. Those issues to me are the relatively easy ones to deal with. My personal issues are the harder reframes.

Jim made me wonder, when I think of Kenyon and his disability, what do I miss most? What I miss most is not speech. Kenyon doesn't communicate with words. We are hopeful he will one day use words. But what I miss most is hearing from Kenyon the words, "I love you."

I've never heard Kenyon say, "I love you," and I would do almost anything to hear him say those words to me, just once.

Sometimes when Kenyon and I are alone at home I will look him in the face and repeat the sentence over and over: "I love you, I love you, I love you, I love you . . . ," just hoping he will respond.

I think of the documentary film *The Teachings of Jon* that tells the story of man with Down syndrome who is nonverbal. His parents tell a story of driving down the

interstate one day when Jon was a teen. From the back seat, Jon said, “Mom, I love you.” They pulled over, crying, praising, and hugging Jon. It was the first and last time he spoke.

I know Kenyon loves me. He communicates that to me in many ways. But I understand that there is something deeply meaningful about hearing those words from someone you love. And it is my personal negotiation of Kenyon’s disability to move beyond asking something of him that is only important to me. It’s not important to Kenyon to say aloud, “I love you,” because he expresses it every day in his own way of communicating.

But I had not thought through this idea of what I miss most. And I don’t know that I would have, if not for Jim’s willingness to open up to me.

The following 10 sentences came during my very last interview with Jim. It was our most intimate sharing with each other. Jim trailed off for a minute in thought at the end of these sentences. I had not heard him at a loss for words; but for a moment, Jim was silent.

What I Miss

JIM: There’s been news about the ability to hook a video camera, a digital camera, right into your eye to send digital signals straight to your retina, basically bypassing the part of my eye that’s damaged.

There’ve been all these initial experiments. I really anticipate having to make that choice someday, or at least being presented with that choice. I think it’s going to happen in the next 20 years. I’m kind of excited about it. I don’t know what I would choose.

If it happens to come at a time when it's close to the time of the birth of my first grandkid, I'm thinking I probably would do it. I don't know. I might just say, "This is normal for me. I'm good. No, thanks."

The thing I think I miss most is seeing the expressions on the face of my kids from across the room. I mean . . . I kind of imagine them, but it would be good to . . . you know

Lost and Found

I got lost. Along that long, straight, Iowa Highway 218 from Washington to Mt. Pleasant, somewhere I missed a turn and kept going. My thoughts raced along with the power lines and telephone poles that zoomed by when looking left or right, but stretched infinitely back to where I'd been and infinitely ahead to where I was going.

Maybe it was the endless sky, the barren fields, the monotone thump of the freeze lines in the concrete highway. Somehow, I got lost.

I found myself an hour south of Burlington, where I needed to cross the Mississippi to get to Illinois, then Indiana, then Kentucky, then Tennessee and, finally, home to North Carolina.

The shortest way back toward Burlington meant taking a two-lane road through nowhere. I found myself alone on that road.

The road stretched out ahead to the horizon as well as behind. I stopped the car and stood on the trunk. I was at a high place relative to the land all around me. The farmland spread unending. I could see a church spire in the town ahead. I could hear a horse in the field behind me.

I stretched my arms wide, one arm pointing toward the road behind me and the other reaching ahead toward home. I looked up. I yelled for as long and loud as I could. It felt really good.

The clouds parted. For the first time in a week, the sun came out. I got back in the car and headed home.

Fellow Travelers

JIM: Like I said, one time way back during the first few minutes you were here, I asked, "Are you more of a miner or more of a fellow traveler?"

I wasn't sure then. And now, I think it is the fellow traveler.

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