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## To Dance Beneath the Diamond Sky with One Hand...Part 2

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**Editor's Note:** This issue comprises the second installment to the forum on music edited by Alex Lubet and Na'ama Sheffi. To view Alex's introduction to the forum and to read the first installment, please view the online version of Volume 4, Issue 1 at [www.rds.hawaii.edu](http://www.rds.hawaii.edu) or contact [rdsj@hawaii.edu](mailto:rdsj@hawaii.edu) to order a print copy.

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# Transformer Man: An Exploration of Disability in Neil Young's Life and Music

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(Beyond) Popular Culture

**Abstract:** This article begins with a short personal narrative of my own struggles growing up with a form of cerebral palsy (right hemiplegia), and the way music – and in particular Neil Young's songs – provided a crucial emotional and cathartic outlet for me. I then examine Neil Young's intimate personal connection with disability, including his own struggles with polio and epilepsy and his experiences raising his two sons Zeke and Ben, both of whom have cerebral palsy (one milder, one quite severe). I delve into many of Neil's songs that either subtly or explicitly explore issues of disability and difference, such as *Mr. Soul* and *Transformer Man*. I conclude by recounting my experience attending the Bridge School Benefit, an annual concert put on by Neil and his wife Pegi to raise funds for the school they founded for disabled children. In sum, this article will attempt to capture something of the way in which Neil Young and other artists have created music that is both personally therapeutic and collectively empowering for members of the disabled community.

**Key Words:** Neil Young, music and disability, music as empowerment

As a child and teenager growing up with right hemiplegia, a form of cerebral palsy that limits the movement and sensation in the right side of my body, feeling different was an unavoidable part of my everyday life. Most boys want to be good at sports – I was no exception. I couldn't be, and it hurt. Most boys take pride in learning to tie their shoelaces – I was no exception. I couldn't learn to tie them, and it hurt. Most boys get nervous about the way they look and move when they're dancing with girls – I got really nervous. My young life with a disability sometimes felt very lonely.

I found very few peers or adults who were willing to discuss my feelings with me directly or honestly. The people around me seemed afraid to hear about my experiences with a disability – when I attempted to voice my growing sense of frustration, pain, and above all, exclusion, the usual response I got was, “Oh...nobody notices it” or, “Oh...it doesn't really matter.” These were nice sentiments, but it was hard for me to believe that nobody was noticing my spastic right arm when I was consistently being called a “gimp” or a “crip” in the schoolyard.

Unable to find real emotional support from most of the people in my life, I found myself turning more and more to music. The emotional intensity and nakedness of bands like Pearl Jam and Nirvana struck a chord with me - here, at least, people weren't averting their eyes from uncomfortable feelings. As often happens to youths living with difference as a fundamental part of their lives, my suspicion of “normalcy” was sprouting up quickly: I remember feeling certain that despite (or perhaps because of) their “unadult” jobs and behavior, Eddie Vedder or Kurt Cobain would have been willing to sit down and honestly talk with me about my disability in a way so many of the “normal” adults I knew seemed unable or unwilling to do. It seemed to me that the world of those who made and loved music was inordinately populated by people who not only accepted difference, but celebrated it. This world was a welcome change from my schoolyard.

As I delved deeper into music, I found myself gravitating somewhat ineluctably towards the orbit of one particular musician: Neil Percival Young, the transplanted Canadian artist who made his home on a ranch in Northern California. Neil Young certainly knew something

about expressing painful feelings with naked intensity. In his country hit “Old Man,” he bares his need for “someone to love me the whole day through” (“Old Man,” 1972), while in his well-known rock anthem of self-loathing he repeats a simple phrase that resonates with anyone honest enough to acknowledge self-doubt: “Why do I keep fucking up?” (“Fuckin Up,” 1990). I knew I’d hit upon something genuine.

But my connection to Neil Young’s music quickly moved beyond his unflinching honesty. The deeper I immersed myself in Neil Young’s literally bottomless catalog, the clearer it became to me that Young was an artist who not only celebrated difference, but he appeared to embody it. In his over 40 years as a professional musician, Young had doggedly resisted the music industry’s efforts to neatly pigeonhole or categorize him in the way it eventually does to almost all of its artists. He ricocheted from solo acoustic nakedness to feedback-soaked garage rock in the blink of an eye, and before you blinked again he was performing with a 10-piece horn section. He was a folk singer, a cowboy crooner, an arena rocker, a Hendrix-esque guitar soloist, an acoustic troubadour, and a bluesman all balled up into one – and you never could predict which Neil would show up to the recording studio or concert stage. He was vulnerable and aggressive and helpless and powerful and shy and scary and funny all at once. I intuitively felt that anyone as willfully resistant to categorization as Neil Young must not have been a big fan of labels and assumptions – assumptions, for instance, like “disabled equals weak” or “handicapped equals helpless.” When it came to Neil Young’s music, normal categories, assumptions and labels didn’t make a lot of sense.

As it turned out, they made just as little sense when it came to his personal life – a life I was fascinated to discover has been touched indelibly by disability in multiple forms. Over his 60-odd years on the planet, Neil Young has experienced a childhood bout of polio that permanently weakened the left side of his body, the

adult onset of severe epilepsy, and most recently, a brain aneurysm that nearly took his life. While most stars might have wanted to distance themselves from any or all of these conditions to preserve an “attractive” public image, Young’s considerable distaste for conventional conceptions of attractiveness enabled him to shrug off the tremendous pressure from his handlers to “keep all this weird polio/epilepsy shit quiet” (MuchMusic TV, 1986). Keeping up an attractive public image was far from the only trapping of fame Young resisted: he was so uncomfortable with widespread adulation that his manager would regularly harangue Young about his “unquenchable determination to destroy your career and take me down with it” (British Radio-2 FM, 1987). In the liner notes to his greatest hits album, *Decade*, Young had this to say about his smash country-pop hit “Heart of Gold”: “Heart of Gold put me in the middle of the road. Traveling there soon became a bore so I headed for the ditch. A rougher ride but I saw more interesting people there” (*Decade*, 1977). Disability, a fixture in Young’s life since the age of six, proved to be one of the most interesting companions that Young would topple headlong into the ditch with. It’s no surprise that an artist so personally and professionally resistant to dominant culture and expectations would allow his experiences and feelings around disability to leak steadily into his music, often at the cost of commercial success. In Neil Young’s life, disability has been alternately triumph, struggle, grief and joy – and in each of these incarnations, it’s been a powerful artistic muse.

“Did I get songs from the [epileptic] seizures? Probably. “After the seizures...you start waking up. Then you find out who you are by looking around. Having to learn my own name – I had to do that a couple of times. Learn who I was. Get familiar with it. Then hear the first LIE – or the first thing somebody would say that wasn’t exactly true – it would be like a fucking terrible trauma to me when I was coming back from these seizures.

It's like being a baby. Anything that's not pure, you go, "What the?" – because you're starting over again, regrouping. Everything's coming back together. I can remember one seizure at the ranch in 1974... probably the last big one I had. It was mind-blowing...so I had just had a grand mal seizure and I went for a walk – and I had just barely figured out that it was my ranch – and this doctor was with me and he was sayin', 'Now, we're not gonna tell people this happened, because it will upset them. The only people who need to know about this are you and me and Russ Kunkel' – a drummer who was there, too. So it was like being born again and wakin' up and seein' everything is beautiful – seein' things for the first time – and then having someone tell you, 'Well, this is not what it seems. We're not gonna tell. People are not gonna know what happened.' So it's a lie. Why should there be a lie? When you're born, I don't think you can conceive of telling a lie. But if you can imagine being born, and within 10 minutes after you're born, you're introduced to the concept of a lie – y'know, you've only been alive for five minutes, and now they're teaching you how to lie. So there's something that happens there" (McDonough, 2003, pp. 176-177).

The effort of uneasily trying to readjust to an impure world manifests itself in many of Young's earlier songs, when he had not yet discovered a medication that helped him control his seizures. In "Mr. Soul," perhaps Young's most well-known song from his days as part of the legendary 1960s band *Buffalo Springfield*, Neil devotes the entire third verse to an oblique exploration of his seizures that leaves the listener feeling the same blurry sense of confusion and loss of control Young felt both immediately before and after a seizure: "In a while will the smile on my face turn to plaster? / Stick around while the clown who is sick does the trick of disaster / For the race of my head and my face

is moving much faster / Is it strange I should change? I don't know, why don't you ask her?" ("Mr. Soul," 1967). There is certainly fear and anxiety in these lyrics, but there is something of an ironic strength and humor to them as well – is the clown's seizure a "trick" he's playing on an unsophisticated audience? What is actually going on behind that innocuous smile – who's winning the race between what the world can see (the face) and what's going on inside (the head)? Perhaps more crucially, which experience – the external plastered serenity or the formless internal combustion – is more real? Young makes no judgments. And even at this early stage in his writing career, Young offers a subtle challenge to the predominant view of disability – in this case, epilepsy – as defective or shameful. Is it really that strange, really such a disaster, that his seizures should change him every now and then? By directing the listener to ask this question of an unidentified female, Young is perhaps commenting on the sexual insecurity that so often accompanies disability. But, underneath the anxiety is a glimpse of the notion that if the woman in question could be thoughtful enough not to see the clown's seizures as strange or disastrous, the clown might suddenly feel quite a bit better about himself without needing the seizures to disappear.

Young wrote several other early songs that explored the feelings of isolation and sexual paralysis than can emerge out of conditions like polio or epilepsy. "Expecting To Fly," another seminal *Buffalo Springfield* tune, gives the listener a sidelong glance at Young's fear of physical intimacy: "There you stood on the edge of your feather, expecting to fly / Well, I laughed, I wondered whether I could wave goodbye" ("Expecting To Fly," 1967). A potential partner may be waiting to fly with him, but Young is planning his exit strategy before the plane gets off the ground. Indeed, the producer of this song, Jack Nitzsche, recalls Young explicitly telling him at the time that "Expecting To Fly" was about "fear of making it with a girl" – specifically, Young's escalating anxiety as he approached his home

one night because a female admirer was waiting for him inside and he was terrified he might have a seizure while with her (McDonough, 2003, p. 278). A friend of Young's during this period named Donna Port remembers trying to set him up with a girlfriend of hers, and how "Neil would spend the night with her, but he'd never take his clothes off. She'd get too close, and Neil would freak out" (McDonough, 2003, p. 188). Port, whose own family had been touched by polio, drew a link between Young's emaciated frame and his sexual reluctance: "His legs were like toothpicks, and one day I just asked him [if he'd had polio]. The look of terror gave me the answer. Then it just flowed out. He was wrapped up in a blanket at the time, crying... We talked a lot about how cruel kids are when you're growing up. It explained a lot... This guy had a heavy load, physically and emotionally... Neil never felt he fit" (McDonough, 2003, p.188).

Not fitting in is undoubtedly a heavy load, but Young bore up under it with increasing defiance and occasional glee as his career moved unsteadily forward. By the late 1970s, his seizures had essentially disappeared and he was happily married to his second wife, Pegi. But disability was still part of Young's everyday existence: His first child Zeke was born with a form of hemiplegia very similar to my own that left his right leg shorter than his left leg and his right hand pinched. As a boy, Zeke "used to hit my [pinched] hand with a spoon and say, 'I hate you! I hate you!'" (McDonough, 2003, p. 472). Zeke acknowledges that he "couldn't accept myself as being – y'know – different... Turning doorknobs, turning on lights, stuff that I couldn't do like other little boys my age would frustrate the hell out of me, and I'd cry until I fell asleep" (McDonough, 2003, pp. 472-473). Zeke's shorter right leg meant he had to wear a shoe brace, and he was regularly mocked by his schoolmates, who called him "Bigfoot." He remembers, "One girl started teasing me about the shoe brace and I took it off and whacked her across the head with it" (McDonough, 2003, pp. 472-473). Many of Zeke's childhood ex-

periences closely mirror my own. Neil Young penned the country song "My Boy" for Zeke, and it expresses both grief over his son's suffering and admiration at Zeke's determination and self-will (1985). Once again, Young's lyrics indicate a far deeper frustration with the pervasive social stigma around disability than with Zeke's actual physical impairment.

With the birth of Young's second son Ben, though, Neil would have perhaps his most profound encounter with disability yet. Ben Young is, in Neil's own words,

"a spastic, quadriplegic, non-oral child... with a big heart and beautiful smile. He's just a wonderful human being... It did something to me... when he was born... Cerebral palsy – nobody really knows what it is. It's just the name for something... It's a lot like a stroke at birth. Or before birth... Ben is very sensitive – we don't know how cognizant he is. His cognitive abilities seem to shift with the wind. Sometimes he's real sharp, other times he's not. There's no strict set of rules with Ben" (McDonough, 2003, p. 545).

Neil and Ben Young share an unusually close relationship, and father and son spend a lot of time enjoying their mutual obsession with model train sets. Ben participates in the activities with the help of an elongated plastic arm attached to his wheelchair that Ben activates and commands by pushing a button next to his head. The system was designed by his father, and an engineer who helped design the electronic arm remembers that when they first got the system working, "I don't know who was more excited... Neil or Ben" (McDonough, 2003, p. 544). Neil himself says now that "I feel we've come a long way – we've been successful dealing with what we've been given to deal with. And we haven't let it destroy us. Y'know, a lot of families break up when this happens with one kid, and we've got two. And they're great kids – I love my kids. It's

just real. This is the condition of life they have” (McDonough, 2003, p. 548).

But the initial years after Ben’s diagnosis were filled with uncertainty, struggle, and self-doubt. For Young, the best emotional outlet remained his music, and the songs that poured out of him during this period are some of the most creative he’s ever written. They are also among his least commercial or accessible – and most widely criticized – compositions. As both a diehard Neil Young fan and a disability advocate, it seems fitting to me that a life as socially marginalized and outside the mainstream as Ben Young’s would inspire some of the most challenging, misunderstood, and ultimately rewarding music of Neil Young’s career.

When Neil Young released his infamous album *Trans* in December 1982, even the most loyal members of his fan base were appalled. Young had recorded most of the songs of the album using something called a vocoder – a device which allowed him to mask and distort his voice to emit eerie, clipped robotic-sounding vocals. The effect of the vocoder was to make it seem as though you were listening to him through a crackly World War II walkie-talkie rather than a modern record player. Young then plugged in these vocal tracks to a giant computer synthesizer he had recently purchased. The results were a series of murky, electronic songs that felt lonely, cold and impenetrable to Young’s devoted fans. Gone were Young’s emotive, quivering voice, the wailing guitar and the pulsating drums. Instead fans were left with lyrics sung in a computerized monotone that made the words almost impossible to understand and synthetic, repetitive keyboard and drum loops. Fans hated it and critics eviscerated it. To most people, listening to *Trans* felt something like trying to wade through a waist-deep swamp in thick, rolling layers of fog. There was simply nothing to grab onto, either musically or emotionally.

So what was Young doing? At the time, nobody had any idea, but fans who knew some-

thing about Ben’s cerebral palsy and who were patient enough to wade through some of the incomprehensibly distant vocals and decipher some of the lyrics might have been able to piece part of the puzzle together. One song in particular, “Transformer Man,” illuminates the source of Young’s motivation for crafting the most unconventional album of a career built upon defying convention.

“Transformer Man, Transformer Man / You run the show, remote control / Direct the action with the / Push of a button” (“Transformer Man,” 1982). Here, Young is addressing his cherished time with Ben in their model-train barn. “Transformer Man, Transformer Man / Still in command / Your eyes are shining on a beam / Through the galaxy of love / Transformer Man, Transformer Man / Unlock the secrets / Let us throw off the chains / That hold you down”. Understood in the context of Neil’s relationship with Ben, the paternal tenderness that shines through here is sharp and poignant. So why would Young choose to submerge this declaration of affection for his son in gauzy layers of synthesizer and flat, robotic vocals?

“*Trans* is definitely out-there. It went way over everybody’s head,” Young tells McDonough in *Shakey* (McDonough, 2003, p. 556). “Here’s a guy trying to tell you something and you *cannot* understand it...If you listen to all the mechanical voices, if you read the lyrics, it’s clear that it’s the beginning of my search for a nonoral, a severely physically handicapped nonoral person, to find some sort of interface for communication. The computers and the heartbeat all have to come together here – where chemistry and electronics meet. That’s what I was getting at. And that was completely misunderstood.

“‘Transformer Man’ is a song for my kid. If you read the words and look at my child in his wheelchair, with his little button and switch on his head, his train set and his transformer, the whole thing is for him. And people... they missed it. Com-

pletely. They put me down for fucking around with things that I didn't understand – for getting involved in something that I shouldn't have been involved in – well, fuck them. But it hurt me, because this was for my kid. I know what those songs are all about, and maybe knowing this story, if you listen to 'Transformer Man,' – you gotta realize, you can't understand the words – you can't understand the words – and I can't understand my son's words. So feel **that**. For me, even talking about this is very difficult, because I want my children to be able to hear and read what I say and feel loved and know that everything is okay. The thing is, it's communication, but it's not getting through. And that's what my son is" (McDonough, 2003, p. 556-558).

"Transformer Man, Transformer Man / Sooner or later you'll have to see / The cause and effect / So many things still left to do / But we haven't made it yet / Every morning when I look in your eyes / I feel electrified / By you" ("Transformer Man," 1982). Ten years after *Trans* was released, Young would perform an effects-free, acoustic version of "Transformer Man" during the taping of a performance for his MTV Unplugged CD, complete with melodic backing female vocals. By 1993, it seems, Young felt secure that enough clear communication was getting through between him and Ben for Ben to know that he was both loved and respected by his father. This newfound security allowed Young to perform "Transformer Man" in the naked, direct way he did during the Unplugged taping, and it allowed his fans to finally see "Transformer Man" for what it is: The gentlest love song of Young's career.

In 1986, Neil Young and his wife Pegi hosted the first Bridge School Benefit, a concert held outside San Francisco to benefit the school they had recently founded for physically and cognitively disabled children, including their son Ben. The school itself "is an educational pro-

gram dedicated to ensuring that children with severe speech and physical impairments achieve full participation in their communities through the use of augmentative & alternative means of communication (AAC) and assistive technology (AT) applications" (<http://www.bridgeschool.org>). The school's mission statement is to be a centre for "ongoing programs, projects and activities that move all people closer to a life without barriers to expression and communication" (<http://www.bridgeschool.org>).

The inaugural 1986 benefit show featured, among others, Bruce Springsteen, Tom Petty and the Heartbreakers, and Young's own occasional cohorts, Crosby, Stills, and Nash. When planning the concert's set-up, Neil and Pegi made the decision to seat all the children enrolled in the Bridge School on an elevated platform behind the stage, directly in the sightlines of both the crowd and the musical performers. This decision carried a powerful symbolic resonance: unlike other benefit concerts, where the actual recipients of the raised funds are kept carefully out of sight so as to "not upset" the audience as well as "shield" the recipients themselves, Neil and Pegi were demonstrating both their pride in the Bridge School children and their faith in the children's personal and emotional strength. Additionally, the Youngs insist that all songs at the Bridge School Benefits be performed acoustically. Hard-rock bands, then, are forced to reinterpret their most popular compositions and present them within this unfamiliar, stripped-down framework. Neil and Pegi's insistence on the acoustic format has caused more than one hard-rock band intense performance anxiety (Marilyn Manson remembers being "scared shitless" before taking the stage), but even this decision fits in with the Bridge School's ethos: Just like the children enrolled in the school, musicians performing at the benefit are discovering alternative modes of communication they might previously have assumed to be ineffective.

The benefit concerts for the Bridge School have continued annually, and over the years,



major recording artists from different generations and across wildly diverse genres have performed to support the Bridge School kids. A (very small) sample of the artists who have played at a Bridge School benefit includes: Bob Dylan, The Grateful Dead, John Lee Hooker, Van Halen, R.E.M., Radiohead, Patti Smith, The Who, Dave Matthews Band, the Smashing Pumpkins, Tom Waits, the Foo Fighters, and Pearl Jam. Many of the musicians or groups have returned to play at the Bridge School Benefit multiple times, leading to close friendships between many of the artists and the children enrolled in the School. In 1999, for example, Pearl Jam's Eddie Vedder (whose band has currently played the Bridge School Benefit 7 times) dedicated the last song of Pearl Jam's set to Maricor, a nonoral quadriplegic young woman whom he'd bonded with over the years. The reason for the dedication? Maricor had just been accepted to Berkeley, one of the United States' top universities. Four years later, Pearl Jam was back on stage at another Bridge School Benefit, and Vedder once again toasted Maricor before starting the band's last song of the evening. This time, Maricor had just graduated from Berkeley with honors.

In 2006 the Bridge School celebrated its twentieth anniversary, and I was finally able to attend the annual concert. I found the atmosphere to be precisely as I'd imagined from years of listening to the live bootlegs of past performances. On their platform behind the stage, the Bridge School kids beamed as musicians turned and serenaded them directly. In between performances, spokespeople from the Bridge School and some of the children themselves thanked the audience and updated us on the school's latest programs and innovations. By the end of the night, it was clear that Neil and Pegi's Bridge School benefit concerts were fundamentally a celebration of the courage, ingenuity, and resilience of the children attending the School. The struggle and pain of growing up with disabilities in an intolerant society was certainly acknowledged by musicians and school representa-

tives alike, but the overwhelming sentiment of the day was that the kids attending the Bridge School were not only building full and rich lives for themselves: they were making a difference by embodying difference with both individual and collective pride.

As I ambled off the concert grounds with the strains of Young's show-ending "Rockin' in the Free World" still ringing in my ears, I noticed that a booth had one of Young's CDs on sale. Wandering over, I expected to see copies of *Harvest*, *After the Gold Rush*, or one of Young's other "hit" CDs on sale. When I looked closely, though, the disc on sale was *Trans*. Grinning from ear-to-ear, I bought a copy and headed off into the warm fall night.

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## Source Notes

All lyric quotes taken from *Neil Young's Complete Music Volumes I – VI*. Published by Warner Bros/ Reprise Records and Geffen Records, 1966 – 2007.

"...keep all this weird polio/epilepsy shit quiet..." Neil Young on *MuchMusic* TV interview, 1986.

"...unquenchable determination to destroy your career and take me down with it..." Elliot Roberts (Neil Young's manager) to Dave Ferrin, 6/5/87 British radio interview, Radio-2 FM.

"'Heart of Gold' put me in the middle of the road..." From Neil Young's liner notes to his (first) Greatest Hits album *Decade*, released in 1977 by Warner Bros/Reprise Records.

“Did I get songs from the [epileptic] seizures? Probably...” Neil Young to Jimmy McDonough in *Shakey: Neil Young's Biography* (pp.176-177).

“...fear of making it with a girl...” Jack Nitzsche to Jimmy McDonough in *Shakey: Neil Young's Biography* (p.278).

“Neil would spend the night with her, but he'd never take his clothes off...” Donna Port to Jimmy McDonough in *Shakey: Neil Young's Biography* (p. 188).

“...used to hit my [pinched] hand with a spoon...” Zeke Young to Jimmy McDonough in *Shakey: Neil Young's Biography* (pp.472-473).

“a spastic, quadriplegic, non-oral child...with a big heart and beautiful smile...” Neil Young to Jimmy McDonough in *Shakey: Neil Young's Biography* (p. 545).

“I don't know who was more excited...Neil or Ben.” Harry Sitam to Jimmy McDonough in *Shakey: Neil Young's Biography* (p. 544).

“I feel we've come a long way...” Neil Young to Jimmy McDonough in *Shakey: Neil Young's Biography* (p. 548).

“*Trans* is definitely out-there...It went way over everybody's head...” Neil Young to Jimmy McDonough in *Shakey: Neil Young's Biography* (pp. 556-558).

“an educational program dedicated to ensuring that children with severe speech and physical impairments achieve full participation...”  
<http://www.bridgeschool.org>

“...scared shitless...” Marilyn Manson to Kurt Loeder, *MTV Television* interview, 2000.

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# People with Disabilities Get Ready: Curtis Mayfield in the 1990s

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**Abstract:** This article breaks with precedent by emphasizing disability's role in the life and work of Curtis Mayfield (1942-1999) and by arguing that his experience of quadriplegia had both positive and difficult dimensions. Analysis focuses on Mayfield's representation by journalists and other writers in the 1990s, and on how Mayfield answered their portrayals as an interview subject and as a musician with his final studio album *New World Order* (1996). Considered within the whole of Mayfield's career, quadriplegia is revealed as one among many difficulties that he answered with critical positive thinking and powerful music.

**Key Words:** quadriplegia, African-American music, civil rights

“When a celebrity is ‘stricken’... editors and producers of national news organizations fall all over each other to run a mass-market variation on the theme, but in terms of narrative structure the celebrity story is simply the same notes scored for a symphony orchestra rather than a string quartet” (Riley, 2005, p. 13).

## Introduction

Curtis Lee Mayfield (1942-1999) was a master of soul, rhythm, and blues with enormous and positive cultural influence in the last forty years of the twentieth century. Mayfield was also a person with disabilities—diabetes and, more significantly, quadriplegia—that he acquired late in life. Images are as important as sounds to understanding relationships between Mayfield's quadriplegia and his music. Three contrasting views of Mayfield lying flat

on his back during the 1990s provide a sort of visual synopsis of public perceptions of his final years. Mayfield crafted the first image with words when recalling what happened onstage at Wingate Park in Brooklyn, New York on August 13, 1990, where a near-fatal workplace accident paralyzed him from the neck down (Williams, 2000, pp. 68-69). Struck by a lighting tower that fell when the weather turned bad, Mayfield could only recall what happened before and after the mishap. One minute he was preparing to join his band members, who were playing the introduction to his 1972 smash “Superfly”; the next, he was looking up at the sky as wind tore through the park and rain fell on his body, struggling to stay conscious and finding that the impact had taken his guitar from his hands and his shoes off his feet (Holtzberg, 1996, p. 42; Williams, 2000). The scenes became staples of media coverage of Mayfield, who confounded many by sharing his story without bitterness. One amazed voice belonged to Sweeting (1997), who thought of the accident as something “that would have driven many people to despair or even suicide” (p. T12).

The second image, problematic as it was prominent, illustrates a 1993 *Rolling Stone* interview that undercut its valuable overview of Mayfield's career by portraying his impairment as victimization (Light, 1993). A full-page picture of Mayfield in bed at his suburban Atlanta, Georgia home, the image's high angle perspective underscores Mayfield's immobility and the photographer/spectator's figurative and literal power *over* him. At first glance, Mayfield looks like he belongs in a morgue, not a recording studio, despite his stated intentions of resuming music performance and production.

Mayfield remains on his back for the third image, a composite that replaces pitiable aspects of the first two images and confirms his history of creating opportunities out of challenges. Various accounts, some by observers and some by Mayfield, create a unified picture of Mayfield recording vocal tracks while lying on his back, at home or in a recording studio, relying on gravity to adapt to singing with his damaged diaphragm and lungs (Burns, 2003; Fields-Meyer, 1997; Harrington, 1999; Obrecht, 1996). This time-consuming method was crucial to Mayfield's final studio album *New World Order* (1996) (henceforth *NWO*), whose title is a metaphorical, if unintended, evocation of changes that Mayfield and others with traumatic spinal cord injury and paralysis experience (Robillard, 2006; Schultke, 2006). I explore some of those transformations, which others have restricted to the backstage areas of Mayfield's life.

Historical contexts are as vital to this analysis as they were to *NWO*. To my knowledge, Mayfield gave no public explanation of the record's title, probably because he saw no need to elaborate on its dissent from the global vision that President George H. W. Bush unveiled in a speech delivered on September 11, 1990, soon after signing the Americans with Disabilities Act (ADA) into law and several months before launching Operation Desert Storm against Iraq (Bush, 1990). In retirement when Mayfield released *NWO*, Bush would have been surprised at the appropriation of his language for very different purposes. Mayfield said his motivation was the "concept of peace, love, get it together, and maybe there'll be a new world order" (Werner, 2004, p. 286). A state of the (dis)union address, *NWO* spoke to the sociopolitical atmosphere of the 1990s as much as "People Get Ready" (1964) and "If There's a Hell Below (We're All Going to Go)" (1970) captured changes and conflicts in their times.

Although he was the subject of considerable media coverage in the 1990s, the artistic and commercial successes that preceded the

onset of quadriplegia are better known than Mayfield's late career achievements. This essay seeks to fill that knowledge gap by concentrating on how Mayfield continued making music and why *NWO*'s songs have continuity with his pre-1990 work and relevance to his post-1990 disability experience. The context encompasses biographical and music business factors that enhance understanding Mayfield's adaptation to impairment and ableism.

This analysis focuses mostly on major U. S. newspaper articles published during a period starting in the second half of 1990 with coverage of Mayfield's accident and ending in early 2000 with news of Mayfield's death. It also includes reportage from British and Canadian papers and U. S. magazine articles for general and specialized readerships, such as *People Weekly* and *Guitar Player*, and books containing previously published or original commentary on Mayfield. A critical reading approach shaped by the social model of disability considers evidence of how Mayfield and his interlocutors represented his life and work before and after the onset of disability. Much of the print media coverage reinforced the common belief that disability is personal tragedy, especially because of the severity of Mayfield's accident and its consequences. Harmful implications of that approach are important, but this essay is more concerned with contradictions in the coverage and with Mayfield's resistance to portrayal as a victim. Also offered are alternative readings that look at disability as only one of many problems Mayfield faced, and not inevitably more difficult than racism and the vagaries of the music business. Too few people truly heard Mayfield when he insisted that, "This accident has taught me a lot. It's just another experience. It doesn't mean you don't wake up with a tear in your in your eyes now and then" (quoted in Charles, 1996, p. 43).

## Career Resurgence and Onset of Disability

Signs of possible career resurgence for Mayfield appeared shortly before his 1990 accident (Mills, 1990). He was emerging from more than a decade of low-profile activity and had reason to anticipate a comeback in the 1990s (Gore, 2000). A re-release of the song “Superfly” as a single in 1988, collaboration with younger artists including Fishbone and Ice-T, and a return to film scoring were encouraging developments (Mills, 1990). Mayfield’s choice of “Superfly” to start what would be his last onstage appearance showed he knew his audience well. The Wingate Park accident and its life-threatening injuries triggered a wave of reverence and concern (Burns, 2003, pp. 246-247). Journalists from across and outside the United States interviewed Mayfield via telephone or in person at his home, where his large family (including eleven children from his two marriages) helped him manage a near-total lack of physical mobility. A host of prominent musicians, but a fraction of the many Mayfield influenced, recorded cover versions of his songs for tribute albums in 1993 and 1994 that also helped the Mayfields with medical expenses (Murray, 1994a; Smith, 1993). The Rock and Roll Hall of Fame inducted Mayfield in 1991 as a founder of The Impressions and in 1999 as a solo artist. Unable to attend either ceremony in person, Mayfield thanked the crowd for his first induction via satellite television and relished its standing ovations (Mills, 1991).

The attention occasionally had a frenetic edge, with admirers seeming desperate to give Mayfield his due before he died. This context intensified the already negative perceptions of his disability, which was hard to separate from its harrowing onset. Even if Mayfield had been paralyzed in a less traumatic way, observers would probably have defined quadriplegia as something he did not deserve—a bad thing that happened to a good person whose humility was rare in the music industry (Mills, 1992).

Some commentators concluded that Mayfield had lost his music-making abilities along with his physical mobility (Himes, 1996; Norman, 1994). They saw quadriplegia as an end to his career, despite Mayfield’s statements to the contrary, and changed the subject to his previous triumphs and his future legacy (Light, 1993; Phillips, 1995). When *NWO* proved that Mayfield was living and working in the present, its release often became a story of overcoming disability instead of another chapter in Mayfield’s long story of working hard to make music no matter what the circumstances (Fields-Meyer, 1996; Katz, 1997).

Much of the post-Wingate Park writing about Mayfield suggested that his positive attitude about living with quadriplegia was unusual (Hoekstra, 1993a; Jones, 1996; Thomas, 1991). In fact, his generally high spirits were in character for Mayfield and common among people with quadriplegia (Gonzalez, 1998; Longmore, 2003, pp. 178-179). Journalists who expected resentment marveled at Mayfield’s acceptance of paralysis, which he expressed with understated melancholy. Variations on the admission that, “Sometimes I can’t help but wake up with a tear in my eye” were Mayfield’s stock answers to questions about his mental state (Charles, 1996; Fields-Meyer, 1997; Holtzberg, 1996; Light, 1993; Mills, 1992). Putting Wingate Park behind him and returning to recording caused some writers to react with combined admiration and incredulity. Commenting on perceptions of the careers of Ray Charles, Stevie Wonder, and Hank Williams, Barnes and Mercer (2001) note that in some instances, “sickness or impairment is credited with adding to the appeal or the insight of the artist” (p. 518). The way in which Mayfield acquired disability and the magnitude of his physical problems excluded him from such consideration. Instead, media observers suggested that Mayfield’s quadriplegia was the worst of a series of problems he faced in his life and a potentially insurmountable obstacle. Their responses overlooked precedents for Mayfield’s resilience, even though biographi-

cal information suggested that his adaptation to disability was unsurprising, if not predictable.

## Early Years

Mayfield learned to solve problems and create opportunities through self-determination and critical distance early in life and never lost that ability. Born in Chicago, Illinois in 1942, Mayfield was the oldest of five siblings including a brother, Kirby, who had mental retardation and died young (Burns, 2003; DeCurtis, 1999). Raised fatherless in a family that was often on welfare, with firm guidance from maternal grandmother Annabell “A. B.” Mayfield and mother Marion Mayfield, Curtis developed strategies for survival in a city that represents both optimism and oppression for African-Americans (Werner, 2004). Reverend A. B. Mayfield’s storefront preaching and folk medicine practice made her an assertive role model. Marion Mayfield sang, played piano, and cultivated appreciation of poetry in Curtis, who started writing songs in his teens (Hoekstra, 1993b). Toward the end of his life, Mayfield called his composition skills “natural,” but he was indebted to his mother and grandmother (Obrecht, 1996, p. 29; Smith, 1993). Unrestrained by social devaluation, these strong women prepared Mayfield for a lifetime of challenges (Brown, 1997; Burns, 2003; Smith, 1993; Werner, 2004; Williams, 2000).

Church and family provided Mayfield’s childhood immersion in music. Adolescence in Chicago’s notorious Cabrini-Green housing project provided a musical apprenticeship (Light, 1993; Werner, 2004). Mayfield had precocious, unconventional interests in guitar and piano that put him outside the norms of playing those instruments. Comfortable with his idiosyncrasies, Mayfield learned to make what was odd to others a source of strength (Williams, 2000). “I used to play boogie-woogie on the piano, and not ever having had lessons I subconsciously re-tuned the guitar to the key of F#,” remembered Mayfield in a 1996 interview (Obrecht, p. 30).

“This way when I strummed across it, it gave me a chord. That’s how I learned to play my guitar, and that’s the way I tuned it all the way up to my accident.”

His attraction to the piano’s black keys and his uncommon guitar tunings marked a confident but never arrogant path that Mayfield took to professional success. If the intimate relationship between Mayfield and his guitar was eccentric, he balanced it with pragmatism about his marketplace relationship with his songs. The Library of Congress heard from Mayfield before the rest of the world did. As a teenager, he sought information on copywriting songs from that source and was decisive in using what he learned (Gonzalez, 1998). Claiming ownership of his work was notable not only for Mayfield’s youth, but also because he avoided the exploitation that plagued many African-American musicians (Gonzalez, 1998; Murray, 1994b; Werner, 2004).

Although praise for his business acumen was not unanimous (Himes, 1996), Mayfield had a record of discipline and persistence that served him well, particularly during the 1990s (Mills, 1992). Royalties from his many hits, which surged in the 1980s and 1990s because of hip-hop sampling, helped Mayfield avoid financial burdens that usually accompany paralysis (Robillard, 2006; Werner, 2004). The comfortable, but not lavish material circumstances that Mayfield earned for himself and his family contributed to his optimism, which he acknowledged in interviews (Light, 1993). Mayfield also tempered his appreciation for rap-generated royalties with ambivalence about the music’s messages and messengers (Werner, 2004).

## Civil Rights Movement

Mayfield’s characteristic balance of belonging to and maintaining distance from communities was evident during the African-American civil rights movement, which coincided with his tenure as a member of The Impressions,

the ensemble he helped found in 1957 and led until 1970, the first of his solo years (Garofalo, 1992; Ward, 1998; Werner, 2004). His writing, singing, and playing put the group's records on "every movement turntable" (Ward, 1998, p. 299), an honored place that Martin Luther King, Jr. confirmed with appreciation for 1964's "Keep on Pushing" (Harrington, 1999). Nelson George spoke for many when he called Mayfield "black music's most unflinching civil rights champion" (quoted in Thomas, 1991, p. 1). But Mayfield was modest about his achievements and resistant to being identified with activism. Stressing the collective nature of rhythm and blues and soul in the 1960s, Mayfield counted himself among Smokey Robinson, the Temptations, Aretha Franklin, Otis Redding, Gladys Knight, and James Brown as a barrier breaker for future African-American musicians (Garofalo, 1992). At the same time, Mayfield followed a personal agenda that he separated from politics (Mills, 1992; Obrecht, 1996; Ward, 1998). Calling himself an entertainer who educated and a "painless" preacher, Mayfield drew a line between art and politics that was dubious in respect to his own work as well as to music that was less socially engaged (Ward, 1998, p. 414).

Scholars, journalists and music critics tend to be more certain of Mayfield's movement credentials than he was (Mengel, 1996; Smith, 1993; Werner, 2004). Ambivalence worked to his advantage in music that reflected and fostered change while eschewing an ideological conformism that marked some elements of the post-1965 movement (Ward, 1998, p. 414). Mayfield fought in the civil rights struggle on his own terms, saw no conflict in endorsing both King and Malcolm X, and challenged the notion that the movement began and ended with the 1960s (Smith, 1993; Werner, 2004). The Million Man March took place in Washington, D.C. in late 1995, just as Mayfield was starting work on *NWO*. Mayfield recognized the convergence by contributing the album's title song to *Get on the Bus*, director Spike Lee's cinematic commemoration of the march, and by praising

(with qualification) Louis Farrakhan's polarizing leadership (Siebert, 1996).

The early 1970s are often considered a time of disillusionment for the millions of U. S. citizens who believed in the African-American civil rights movement. Music by Marvin Gaye, Sly and the Family Stone, Stevie Wonder, and Mayfield acknowledged that period's setbacks with no loss of resolve. Mayfield's *Superfly* soundtrack (1972) was the most arresting demonstration of his critical distance, a career watershed that ensured Mayfield's reputation for decades after the controversial movie's release. Uncomfortable with the film's tone after watching a rough cut, Mayfield took a skeptical stance that kept *Superfly*'s score from celebrating gangsterism and prevents the movie from seeming as dated as other "blaxploitation" efforts (Mitchell, 2000). The film also featured a cameo by Mayfield that prompted Gonzalez (1998) to compare Mayfield to a "geek" (p. 232). Mayfield's anomalous image embodies his detachment from values he opposed in *Superfly* and foreshadows his future estrangement from an ableist music business that prefers "artists [who are] exceptionally physically attractive by normative standards" (Lubet, 2006, p. 1121-1122) and where "prominent figures with visible disabilities are virtually unknown."

In the 1980s, hip-hop artists began sampling *Superfly* and other Mayfield music to enhance their work's credibility. Although he had reason to be proud of *Superfly*'s resonance when he stepped onstage in Brooklyn in August 1990, Mayfield was concerned simply with pleasing an audience that had come to see and hear him as the headlining act. No matter that the terms of Mayfield's contract guaranteed him payment if the weather prevented him from performing (Mills, 1992). For Mayfield, commitment to his fans was essential to music as a way of making a living and a way of life.

## Media Portrayal After Wingate Park

Journalistic coverage of Mayfield after Wingate Park combined elements of an anticipated comeback story with an unanticipated deathwatch. Media interest would have been significant had a temporarily able-bodied (that is, “non-disabled”) Mayfield enjoyed a career revival in the 1990s, but quadriplegia raised attention to a level he had not known since *Superfly* (Harrington, 1999). In some respects, the coverage exemplified Thomas Couser’s idea of “hyper-representation” that “subjects people with disabilities to objectifying notice in the form of mediated staring” (2006, p. 399). However, there was a stronger tendency among writers to look into Mayfield’s past and away from his disability. Lengthy career retrospectives were common in articles about Mayfield in the 1990s and were valuable for what they taught readers (particularly younger readers) about his significance. At the same time, a predominantly tragic tone made the information read like obituary copy. In a review of several Mayfield re-releases and compilations, Himes (1996) wrote about Mayfield and his career exclusively in the past tense. Uninformed readers would have been justified in assuming that Mayfield had already died.

Mayfield’s role as an interviewee proved he was very much alive and able to deflect the sentimentality journalists aimed at him. His comments were a “reality check” that refuted the pessimism in many articles. An excerpt from the *Rolling Stone* interview reveals that the facts of Mayfield’s life were incompatible with the pity the photograph encouraged. “I live for the music,” said Mayfield. “There probably have been four or five songs introduced just based on our conversation. Hopefully, with the voice activators and different things that are coming out... I can be as independent as possible [and] contribute once again in this business” (quoted in Light, 1993, p. 66). In the same interview, Mayfield revealed, albeit unintentionally, that assistive technology was vital to his career long before he acquired disability. Thanking God for

microphones and amplifiers, Mayfield credited that equipment with making him a successful performer despite his vocal limitations (Light, 1993, p. 63).

The homogeneity and predictability of mainstream commercial journalism have particularly negative implications for coverage of people with collective histories of social disadvantage (Riley, 2005). Mayfield’s media portrayals are tied to devaluation and stereotyping of people with disabilities and should be answered with critical media literacy, which Bell Hooks (1996) and Irving K. Zola (1985) identify as a strategy for social change. When informed by the social model of disability, media literacy can dismantle the tragic frames that journalists put around Mayfield and similar individuals and groups. Contexts that acknowledged disability rights and culture would have situated Mayfield within communities of people with quadriplegia and generated more accurate stories. Along with credibility, originality is a factor that requires re-considerations of language and style in disability reportage. Riley (2005) notes that “avoidance of stock phrases and clichés is a point of professional pride among the better class of journalists” and not just a concession to what “curmudgeons” call “political correctness” (pp. 51-52). The sources for this analysis had room for such perspectives without sacrificing wide audience appeal, but few writers made even minimal effort to explore the relevance of Mayfield’s disability experience to the 1990s, a crucial decade for disability rights, culture, and studies.

Comparing Mayfield’s circumstances with those of the majority of “dependent paralyzed people” (Robillard, 2006, p. 1198) illustrates some differences that disability awareness would have made in the coverage. In several stories, Mayfield noted that he was fortunate in material terms (Bauder, 1994; Murray, 1994b; Norman, 1994; Selvin, 1994). Unlike Mayfield, most people with quadriplegia lose their jobs and medical insurance and face pressure “to sell their homes and draw down their financial assets”



(Robillard, 2006, p. 1198). Such facts need not have prevented journalists from showing the specificity of Mayfield's experience of paralysis. Moreover, Mayfield almost certainly would have welcomed the broader context, given his critical consciousness of economic inequalities in the U. S (Werner, 2004).

The unusual circumstances of Mayfield's acquisition of disability also set him apart from many people with quadriplegia. Causes of spinal cord injury, from most to least frequently reported, include motor vehicle crashes (46.9%), falls (23.7%), violence (13.7%), sports injuries (8.7%), and other/unknown (7%) (National Spinal Cord Injury Statistical Center, 2006, p. 1). Although the Wingate Park accident had a violent impact on Mayfield's body, his injury fit the other/unknown category rather than the violence category, which refers to willful acts of violence and often to gunshot wounds (National Spinal Cord Injury Statistical Center, 2006, p. 1). A study by Devlieger, Albrecht, and Hertz (2007) shows the disproportionate impact of such incidents on young African-American men. Their ethnographic research study took place in rehabilitation hospitals in Chicago, where African-American men developed their own disability cultures and described their lives before and after paralysis in personal narratives that had much in common with stories Mayfield told in his songs.

When discussing the Wingate Park accident, journalists turned an undeniably traumatic incident that also injured several concertgoers, including children, into melodramatic tragedy. In reality, this was a workplace accident whose magnitude should have been conveyed through careful contextualization. A few reporters addressed the possibility that Mayfield's mishap was avoidable. Questions about the stage area's safety prompted a New York City labor union representative to challenge promoter and former New York state senator Martin Markowitz in the press (Paulucci, 1996) and led Todd Mayfield (Curtis's manager and oldest son) to take legal

action against Markowitz's insurance company (Mills, 1992).

However, media attention to the controversy was muted. Mayfield would not discuss it, the lawsuit was settled out of court, and a somewhat defensive Markowitz insisted that "we all feel terrible" about the accident, which was an "act of God" (Mills, 1992, p. G1). In Atlanta when his father was injured, Todd Mayfield felt guilty about missing his chance to talk Curtis out of going onstage (Mills, 1992, p. G1). Even if journalists had been more willing to investigate the accountability of Markowitz and Todd Mayfield, the major problem was their reliance on clichéd language and tragic storylines that mystified the incident and trivialized concerns for the safety of performers and audiences.

A more complex, affirmative perspective on disability in coverage of Mayfield would have worked against what Paul K. Longmore (2003) calls "the context of a health care system and a society pervaded with prejudice and discrimination against people with disabilities" (p. 178). Surveys show discrepancies between physicians' negative assumptions about quality of life with paralysis and the positive outlooks that people with quadriplegia have (Longmore, p. 178). Fictional characters whose paralysis made them want to end their lives had considerable cultural capital, represented notably by the protagonist of stage and screen versions of *Whose Life is it Anyway?* (Longmore, 2003, pp. 119-122). Furthermore, despite the ADA and the momentum of disability studies in the 1990s, Dr. Jack Kevorkian's campaigns for assisted suicide and against the survival of many people with disabilities received more media attention and support from the general public (Longmore, 2003, pp. 175-203). In this atmosphere, Mayfield's resources of family, finance, and optimism were indeed precious.

Only one text featuring Mayfield with quadriplegia and published during his life diverged significantly from normative disability report-

age. *Portrait of a Spirit: One Story at a Time*, a Canadian book profiling twenty-five U. S. citizens with disabilities who narrate their experiences in interviews, looks somewhat like a coffee-table book but is solidly within the social model of disability (Holtzberg, 1996). Many of the interviewees, including Mayfield, resided in Georgia and had ties to Atlanta, which was hosting the Summer Olympics and Paralympics in 1996. Several Paralympians appear in *Portrait*, one of the most diverse disability-based texts in its attention to impairments, age, class, ethnicity, gender, race, and occupation. Mayfield posed for his black and white portrait at home and in his wheelchair (Holtzberg, 1996, p. 40). The image's somber silhouette conveys a sense of Mayfield's difficulties without rendering him helpless, as the 1993 *Rolling Stone* photograph did.

Christopher Reeve, whose spinal cord injury occurred one year prior to *Portrait's* publication, contributed a foreword to the book but was not interviewed or photographed. For many disability rights activists, any role for Reeve would have been objectionable. However, *Portrait's* context makes Reeve's presence seem a concession to marketability. The musical force behind *Superfly* and his cohort, in which "average" people with disabilities outnumber better-known figures like former U. S. Senator Max Cleland and disability rights advocate Mark Johnson, overshadow the erstwhile Superman. Even though Mayfield's interview repeats information he gave journalists in previous accounts, his chance to address the reader in a more direct manner highlights his agency, as does the editor's note about *NWO's* release (Holtzberg, 1996, p. 41). The difference that a positive context makes is hard to overstate. *Portrait* brings Mayfield into a community and preserves his individuality. With acknowledgment of disability rights and culture and respect for leaders like Judy Heumann and Irving K. Zola, *Portrait* maintains progressive integrity while reaching out to a general audience, just as Mayfield did with his songs.

## Mayfield's Career After Wingate

Mayfield's will to resume work was stronger than doubts he sometimes expressed. Some journalists were flatly pessimistic about the prospect of more Mayfield music in the 1990s, an outlook that Phillips (1995) expressed in an article blending career appreciation and career autopsy. Mayfield responded with *NWO*, astonishing writers who called the accomplishment "inspirational," "miraculous," and "amazing" (Obrecht, 1996, p. 29; Siebert, 1996, p. C8; Sweeting, 1997, p. T12). But the hard work that went into *NWO* was no more mysterious than the Wingate Park accident was tragic, and no more remarkable than his self-determination during the African-American civil rights movement. True, Mayfield made demanding adjustments and struggled with the loss of his guitar-playing abilities and an intimate relationship with the instrument itself, which he described as "part of his body," "another person," and "a brother" (Fields-Meyer 1997; Obrecht 1996). Writing songs with the help of a voice-activated computer was a tough transition from reliance on paper, pen, and keyboards. Of all the new techniques, Mayfield's need to lie down while singing was the most publicized. He required frequent rest breaks during sessions, but *NWO* showcases the beauty of his voice and connects with Mayfield's pre-1990 work, even when the record's production is too glossy.

*NWO* begins with its title song, which shows that the album's best music relies more on understatement than overproduction. A slow pulse tempo and stop-frame lyrics enhance Mayfield's observation of an infant's emergence into a world of privation and victimization. In the second line, Mayfield alludes to his painstaking singing process:

Darkness no longer, a child is born  
Mother shed tears of joy as baby test his  
lungs  
My daddy's not there, where he ought to  
be

Somewhere in Georgia skinning and  
 shooting craps on his knees  
 Another victim born out here in the hood  
 And based on statistics it really ain't all  
 that good  
 Welfare takes the tab and daddy can't sign  
 And can't be seen, the family becomes a  
 crime  
 The hunt is on and brother you're the  
 prey

The empathy that made Mayfield a singular songwriter is as strong as ever. Living at home with quadriplegia took nothing away from his social awareness. Metaphorically, Mayfield is the “baby test[ing] his lungs,” a veteran vocalist with an impaired diaphragm relearning his craft. His voice is also that of the mother, absent father, and hunted brother. Moreover, the informed listener knows that Mayfield sings from experience when referencing the stigma of welfare.

Mayfield often said he wrote songs mainly for himself (Mills, 1992; Obrecht, 1996), but there is no self-absorption in *NWO*. Several songs, such as “Ms. Martha,” are stories in which Mayfield observes or inhabits characters and displays his descriptive skills. Mayfield admires how Ms. Martha watches over her urban surroundings from her porch. She endures, even while witnessing effects of pervasive crime on her surroundings and her son. Longtime peer and friend Mavis Staples, an ideal artist to help deliver positive messages about African-American women, is Mayfield’s singing partner on “Ms. Martha.” Her high opinion of Mayfield matched Mayfield’s respect for Ms. Martha (Mills, 1992). Staples may have been the only person who envisioned Mayfield returning to the concert circuit. If Prince could bring a bed onstage for his act, she reasoned, why couldn’t Mayfield? (Werner, 2004, p. 286).

The title of the first-person “Here but I’m Gone” implies Mayfield will narrate the physi-

cal and psychological dislocation associated with quadriplegia (Robillard, 1996; Robillard, 2006). Instead, Mayfield uses the persona of a substance abuser (who could be Ms. Martha’s son) to convey the experience of self-imposed immobility that entails immaturity and vulnerability. Mayfield’s narrator explains that he is, “Porched up in a rocking-chair / With my feet all bare / Rolling my blunt in a cigar wrap... Live an adolescent mind / Waiting for my high, quiet as it’s kept / ... Around the boys I play my part rough / Keep myself tough enough / Never to cry / Don’t really want to die.” Speaking more than singing, Mayfield uses hushed tones to render the resignation of this character and the force of his bleak tale.

A remake of Mayfield’s 1970 solo song “We People who are Darker than Blue” is at *NWO*’s center to warn listeners against living up to oppressive definitions that are part of a victim-blaming, culture of poverty ideology. Reiterating the original version’s call for multi-racial solidarity in a political context shaped by a Republican Congress’s Contract with America and a Democratic President’s draconian welfare reform, “Darker than Blue” champions interdependence, a value whose personal significance for Mayfield equaled its social urgency.

When Mayfield ventures into what seems unquestionably personal, even private territory on “I Believe in You,” a duet with Sandra St. Victor, the fact of his quadriplegia makes the song’s romantic and sexual subject matter socially resonant. St. Victor assures Mayfield that “You’re my kind of man, with a mind completely rare / We feel the touch, ‘cause we know each other care / The time is now, so we try ourselves for size / Your smiling face, bring a sparkle to your eye / So sensitive we give / It’s your ecstasy, now caressing me, with our feelings free.” One of several songs of intimate love on *N.W.O.*, “I Believe in You” is a necessary reminder that people with disabilities are sexual agents regardless of the severity of their impairments.

The most musically buoyant song on *NWO* also has its most trenchant lyrics. Deceptively danceable, “The Got Dang Song” sends the kind of message that made Mayfield a role model for Bob Marley and other reggae musicians who heard revolutionary spirit in Mayfield’s work with the Impressions and as a solo act (Burns, 2003). Surveying a planet rife with class and race-based iniquities, Mayfield contrasts the physical beauty of developing countries with their harsh economic straits, delineates the struggles of people denied living wages, and paints a vivid picture of urban mayhem. The closing verses of “Got Dang” express a bitterness Mayfield never voiced in his interviews:

Saw him from the shadow when he shot  
the gun  
Through the ghetto jungle away he run  
Live in the city, ain’t going nowhere  
Few folks share and ain’t nothing fair  
Oh could there be a conspiracy  
To thrive on me, a minority  
Some folk say to suck it up  
Ain’t got no straw, ain’t got no cup

These six songs are the most compelling music on an album that sometimes provides a merely pleasant listening experience, with questionable production values and a large cast of collaborators who occasionally overwhelm Mayfield. Despite its unevenness, *NWO* ended Mayfield’s recording career on a positive note. Burns (2003), an admiring chronicler of the Mayfield legacy, proves that respect does not foster insight when he observes that “once you begin to get over the miracle that Curtis ever managed to record [*NWO*], it is only then that you begin to appreciate [*NWO*] without any further reference to such consideration” (p. 234). I argue for and from an opposing viewpoint, not just in respect to Mayfield and his music, but also to the spectrum of individual experiences and social constructions that disability studies interrogates. Disregarding disability is a barrier to

the more positive, complicated, and surprising readings that the stories of all people with disabilities deserve.

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# "Hear Us Shout:" Music Celebrating Disability Pride and Liberation

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## (Beyond) Popular Culture

**Abstract:** An exploration of a sampling of music about disability issues, primarily from musicians with disabilities. The focus of the music discussed in this article is protest, power, oppression, and resilience. References and websites for the musicians discussed are included when available.

**Key Words:** Disability rights, Disability Culture, music

### Crip Music

A beat behind, sycophant, you  
Sisyphus, roll and run  
again and again  
Sybil whistle tune, mournfully  
Whistle in the dark  
The shoe steps the rhythm  
Behind, behind, behind you  
With the crutch cane stick beat  
The cripple who ripples across  
The street with the wheel on the rack  
Rackle and giggle the cripple  
Till the music stops  
We step out  
And then, and then, it builds  
The sound, and the beat  
And the melody of the cane  
And the melody of the crutch  
And the melody of the wheel  
And the tap of the stick  
And the tick of ventilators  
Dilate, pulse

Push breath through the street  
Roll forward and on  
The beat in a circle  
We move, we move  
The line held firm  
The song lifting  
(Petra Kupperts, 2007)

I use poetry about music and dancing to bookend this essay because music cannot be played in this format. I hope to convey, through these two poems, the feelings of music that attract me to that art form.

I came of age in the US Midwest in the 1960s. At that time, many political, social, and cultural movements captured the public's (and my) imagination: Berkeley, California became the home of the Free Speech movement (which spawned many more activist movements in the San Francisco Bay Area); in the southern states, the civil rights movement; from various locales, the women's movement and the anti-Vietnam War movement. I identified with all these reform-minded activities. Popular music both reflected and stimulated aspects of these various protest movements. During the 1960s, there were a bevy of antiwar songs. Perhaps the most radical was Country Joe McDonald and the Fish's *The Feel Like I'm Fixin' to Die Rag* (1965):

So put down your books and pick up a  
gun  
We're gonna have a whole lot of fun!  
And it's one, two, three what are we fighting for?  
Don't ask me, I don't give a damn  
Next stop is Vietnam

While I identified with all of these reform movements of the late 1960s and early 1970s, I did not yet identify myself as an individual with a disability. But in the early 1980s when I became a part of the disability rights movement, I sought various cultural representations of my new movement home, including music. I still do.

When I think of a disability rights song, the first criteria is that the content of the song has something to do with the experience of disability. Frequently, but not always, that content is generated by someone with a disability. Sometimes an individual with a disability creates music that may not initially seem disability-related, yet nonetheless relates, however subtly, to the musician's disability experience. There are also musicians with disabilities who seem to have little to do with the disability rights movement, at least in their music.

This is a survey of music I know, not comprehensive and primarily limited to English language lyrics. It constitutes but a sampler of music that celebrates disability pride and liberation.

I am compelled to begin with Jane Field because I have used her music for many years in presentations. In 1994 Field released *The Fishing is Free*, a classic song collection. The first two lines below are the title song's refrain:

Don't you wish that you were disabled?  
Disabled is the better way to be.  
When we go out it's really neat,  
we're always sure we'll get a seat  
Oh, don't you wish that you were just like me?

Field utilizes humor to describe various disability life experiences, including going through the back doors of buildings to get inside, and not having to pay for a fishing license. The trade-offs are clear in the refrain. The breaks one gets from becoming disabled are so compel-

ling that those who do not have a disability will surely want to acquire one. This song collection also includes "Quickie's Goodbye," a tribute to a loyal wheelchair; a love song, "One Flight of Stairs;" and a classic anthem to our sexuality, "Disabled People Do It!" another presentation favorite.

The nondisabled human service professional, Peter Leidy has recorded three CDs about "human serviceland." On *The Great Escape*, several songs describe survivors and escapees from institutions. In folk style, Leidy sings the "Darwin Ness Polka" about a man who finally gets out of an institution after "47 years staring at the same walls." When Leidy sings about Darwin Ness he's now "been out 20 years and there's no time to rest." *The Great Escape's* title song, tells the story of "Charlie [who] was locked up there at the age of 9, having been found guilty of committing no crime." At the age of 23, in 1967, "Charlie ran away, he traveled night and day... he took a holiday," and in what might seem to be a classic understatement, Leidy sings "he's gone and he won't be coming back," because Charlie realizes "at least I know I'm free, may no one ever take that from me." "The Ballad of Self-Directed Joe," sung in the style of the "The Ballad of Jed Clampett" (Henning, 1962; also known as the *Beverly Hillbillies* theme song) narrates the tale of a bureaucratic mistake that has made Joe rich. Leidy sings about "choice, control, dignity" and says that though the state sought Joe "he was last seen lying on a beach in Mexico." Finally, the all-encompassing *Inclusion* states unequivocally "we all belong" and everyone should pay attention because we are "all invited to come along." Emulating earlier civil rights songs, Leidy intones the disability rights emphasis that "inclusion is about change and change will come." In case the listener has not figured it out yet Leidy explains, "all means all" and "together we're better, together we're strong."

Perhaps, the two best-known singer-songwriters who focus on disability in their music



are Jeff Moyer and Johnny Crescendo. Moyer, who is blind, lives in Ohio. He first gained notice in the late 1970s as the resident musician of the 1977 sit-in at the San Francisco Federal Building. Until recently, this was the largest take-over of a US government building in US history. Demonstrators demanded the government implement regulations to enforce a law known as “Section 504,” that is widely viewed as the first US law protecting the rights of individuals with disabilities (Brown, 1994, p. 61, DREDF, 1999). I often play Moyer’s song, “For the Crime of Being Different” which focuses on his brother who was institutionalized because of a developmental disability:

For the crime of being different,  
for the crime of being slow  
For the crime of not quite fitting in,  
we sentence you to go  
Where you will be with others  
who are also of your kind  
Far, far away from city lights,  
out of sight and out of mind.

The sentence is quite final,  
there can be no appeal  
You have no right of protest,  
no defense nor free man’s bail  
Within the institution,  
away from prying eyes  
Drugs and grinding tedium will become a  
way of life.

Through the power of the people  
and in the wisdom of the State  
We sentence you to go away  
and live your star-crossed fate  
Perhaps in time these walls will fall,  
these prisons will be shunned

But til that time this sentence stands,  
the State’s will shall be done.

For the crime of being different,  
for the crime of being slow  
For the crime of not quite fitting in,  
we sentence you to go  
Where you will be with others  
who are also of your kind  
Far, far away from city lights,  
out of sight and out of mind.

© Jeff Moyer 1986, Used with author  
permission

Originally from England, Johnny Crescendo now makes his home in Philadelphia, Pennsylvania. A founder of DAN, the Direct Action Network, modeled on the US street activist group ADAPT<sup>1</sup>, that focused first on accessible transportation, and now works to get people out of nursing homes and other institutions, of the US, Johnny’s songs relate tales of disability pride, protest, and rights. (<http://www.johnny-crescendo.com/page6.html>). His song, “Not Dead Yet” protests physician-assisted suicide:

I’m lying at the gates of heaven  
I’m not dead yet...  
Doctors popping in with pills like a  
graveyard junkie...  
Assisted suicide is funky...  
My mother and father know what’s best  
They want to kick Joey out of the nest...  
I’m lying at the gates of heaven  
I’m not dead yet...  
I was kind of amazed to see St. Peter roll  
up in a wheelchair  
I said “hey Pete, I want to go back.”  
He said ‘go and give shit to Dr. Quack.’  
I’m lying at the gates of heaven  
I’m not dead yet.

Robin Surgeoner is another English singer who, with two other musicians, is known as Angryfish. Their CD, *Barbed Wire and Pot-Holes*, meant to be played loudly, narrates the story of a man's awakening from being a person with a disability to being a member of an oppressed group and learning what he can do to change the world for the better. It is the first complete story CD I have encountered by a person with a disability about the disability experience.

Also in the loud music genre, Beethoven's Nightmare, based in Honolulu, bills itself as the first deaf rock'n'roll band in the world. Their CD, *Turn It Up Louder*, features the following partly satirical lyrics from the title song:

If you're looking for a good band  
Check us out  
Check us out  
If you're looking for a good band  
Count us in  
If you're looking for a good sound  
Hear us shout  
If you're wondering what we're all about  
We're the only deaf band in the world  
If you can't understand all the words all  
we need to do is  
Turn it up louder  
Yeah, turn it up louder

Beethoven's Nightmare "listens" to the vibrations of the music, as do audience members who may be deaf. They were recently featured in a Public Broadcasting System documentary, *Through Deaf Eyes* (<http://www.pbs.org/weta/throughdeafeyes/about/index.html>).

Musicians have also addressed what might be considered more subtle disability issues. The late Kim Palmer succumbed to Multiple Chemical Sensitivities in 2006. An excerpt of her 1993 "Allergic to the 20th Century" appears below:

Industrialized, deodorized, volatized for  
my demise!

PARDON-MOI, DON'T MIND ME  
I'M JUST ALLERGIC TO THE 20TH  
CENTURY

PARDON-MOI, DON'T MIND ME  
I'M JUST ALLERGIC TO THE 20TH  
CENTURY

Take me back in time where I'm away  
From pollution's contribution to our  
modern day

Where doctors don't just look at me and  
scratch their head

And there aren't any flame retardants in  
my bed

And no-one at MacDonald's eats what I  
can't

Appointing me the ultimate renunciant

Where I can hide from the hydes to save  
my hide

Formaldehyde, benzaldehyde, pesticide,  
I'm paralyzed!

PARDON-MOI, DON'T MIND ME  
I'M JUST ALLERGIC TO THE 20TH  
CENTURY

PARDON-MOI, DON'T MIND ME  
I'M JUST ALLERGIC TO THE 20TH  
CENTURY

Elaine Kolb, who wrote the first ADAPT anthem, "We Will Ride," (1994) sings the song in a folk/spiritual style:

We will ride

We will ride

With the strength of human justice on  
our side

By the grace of God above

Our battle cry is love

And we will ride

We will ride

Far too many people have been suffering  
too long  
We won't accept excuses  
Right is right and wrong is wrong  
And it's wrong to try and keep us waiting  
for some charity  
So let's get ourselves together here and  
now, you and me.

There are many other musicians with disabilities who focus on disability issues. Their work may often be found on [www.youtube.com](http://www.youtube.com) by searching the phrases, "disability" and "music." "Making Love in the Handicap Toilet," (<http://www.youtube.com/watch?v=AmJ6FDj9R1k>) is a video by "Boys on Wheels," fronted by the Swedish comedian, Jesper Odelberg.

In the 2006 collection, assembled by England's Robin Surgeoner, Lindsay Carter's "Useless Eaters" uses the Nazi phrase for individuals with disabilities to address today's bioethics discussions:

If just one gene's out of whack  
They're looking to abort us...  
They call us useless eaters  
With fucked-up DNA  
All we want is the chance  
To show you how we love our lives  
But the movers and the shakers  
Are scared that we'd change your minds  
We're not gonna let you wipe us out  
We're here to stay  
Our genes are fine  
Our DNA is A OK...  
Our lives aren't a tragedy  
Your life without us is

Music has the ability to be soothing or rousing, feelings needed at various times during the struggle to overthrow oppression and attain rights. Music may also be educational, and I

hope that this sampler of disability rights music has been. It can also be inspiring. I conclude, as I began, with a poem. This is one I published in 1995 after I learned, along with many others, to enjoy dancing from our wheelchairs:

### The Wheelie

There's a new dance craze makin' the  
rounds  
Don't matter bout the speed or sounds.  
Going to boogie in a new space  
Cranking it up with a different pace.  
First thing ya gotta do  
Is be prepared for something new.  
Gotta get off your heels  
And move onta your wheels.  
Take your chair onta the floor  
Make them rhythms roar  
Wheelies speed and soar.  
Skid your wheels  
Hear the squeals,  
People watchin' ya twist  
Wondrin' what they've missed.  
Make a splash  
Roll 'n' slash  
Send your chair onta the floor  
Make them rhythms roar  
Wheelies speed and soar.  
Do the wheelie  
Be a big dealie  
Do the wheels  
No need to stay on your heels  
Watch the sidewalls soar, flash and more  
Them dancers diggin' to their core.  
Listen to them rhythms roar  
Wheelies speed and soar,  
Be prepared for somethin' new  
It's a craze catchin' on  
with more than a few.

Off your heels  
On your wheels  
Slip 'n' slide 'n' ask for more  
Make them rhythms roar  
To a new folklore.

**Steven E. Brown**, an editor of the *Review of Disability Studies* and assistant professor of disability studies at the University of Hawai'i is also the co-founder of the Institute on Disability Culture (<http://web.mac.com/disculture/>), a poet, essayist, and speaker. A collection of essays, *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride* is available at many online bookstores. He may be contacted at: [sebrown@hawaii.edu](mailto:sebrown@hawaii.edu)

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## Musician Web Sites

- Angryfish: [www.angryfish.co.uk](http://www.angryfish.co.uk)
- Beethoven's Nightmare: <http://www.beethovensnightmare.com>
- Elaine Kolb: <http://community-2.webtv.net/DREAMprod4U/ElaineMarieKolb/>
- Jeff Moyer: [www.jeffmoyer.com](http://www.jeffmoyer.com)
- Jesper Odelberg: <http://www.odelberg.se/>
- Johnny Crescendo: [www.johnnycrescendo.com](http://www.johnnycrescendo.com)
- Kim Palmer: <http://www.angelfire.com/az/ox/>

## Endnotes

- <sup>1</sup> (American Disabled for Accessible Public Transit was the initial acronym, then changed to American Disabled for Attendant Programs Today, after the passage of the Americans with Disabilities Act in 1990. Several years ago, the group decided to stop trying to fit the letters to any acronym. For history of ADAPT, see [www.adapt.org](http://www.adapt.org))

# Music to My (Deaf) Ears: The Installation Work of Joseph Grigely

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## Beyond Disciplinarity

**Abstract:** The installations of artist and literary theorist Joseph Grigely compose memories, mannerisms, messages, (mis)communications, and music to explore the perceptions of and interfaces between deaf and non-deaf worlds. Grigely has been deaf since the age of ten. His visual and literary works exhibit memory and communication as multi-sensual and fragmented, while they deconstruct stereotypes of deafness.

**Key Words:** Artwork, deafness, music

“Can you feel the music?”

“It’s just hard to be a rock star after say, 33.”<sup>1</sup>

The work of artist and literary theorist Joseph Grigely composes memories, mannerisms, messages, (mis)communications, and music. The pieces convey the various meanings of the verb *to compose*: to invent, to create, to collect and arrange, to write text or music, and to make art. His art installations, the focus of this paper, are multimedia and multisensory compositions. They make visible improvisational, fragmented, and dissonant rhythms and voices. These works and their musical themes inform Grigely’s larger project of exploring the perceptions of and interfaces between deaf and nondeaf worlds.

Music reverberates throughout Grigely’s written and visual forms, which seems at first ironic in light of Grigely’s deafness (due to an



Fig. 1: Joseph Grigely, Remembering is a Difficult Job but Someone Has to Do It (2005)

accident at the age of 10). His installation *Remembering is a Difficult Job, But Someone Has to Do It* (2005) (fig. 1) centers on the artist's fond memories of the television show "Gilligan's Island"; clips of the show's introduction and unforgettable jingle are projected throughout the gallery against theatrical backdrops (photographs of ocean scenes), film stills of the cast, and imagined visions of a fictive paradise. The work ties visual culture and, most profoundly, sound to Grigely's memories of childhood, such that it encompasses his memories of hearing and embodied perceptions prior to his accident. The work portrays the phenomenological experiences of hearing loss in a multi-sensorial experience for the viewer, as the music jingle becomes a tactile, visual element in the piece. Grigely's recent work *St. Cecelia* (named after the patron saint of music) takes these themes further, as he collaborates with the Baltimore Choral Arts Society to create a video of Christmas carols, performed by the choir and rewritten by Grigely to reflect common misperceptions of lyrics.<sup>2</sup> Grigely here comments on the nature of perception for individuals with all levels of hearing capability, for the jumbling lyrics in order to keep the rhythm of music intact is a common mistake for all, and yet particularly amplified when one is lip reading.

This kind of amusing juxtaposition of words and mistaken meanings characterize Grigely's most pervasive visual work. The two snippets quoted above are drawn from Grigely's series of *Conversations with the Hearing* installations, in which he assembles on gallery walls and incorporates into three dimensional installations pieces of dialogue written on paper for him by nondeaf people. The random records of speech often become ironic and humorous in juxtaposition and lead the viewer to question the arbitrary nature of communication. For example, in what context does one respond, "It's hard to be a rock star after say 33"? One could imagine a conversation partner writing to Grigely, "Can you feel the music?," due to his deafness, although this phrase is also a familiar dance expression. By

sampling such comments and mediating them through visual arrangement, Grigely frames his own fragmented perceptions of communication in a world that does not accommodate deafness. These themes extend beyond the perceptual frames of Grigely's body, as the works visually portray the disjointedness and performativity of all human memory and communication.

Irony is at the heart of Grigely's work. His primary subject is visual and oral mediation and the mixed messages inevitably produced. Communication, particularly in our technologically driven culture of emails, cell phones, text and instant messages, the internet, and online chatting and blogging, is endlessly disjointed. Despite, and perhaps because of all the communicating devices at our hands, lips, and ears, miscommunication defines contemporary culture. Similarly, memory proves always multisensory and fragmented. For Grigely, remembering the musical jingle to Gilligan's Island is no more a feat than anyone, hearing-impaired or otherwise, recalling music or words from the past. The show itself and viewers' memories of it are based in imagination. What most people remember iconically and exclusively from the musical jingle is the repetition of, "A three hour tour, a three hour tour," as well as the melodious run down of the cast's identities, from Gilligan to Mary Ann. Again, such random sampling composes human memories and experiences.

The seemingly antithetical, indeed ironic juxtaposition of music with deafness is Grigely's point. The notion that those with hearing loss cannot experience and enjoy music is a common misconception, for the majority have some range of aural access to music along the spectrum of hearing loss, and all people (deaf and nondeaf) experience music orally, visually, and sensorially to varying degrees; after all, "feeling the music" can elicit a physical and emotional act of memory, joy, or catharsis. Music educators Ann-Alice Darrow and Diane Merchant Loomis (1999) investigate how pervasive stereotypes of deafness in the media affect perceptions about

students with hearing loss, finding repeated scenarios in cultural representations in which nondeaf characters pity those with hearing loss for their inability to hear music. Music defines the “lack” associated with deafness in popular representations. The work of many deaf musicians, such as Jamie Berke, percussionists Evelyn Glennie and Shawn Dale Barnett, and the rock band Beethoven’s Nightmare, as well as the popular Gallaudet Dance Company and a 2000 production of the musical *West Side Story*, performed at MacMurray College in Jacksonville, Illinois, with students from the Illinois School for the Deaf as the Sharks *Deaf Side Story* (Rigney, 2003), adamantly challenge this false assumption. Likewise, Grigely’s work takes to task the assumed disconnection between deafness and music. Darrow and Loomis add that making rhythm visual greatly adds to deaf students’ perception and enjoyment of music; in relation, Grigely creates a rhythm of words and sounds with his artwork, making visual the dynamics of conversation and music. Darrow and Loomis define the popular assumption that a hearing impairment forecloses one’s access to music as a form of ethnocentrism – the act of judging and degrading another culture by the standards of one’s own. Grigely’s work turns the tables on such ethnocentric biases and historical practices. His *Conversations with the Hearing* installations invert the scenario of the Western “able-bodied” scientist studying the deaf “Other,” as he performs an archeology of conversations, records nondeaf culture in fragments, and displays his archive (Davidson, 2002). Grigely’s hearing loss and need to communicate with nondeaf populations make this work possible, as deafness becomes the source and inspiration for art.

Grigely also inverts the traditional hierarchy of oralism and sign language in the Deaf/deaf community. The distinction between these two terms relates to whether one was born with or acquired deafness, how oral one is or chooses to be, and how one identifies himself or herself. People who are “deaf” tend to be more oral, as many (like Grigely) have been at one time part

of the nondeaf population. This term often refers to hearing-impairment in general, whereas “Deaf” individuals share a common language of sign and consider themselves a linguistic minority. Oralism, the practice of communicating through speech versus sign language and the predominate basis of deaf education, has a long ideological history, associated with not only ableism (ethnocentrism of the nondeaf), but also eugenics of the “deficient” (Mirzoeff, 1995). According to these traditions, deaf people were supposedly “cured” when they could most conform to the nondeaf, oral world.

The privileging of spoken over written word, which Grigely’s works challenge, transcends deaf histories. In Western theology and theory, the oral word is associated with truth and logic. Jacques Derrida and other post-structuralists have interrogated these traditions in their questioning of language as a basis of knowledge. Derrida coined the term “deconstruction” to describe literary and visual acts that invert and confuse conventional language systems. Deconstruction bears implications well beyond the scope of this paper, but the elements most relevant to Grigely’s work are pervasive fragmenting and quoting ironically, taking quotes in and out of context, and, in these acts, critiquing convention and systems of knowledge. In relation, deconstruction as a practice also involves Roland Barthes’ theories surrounding the death or demystification of the notion of a self-contained, original, independent author/speaker. Deconstructive tendencies arise in Grigely’s assemblages of fragmented and decontextualized quotes, whose anonymity further suggests a gesture toward the irrelevance of the specific speaker or author in favor of foregrounding the perceptions of the viewer/reader. Grigely showcases how communication and memory are illogical – nonlinear, random, and incomplete.

Grigely is well-versed in these theoretical practices. His book, *Textalterity: Art, Theory and Textual Criticism* (1995), asserts the significant changes in meaning and connotation of texts

(both visual and literary) over time. He argues that new contexts inform and transform historical texts' signification and how the viewer/reader makes meaning of history itself. Grigely writes: "As a consequence, textualterity is less related to the medium of a work than to the ways or processes in which the work is disseminated" (p. 53). Grigely asserts that the ultimate significances of texts and viewer/reader's perceptions of them is always codependent on the texts' mediation over time and in and out of contexts. For Grigely, all texts are multicontextual and accumulate fragmented meanings.

Themes of deconstruction and accumulation materialize in Grigely's artworks. In wall hangings such as *Multiples* (2000) (fig. 2) and *223*

*Conversations* (2005) (fig. 3), Grigely assembles notes written to him in a variety of situations and on a variety of media. These works display doodles, scribbles, cartoons, and nonlinear fragments recorded on materials that are themselves taken out of context: notebook paper, post-it notes, postcards, stationary, envelopes, menus, napkins, pieces of tablecloths, matchbook covers, gallery programs and brochures, foreign bills, claim-check stubs, registration cards, recipe cards, and pages from magazines and catalogs. The media or fabric of these works crosses genres of high and low art while crossing public and private social settings. The collection of these fragments into the shape of a traditional painting or mural presents the false illusion of integration. In *Multiples*, different sized, but all

Fig. 2: Joseph Grigely, *Multiples* (2000)





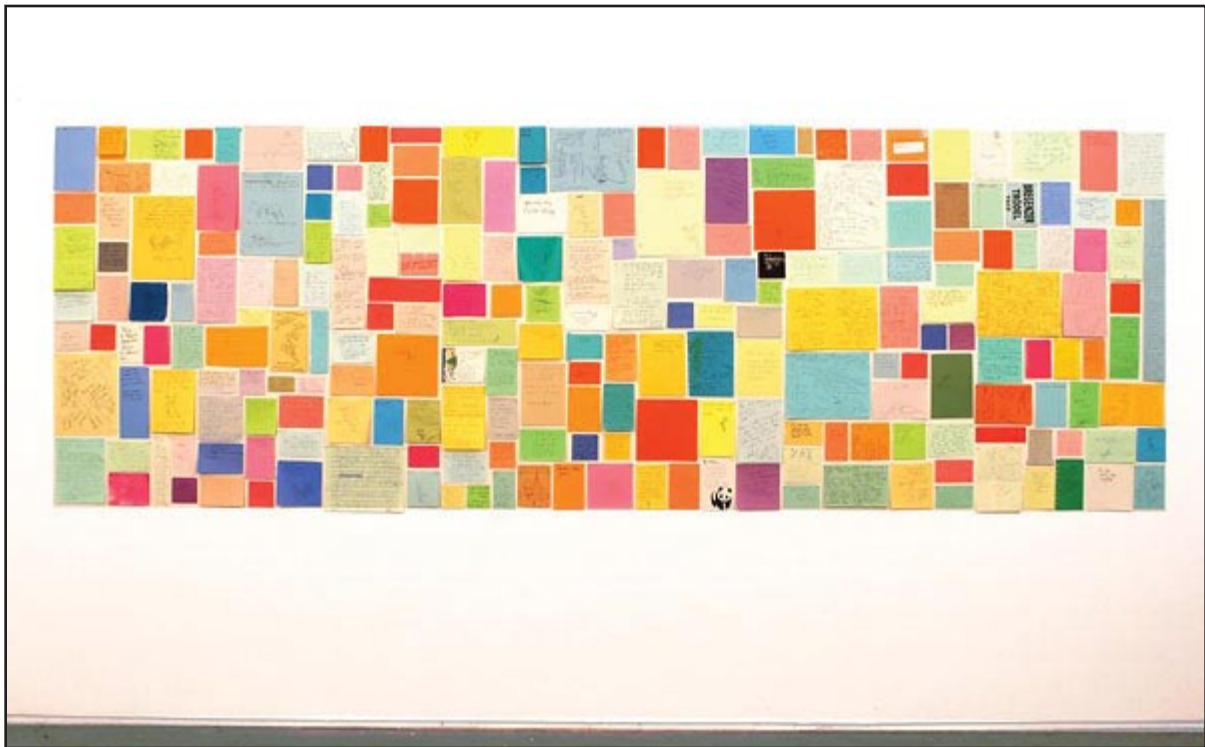


Fig. 3: Joseph Grigely, *223 Conversations* (2005)

straight-edged index cards, sheets of colored paper, scraps from small note pads, and the back of an envelope, all in various shades of blue, are evenly spaced and assembled in a perfect square. From a distance the work resembles a colorfield painting by Mark Rothko or an example of Yves Klein's canvases saturated with his trademark blue. In *223 Conversations*, different colors and sizes from a variety of transcribed materials are arranged in rectangular mural; from a distance it looks like an abstract painting, in a geometric pattern that traditionally in art history contains no tangible subject matter. However, the work is composed of communication. As one gets closer to translate the texts on the individual pieces of *Multiples*, written in all directions, one encounters: "She scored some VIKADIN [sic] (pain reliever) mixed w/liquor = superfun"; "sex kitten"; "Olivier very good friend"; "that's not what I'm taking about"; a sketch of a cartoon dog about to be hit by a flying newspaper and staring down at a gun; and "What? Not in a bar! I thought you said Ass." These curious and humorous sound bites implicate the viewer

in eavesdropping and escape explanation. The works depict visually the vivid color of conversations in a chorus of dissonant voices.

Davidson (2002) has described Grigely's work as the perception of communication when "encountered through a deaf optic," choosing a strategically ironic concept that underscores the multisensory and multilingual experience of communication for deaf people through fragmented acoustics, lip reading, body language (sign, gesture, and expression), and contextual clues. With these disjointed puzzles, Grigely recreates for the viewer his own embodied experience of interpreting "conversations with the hearing" while suggesting that the nature of all communication is puzzling.

Grigely deconstructs communication, particularly in the creative media of literature, art, and music, as purely oral OR visual. Like his methodology in *Textalterity*, Grigely's visual art methods frame images as texts, but specifically ones that are interpretively open for and lost in translations. In the booklet *Vox Populi*



Fig. 4: Joseph Grigely, image of a Canello painting from *Vox Populi* (2003)

(2003) (fig. 4), Grigely reproduces works by the famous 17th century painter of Italian cityscapes, Canaletto, literally turning art into a text. A life-size fiberglass sculpture of a dog drawn from one of Canaletto's works, titled *Dog from Canaletto's Riva Degli Schiavoni* (2003) (fig. 5), stands in for a viewer posed outside the frame and external to the conversations inside the paintings.

Art critic Frank Nicholas (2004) has likened this pairing of the dog with the paintings to the relationship of any beings that speak different tongues and communicate through combinations of gestures and sounds. Canaletto's paintings were popular among tourists to 18th-century Italy and served as souvenirs and fragmented memories of travel. In art history, conversation pieces are paintings of people engaged in socializing and leisure. They are traditionally silent, yet portray conversation and exchange through gestures and body language, similar to sign language (Mirzoeff, 1995). Painting, sculpture, photography, and a range of artworks communicate through visual and textual cues, and in this sense most art is nonoral in its communicative modes. Art historian Nicholas

Mirzoeff underscores how all artwork, with its multiple forms of communication, is always dynamic, gestural, and open to interpretation and individual perception. In these ways, Mirzoeff compares art with performing sign language and with deafness itself. The means by which visual art mediates its content, context, and expression is always fragmentary, multi-sensual, performative, and subject to endless misunderstandings, as Grigely's art makes vivid. His subject matter is the nature of mediation.

Grigely's modes of mediation are most musically analogous to electronic sampling. Music historian Mark Katz (2004) explains that digital sampling is a type of computer synthesis in which sound is rendered into notated data. Katz writes: "On the simplest level sampling works like a jigsaw puzzle: a sound is cut up into pieces and then put back together to form a digitized

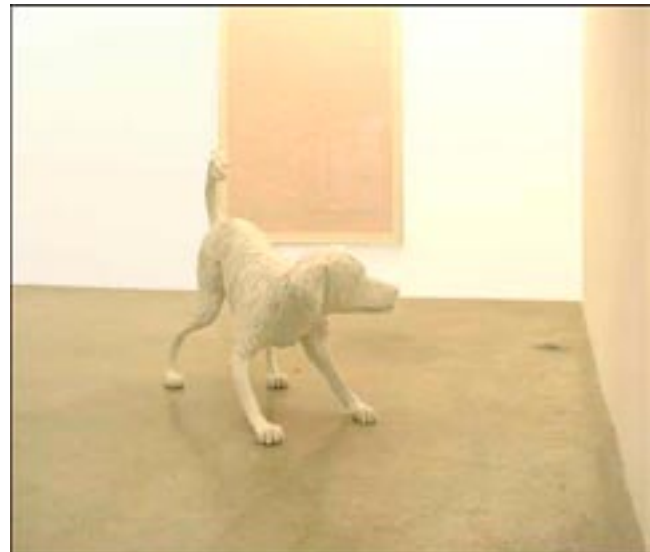


Fig. 5: Joseph Grigely, *Dog from Canaletto's Riva Degli Schiavoni* (2003)

'picture' of that sound" (p. 138). Katz's description of musical sampling resembles Grigely method of making sound visual and "puzzling." Parallel to musical sampling, Grigely quotes, fragments, recontextualizes, and mediates sound into a unique arrangement. A remixed musical piece, according to Katz, composes representations of original sounds, on which infinite ma-

nipulations to tempo, pitch, reverberation, and frequency are performed. These sounds can be “reversed, cut, looped, and layered” (p. 139). Grigely makes this process visual in his *Conversations* installations, as the colors of the materials written on, variations of writing style, scribbling and doodling, and the juxtapositions of the comments change the tone, pulse, and flavor of the individual quotes.

Many of Grigely’s scholarly articles also employ sampling methods. In 1986, he produced a series of 32 postcards to the artist Sophie Calle in response to her exhibition, “The Blind,” in which she photographed a series of blind people, asked them to describe their notion of beauty, and recreated what she interpreted from their responses in a photograph. Grigely found the exhibit problematic in its exploitation of blindness as a metaphor and because of Calle’s ethnocentric mediation of what the subjects “saw” as beauty. On these postcards, he sampled the conventional discourses of disability represented in Calle’s (in his opinion) ableist work. He also included his own embodied experiences as a deaf person perceiving the work. The content of these postcards was assembled in an essay that serves as art and disability commentary (Grigely, 2000).

A more recent essay by Grigely, “Blindness and Deafness as Metaphors: An Anthological Essay” (2006), follows in this vein, as he assembles a series of quotes from a variety of writers who engage problematic metaphors of blindness and deafness. Among the analogies in these clips, blindness and deafness symbolize ignorance and acts of ignoring the “truth.” This random sampling demonstrates the repetition and pervasive dissemination of these derogatory metaphors in culture, in sources ranging from popular media to postmodern art to critical race theory. The varying sources are samples and arranged to create a larger narrative of cultural ableism. Finally, Grigely assembled a similar narrative drawn from historical scholarship on deafness from the Renaissance to the present, which he titled

*Deaf & Dumb: a Tale* (1994). As in his other sampling acts, the original context is indicated, yet fragmented for discursive comparisons. The materials, which demonstrate that deaf people have been medicalized, demonized, pitied, infantilized, and eugenized historically, create a metonymic pattern. The underlying cultural narrative associates deafness again with ignorance and individual failure to “overcome” affliction.



Fig. 6: Joseph Grigely, *Blueberry Surprise* (2003)

In Grigely’s visual works and in musical sampling, fragments of manipulated sound are drawn into larger rhythmic compositions. Grigely’s visual sampling compares to Katz’s (2004) example of the composer Paul Lansky. In *Notjustmoreidlechatter*, Lansky digitally manipulates speech into rhythms of musical sound. In all his prior work, rather than quoting original music Lansky draws on the rich music of everyday life, from conversations to the background “noise” of private and public spaces. Katz writes: “*Notjustmoreidlechatter* wonderfully demonstrates the musical and aesthetic potential of digital technologies. Like an alchemist, Lansky transforms the ordinary into the precious, where a spoken word becomes a superhuman chorus” (p. 144). Similarly, Grigely draws multiple voices into a

kind of magical, electronically produced chorus. In *Blueberry Surprise* (2003) (figs. 6 and 7) (displayed alongside *Vox Populi* and *The Arch of Septimus Severus*), Grigely presents a digital print that loops conversation fragments in alternating red, orange, and black electronic font, relating to how Katz identifies the process of manipulating sound in digital sampling. Samples of the type read: “Coney Island Cap Ferret Irish people”; “lots chives & parsley lots cheese on top”; “ashtrays, tools. They sent a robot down.” The work is composed of notes, literally, and Grigely creates a colorful rhythm of voices and notes with beats of endless chatter and punctuated statements. Katz describes Lansky’s technique as creating an illusion of clarity, which questions the viewer’s desire to extract clear meaning from the music. Similarly, Grigely’s patterns and dissonant melodies ask his viewers to experience sound sensually rather than cerebrally – to stand back and take in the view.

The puzzling and indecipherable components of Lansky’s and Grigely’s works are aesthetic and symbolic. Katz describes the “countless unintelligible voices” in Lansky’s *Notjustmoreidlechatter* as “what one might take for the Babel of legend.” “Babel” signifies a confusion of voices, particularly in singing, as well as a scene of noisy confusion. Derived from the Hebrew Babylon, the term Babel originates from the Biblical story in which humans attempted to build a tower high enough to reach Heaven. According to the scripture, God intervened by confusing the languages of the builders so they could not communicate, therefore preventing human access to Heaven and producing the origin of different languages on Earth. Grigely’s work composes such a Babel of voices, exemplified by the commissioning by and including of his work in a 1999 exhibit at the Ikon Gallery titled *Babel: Contemporary Art and the Journeys of Conversation*. The 11 artists’ work featured in the exhibit share themes of translation, interruptions, alphabets, relationships of text and image, language taken in and out of context, Freudian slips, utterances, chatter, and commu-

nication losses. Grigely’s work incorporates all of these subjects in his sampled and mediated visual fragments and oral bites.

Similarly, the 2006 Alejandro González Iñárritu film *Babel* incorporates manifestations of the Babel metaphor in a specifically contemporary, technological, global culture. The metonymically related stories that take place across the globe in the film are thematically linked by the loss of communication, despite the characters’ desperate attempts to cross language and cultural borders, to utilize cell phones and other information systems, and poignantly, to communicate in a variety of languages, including those of the deaf.

One of the main characters, Chieko (played by Rinko Kikuchi) is a deaf Japanese teenager struggling with the suicide of her mother and her raging and confusing sexuality. Like many teenage girls, no one seems to understand her, which is amplified by the fact that she communicates with the nondeaf world, like Grigely, through sign, lip reading, body language, and written notes. The film captures her perceptual experiences. For example, a scene in a dental office waiting room eliminates audio sound, and the gestures, actions, and movements of lips – observations of everyday life – seem random and incomprehensible through the background silence and through Chieko’s eyes.

In a later scene in a disco, Chieko’s perceptions of the strobe lights and ear-piercing American techno music are intensified by the intermittent absence of only the musical sound and by the camera’s fast editing. Chieko “feels the music,” which is also intensified from her use of drugs and alcohol. In this Babel of sensory stimulation, Chieko’s deafness does not prevent her from having a powerful moment of understanding. No words are necessary as she witnesses the boy she has a crush on making out with her girlfriend. The silence surrounding her as she walks home captures her feeling of isolation and complete absorption in her internal world.

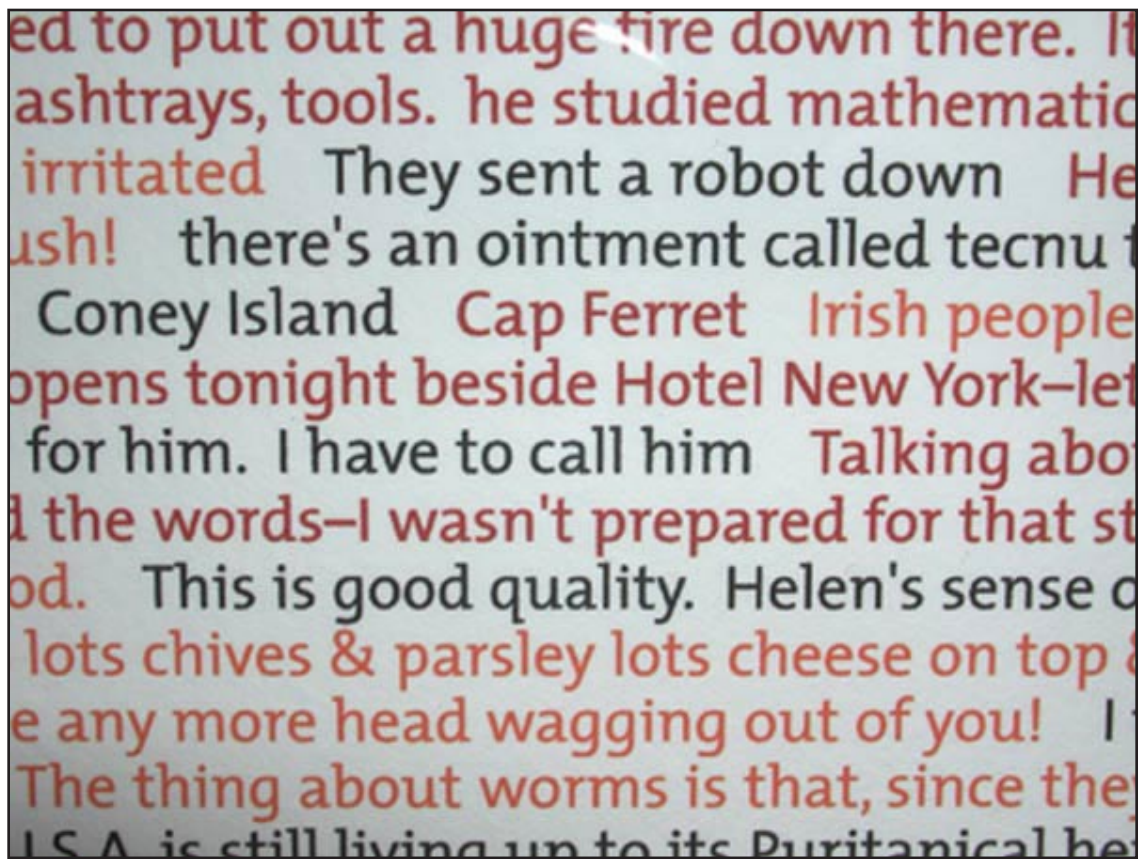


Fig. 7: Joseph Grigely, detail from *Blueberry Surprise* (2003)

Larger themes of the film manifest in Chieko's interaction with technology: dancing in the disco, signing with her deaf girlfriends through portable video devices, text messaging, becoming alerted by timed lights in her apartment, and channel surfing the television, during which she briefly touches on a news story about a shooting in Morocco that, unbeknownst to her, is connected to her family history. These technological media both enable and disable her communication with others. Tragedies in Babel among all the characters occur because of misinterpretations and assumptions of the "Other." Those in power cause anxiety and provoke defiance in the marginalized, producing the disempowered to react with violence and destruction. In reaction to boys who have rejected her because of her deafness, Chieko signs angrily to her deaf friend: "They look at us like we're monsters° I'll show them the real hairy monster," as she removes her underwear and prepares to flash

them. She becomes or shows the "monster" they assume her to be. Meanwhile in the film, random, unpredictable relationships arise that cross cultural, geographic, and communicative barriers. Characters make unexpected connections emotionally, despite the seemingly divided world.

This kind of metaphoric border is the site of Grigely's work. His works take place in the interactions between the deaf and the non-deaf and capture the dynamic intersections of cultures and languages. Nicholas Mirzoeff states (1995, p. 10-11):

"Deafness can never be stable or essential, but is always a cultural construction in need of renewal, and an image in need of focus and definition....In order to visualize deafness, a screen must be created and defined, which in

turn requires that it be framed; that is, have defined borders and parameters. Neither the hearing nor the deaf live in self-contained worlds, but are interdependent on each other. For as the hearing look at the deaf, the deaf look back and disrupt or confirm the image produced. The result is what I shall call the 'silent screen' of deafness, which depicts neither the deaf themselves nor the view of the deaf seen by the hearing, but rather the product of the interaction of the two looking at each other. It takes two people for deafness to be seen, one with hearing and one without. The screen is the product of the intersection of two gazes which forms a certain space for perception, making it possible (in this case) to see the deaf within a category known as deafness. This notion of the screen is derived from that proposed by Jacques Lacan: 'the screen is the locus of mediation' between the gaze and the subject of representation."

The screen, which Mirzeoff's describes as the interaction between deaf and nondeaf worlds, pixilates in Grigely's work. His compositional frames perform and record the performances of such interfaces.

Grigely's work both documents and embodies performances. At the Barbican Art Centre in London, Grigely composed *Barbican Conversations* (1998) from exchanges with visitors whom he approached at the centre. He sampled these interactions and printed them on brochures and posters, which were redistributed throughout the Art Centre's information and communication systems. Here, the pieces document live performances and take part in multiple forms of performative exchange. Katz (2004) states that

quotations and sound fragments that are decontextualized and recontextualized in digital sampling are only complete when performed, such that by nature sampling is a performative form of quotation (p. 140). One of the main tenants of performance art is the engagement of the artist's work/body with the viewer. The interactions with viewers and live audiences compose performance pieces. Because Grigely extracts the identity of individual speakers in his quotes, like how most musical sampling eviscerates any meaning attached to the original song/sound, the works are about perception of the viewer/speaker. Their main subject is the medium of conversation and the dynamics of communication rather than the specific content of the words. The viewer/listener then becomes a performer/reader and part of the performance.

With metaphorical turntables, Grigely's visual, oral, and written mixes turn the tables on conventional language and knowledge, most explicitly, but not exclusively about deafness. Darrow and Loomis (1999) note that mis- or lack of communication between deaf and non-deaf communities lead to misunderstandings and false stereotypes. But within the interfaces of cultures and languages, albeit fragmented, unexpected relations do occur, as they do in the film *Babel*. Connections go hand-to-paper, sign-to-sign, lips-to-eyes, alongside misconnections. Grigely's work, in highlighting and documenting the flavors, melodies, and colors of social interactions, suggest that all communication is a multimedia performance, composed of gestures, expressions, body language, and intonation. All means if communication contribute to the rhythm of seeing, speaking, performing, quoting, talking, talking back, uttering, chatting, and labeling.

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## Endnotes

<sup>1</sup> These phrases from Grigely's work are quoted in Scott, 1999.

<sup>2</sup> *St Cecelia* will be exhibited May 5-August 19 at The Contemporary Gallery in Baltimore, MD.



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# Les Paul at 91

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**Abstract:** Guitar legend Les Paul continues to perform to enthusiastic audiences as a nonagenarian whose age and impairments impact his playing technique. This essay describes the exemplary sociocultural relations that permit Paul, a person with disabilities largely a function of advanced age, to continue his career as a productive, respected, and affectionately esteemed member of a community.

**Key Words:** Les Paul, musicians with disabilities, aging

In August 2006, I caught guitarist Les Paul's regular Monday evening gig at the Iridium on Broadway in Manhattan. Ninety-one at the time, the legendary instrumentalist and inventor played two shows in short succession to packed houses. His weekly outings at this lovely New York club have welcomed such guests as Paul McCartney, Keith Richards, and Tony Bennett. He is the only member of both the Rock and Roll Hall of Fame and National Inventors Hall of Fame, the latter for such modern musical marvels and necessities as the electric guitar (the Gibson "Les Paul" model remains an industry standard to this day) and multi-track recording.

While it's unlikely many of Paul's fans see it this way, his shows are exemplars of disability culture or, perhaps more accurately, the inclusion of disability in culture. Another of the guitarist's claims to fame is his mode of recovery from a serious auto accident in 1948, in which he broke his right elbow and faced the prospect of amputation. The limited orthopedic surgical technique of the time mandated that to save his arm at all required that it be set immobile. Paul opted for placing his arm permanently in playing position such that he could continue to perform. What is doubtless a serious mobility

impairment with regard to many other activities – the injury turned Paul into a left-handed writer -- his locked arm appears to have had no permanent impact on his playing; indeed, many of his major recordings and performances lay ahead of him post-injury. What has affected his playing, though, is the arthritis that began later in life, and perhaps also additional aspects of aging. Particularly with regard to sheer velocity, a normative expectation of any jazz virtuoso and in his heyday one of the guitarist's fortes, Les Paul simply doesn't play as he once did; he doesn't even come close.

In some other musical idioms, notably Western classical music, Paul's now limited technical facility would have forced him into retirement, perhaps long ago. Classical music's requirement to perform a standard, canonic repertoire in a standardized, canonic manner, with a one-size-fits-all technique, would surely have had him drummed out of the business once he couldn't keep up with younger players. But, in all fairness, it's also unlikely that another jazz musician of less than Paul's iconic status would still be working if similarly impaired, devoid of Paul's legacy of earlier glory days, memories of which inform his current performances for his devotees every time he simply shows up, not unlike the performances of certain aging rockers who mostly fall back on the oldies they recorded before they became oldies themselves.

Still, that Paul is feted weekly by a prestigious club full of admirers in the jazz capital of the world is, especially from the perspective of disability culture, a thing of beauty and a joy for the foreseeable future. Further, his performances backed by a broadly multigenerational trio of considerably younger players manifest many el-

ements of a bold and optimistic paradigm for a new praxis of disability in music.

We live in a time when, virtually regardless of the nature of one's impairment, a combination of technology and the enlightened thinking of at least some communities make a rich participatory life in music possible. Unfortunately, mainstream values have thus far failed to keep pace with either technological or philosophical progress in music making. And while Les Paul is surely one of the greatest and most influential technological innovators in the history of music, it is not his or other's material inventions, but the attitude of great sophistication of the community comprised of all involved in his shows, that enlightens with regard to matters of disability and aging these weekly celebrations of his near century-long dedication to musical excellence.

If the guitarist's hands no longer move as fast or tirelessly as they once did, there is much that remains in his musicality to be enjoyed, as well as some elements that are better than ever which flow directly and unambiguously from his maturity. The younger players in his multigenerational quartet are there to pick up the technical slack by providing the stunningly fast barrages of notes that he no longer plays. While Paul is no longer a speed demon, his compositions, arrangements, interpretations, instrumental innovations, and the exquisitely unique sound of his guitar and amplification remain to spark these younger players to want to share his stage, along with the many jazz and rock legends who simply show up to pay homage. While playing less notes than in his youth, Paul sings and banters. No longer able to set his strings afire, his near-century of musical and life experience has only enhanced another of his artistic gifts; that of sharing stories. He is a spectacular raconteur, mostly hilarious, occasionally touching and wistful. Unlike the performances of some aging rockers, for whom maturity seems impossible simply to accept as natural, there is neither denial nor an excess of nostalgia.

That Paul's ensemble is represented by four generations and includes both sexes -- the youngest member is Ms. Nikki Parrott, an Australian bassist -- is likely happenstance. Nonetheless, their unusual demographics feel like part of the celebration. Much of the humor is brazenly risqu\_, both gay and straight, uproariously funny, and always sex positive. Ms. Parrott, an obvious focus at times, gives even more than she gets.

The importance of this substantial component of the show -- whose comedic/theatrical element rivals the musical component in time allotted -- should not be underestimated as a manifestation of disability culture. It is a veritable orgy (in the best sense) of sex-positive banter in which a mobility-impaired nonagenarian's continued vitality and passion are fully acknowledged, essential, and accepted as utterly natural. It is not only that this elderly man, his impairment largely a function of his age, is fully supported in leading a rich life of culture, friendship, and honor by his community comprised of bandmates, the music industry (in the form of clubs, the Iridium and earlier Manhattan's Fat Tuesday, that have hosted Paul's weekly gigs since 1984), and his many fans. The technical musical limitations that have come with age have been replaced with a gigantic and growing capacity for humor and stories, which, like a good wine, doubtless improves over time.

What may be the greatest glory of this tableau, in which neither age nor impairment impede life's best (and bawdiest) joys, is its indigenous naturalness. Other cultural praxes in which the elderly and, much less often, people with disabilities, are awarded status of honor and engagement are well known. But these are mostly regarded in the West as exotic; the Confucianism of East and Southeast Asia may be most familiar. What happens at the Iridium on Monday nights, full of the signification of instrumental virtuosity and sexual boasting, is entirely a product of American vernacular sociomusical praxis. It is hardly a typical product -- American popular culture is far from devoid

of an obsession with callow youth – but it is nonetheless one whose elements derive from a rich tradition in which musical performance, in both its sounds and its staging, serve to display prowess, often by African-Americans who might otherwise be regarded as powerless. (Although Paul’s group *du jour* was entirely white, the African-American origins of its jazz music and jazz humor are undeniable). At these Monday night gigs, power belongs to the old and impaired, whose breadth of experience has rendered wise (though also to the group’s junior member and only woman Ms. Parrott, whose role in the banter is second only to Paul’s and includes, “I Like Big Instruments,” her erotically-charged encomium to her double bass and another type of large tool that remains unsung).

That there is this glorious weekly celebration of the genius of age and impairment by means of musical and sexual signification would mean little were the Iridium not wheelchair accessible, but it is, and this is noted prominently on their web page (<http://iridiumjazzclub.com/>). (The club is also smoke-free). Those who make the pilgrimage to hear this guitar legend get a great deal more and better than just a concert, in the form of a rare dialect of disability culture that also embraces the concerns of age. It is a must-see for New Yorkers and visitors. Do not hesitate, as Les Paul will be 92 by the time this essay makes print. Be there or be square.

### Notes

While the biographical and other background information in this article is readily available from numerous sources on and doubtless beyond the Internet, likely the best and most enjoyable presentation is the 2007 DVD documentary *Les Paul – Chasing Sound!*, premiered on PBS in July 12, 2007, after this essay was completed. Among its many vignettes are those in which the guitarist/inventor speaks candidly about his impaired arm and his arthritis.

Directed by John Paulson and written and produced by John Arntz, *Les Paul – Chasing Sound!* is the work of John Paulson Productions of Falls Church, Virginia. At this writing, a ten-minute trailer and nearly three minutes of outtakes are available for viewing at <http://lespaul-film.com/>.

**Alex Lubet**, Associate Editor of RDS and co-editor of this special forum on disability and music, is Morse Alumni/Graduate & Professional Distinguished Teaching Professor of Music, American Studies, and Jewish Studies at the University of Minnesota. A composer, multi-instrumentalist, theatre artist, and author, he has been called the “dean of the field” of disability studies in music. His writings on music and disability have appeared/will appear in *RDS*, *Disability Studies Quarterly*, *Encyclopedia of Disability* (Sage), *Medical Problems of Performing Artists*, *Highway 61 Revisited: Bob Dylan from Minnesota to the World* (University of Minnesota Press), and *Richard Wagner for the New Millennium: Essays in Music and Culture* (Palgrave Macmillan), edited by Lubet, Matthew Bribitzer-Stull, and Gottfried Wagner.

## Book Review

**Title:** Beyond Victims and Villains:  
Contemporary Plays by Disabled Playwrights

**Editor:** Victoria Ann Lewis

**Publisher:** Theatre Communications Group,  
2006

**Paper, ISBN:** 1-55936-250-2, 406 pages

**Cost:** \$19.95 USD

**Reviewer:** Markus Wessendorf

Even though many previously excluded communities, from gays and lesbians to African Americans to Chicanos, have successfully made inroads into established American theatre since the 1960s, this has not been the case for playwrights with—and writing about—disabilities. While many disabled theatre artists have found a niche in stand-up comedy, performance art and the occasional grassroots theatre group, disabled writers using the traditional genre of drama to represent disability issues rarely see their work produced or performed by major theatrical institutions.

Victoria Ann Lewis, the founder and past director of Center Theatre Group/Mark Taper Forum's Other Voices Project, has edited *Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights* to "encourage professional, academic and community-based theaters to produce the plays included" (xv). Lewis's anthology covers a wide range of American and Canadian plays that were written by disabled dramatists between the 1960s and 1990s and, with one exception, professionally produced. Only one play in the collection represents dramatic realism: David Freeman's *Creeps*, which is set in the men's bathroom of a sheltered workshop for people with cerebral palsy. Each of the other plays combines various dramatic styles and techniques: realism and epic theatre (Lynn Manning's *Shoot!*), surrealism and expressionism (Susan Nussbaum's *No One as Nasty*), vari-

ety show and postmodernism (Charles L. Mee, Jr.'s *A Summer Evening in Des*, and P.H. \*reaks: *The Hidden History of People with Disabilities*, a collaborative project developed and adapted by Doris Baizley and Victoria Ann Lewis herself). In addition, the anthologized plays relate the experience of disability to a wide range of themes and concerns: racial discrimination and violence (*Shoot!*), the carnivalistic celebration of multiple body types beyond restrictive notions of normality (*A Summer Evening*), representations of disability throughout history (P.H. \*reaks), the struggle for independent living (John Belluso's *Gretty Good Time*, *Creeps*, P.H. \*reaks), relationships and sexual expression (Mike Ervin's *The History of Bowling*, P.H. \*reaks, *Gretty Good Time*), and the dependence on personal assistants often complicated by issues of class and race (*No One as Nasty*).

In her introduction to the anthology, Lewis provides valuable background information on the social, political, and legislative struggles of the disability community that have informed the included plays. Since *Beyond Victims and Villains* was published by TCG, the national organization for American non-profit theatre with more than 440 member theatres in 47 states, it can be hoped that more community and regional theatres will take note and change their attitude towards producing plays by disabled playwrights. There is a chance that one of the plays included in *Beyond Victims and Villains* will soon open at a theatre near you.

**Markus Wessendorf, Ph.D.**, is Associate Professor at the Department of Theatre and Dance at the University of Hawai'i at Manoa. He is currently working on a book on "Post-9/11 Plays: Critical Engagements with Terrorism and the 'War on Terror' in Contemporary Theatre and Performance." Email: wessendo@hawaii.edu

## Book Review

**Title:** Disability Rights and Wrongs

**Author:** Tom Shakespeare

**Publisher:** Routledge, 2006

**Cloth, ISBN:** 978-0-415-34718 9, 240 pages

**Paper, ISBN:** 978-0-415-34719-8

**E-book, ISBN:** 978-0-203-64009

**Cost:** Cloth: \$125.00 USD, Paper: \$35.95 USD

**Reviewer:** Peter W. Dowrick

As the potential reader may suspect from the play on words in the title, the author has a British sense of humor. Indeed, his book, “re-examine[s] some of the key principles of the British disability rights movement” (p. 198). I recommend reading the succinct chapter 13 “Concluding Thoughts” first, for a perspective on this thoughtful and thought-provoking book. It is generally accessible and well-written, notwithstanding a number of misspelled words and grammatical oddities. Electronic and print versions are available.

The book will, or should, be read by students and scholars in disability studies. That may mean university departments of sociology, public health, psychology, or education. It should, but probably will not, reach most specialized training programs for medically-oriented professionals – although it provides extensive and valuable examinations of the so-called medical model of disability. The book is designed to reach disabled people also, particularly self-advocates, and family members, although it does not compromise on its expectations of the educational background of the reader.

Tom Shakespeare is highly informed – personally and professionally. He identifies his own achondroplasia (“dwarfism,” p. 4), inherited from his father (remarkably named William,

and a physician facing many prejudicial obstacles) and transmitted to his children. He has held faculty positions at Sunderland and other British universities. In this book, he cross-examines most of the strongly held positions of the European disability movements, thus setting up controversy, as announced on the book cover. However, on every issue he looks at all sides, and comes through as a negotiator, effectively identifying the middle ground.

For example, in chapter 9 he considers care, support, and assistance. First, he expresses solidarity with other self-advocates for the goals of maximizing independence and choice, while minimizing abuse and paternalism. He describes the more radical views in the fight to escape care and its often unwanted baggage. Then he emphasizes (at length) the complexity of the debate, including the value of *some* kinds of care, support, or assistance, for *some* circumstances. He offers a complex, “pluralist approach” – which might, in my view, be just flexibility with informed choice.

Chapter 11 is entitled “Love, Friendship, Intimacy.” Dr. Shakespeare seems well qualified on this topic, as a person and as a sociologist, as he is on many of his topics (e.g., Shakespeare, Gillespie-Sells, & Davies, 1996). This chapter is different from the others in that the author offers some how-to information, although more descriptive than procedural. He notes this topic is neglected, even avoided, in mainstream disability studies—although there is considerable literature on it related to people with mental illness or intellectual disabilities.

I have said this book is generally accessible. However, some arguments are long, and include unexplained esoteric terms, such as “medical gaze,” “genealogical method,” and post-structuralism.” The “Conclusion” section at the end of each chapter is helpful, but readers should not expect a summary, rather concluding remarks that often digress into new areas. As always, I would love a version of the book that more

succinctly and directly made its points, and was half as long.

I recommend this book, which is not overall as radical as it is promoted to be. At the end of chapter 2, the author says, “Disability studies would be better off without the social model, which has become fatally undermined by its own contradictions and inadequacies.” These are fighting words in the UK and Europe. But better to read the last chapter before the “Introduction.”

**Peter Dowrick, Ph.D.**, is Professor of Disability Studies and Graduate Studies in Psychology at University of Hawai‘i. Dr. Dowrick received the 2005 Distinguished Contribution to Practice Award of Division 27, American Psychological Association, for his work in prevention and community action. Visit [www.creating-futures.org](http://www.creating-futures.org).

## Reference

Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). *The sexual politics of disability*. London: Cassell.

## Book Review

**Title:** *The Amputee’s Guide to Sex*

**Author:** Jillian Weise

**Publisher:** Soft Skull Press, 2007.

**Paper, ISBN:** 1-933368-52-7, 84 pages

**Cost:** Paper \$14.95 USD

**Reviewer:** Johnson Cheu

It is too bad that there is a paucity of disability poetry out there in the mainstream, that disability arts in general are often underground, found in independent film festivals, and online at artist’s websites; that disabled actors on mainstream television shows playing characters is pretty much reduced to Mitch Longley on

*Las Vegas*, or whatever Daryl “Chill” Mitchell is playing at the moment. In the face of all of this, I imagine that I am not the only one salivating over a new poetry collection by a disabled writer, particularly one with a title as tantalizing as *The Amputee’s Guide to Sex*.

It is not Jillian Weise’s fault that she has to deal with all these expectations, that I enter the collection with a certain *hunger* and that, somehow, at collection’s end, I am left still thirsty, still wanting *more*. But somehow, ironically, also wanting *less*. I was fifty pages into the collection before I read a poem that did not directly invoke a lover, the body, sex, pain, or disability. Of course, what should I have expected from a book thus titled? It is a Catch-22. We want artists to do what they are known for, but also to show, versatility, and growth. That usually means for critics, writing that is somehow outside of yourself, not merely autobiography. Whether that is a fair criticism or not, people make it. Justin Timberlake’s second album *FutureSex/LoveSounds* (2006) is regaled by most critics as showing such growth precisely because it is not as openly autobiographical as *Justified* (2002). Though this is Weise’s first book, it probably says something that my initial read of the book left me saying to myself, “Ok, I get it. Write about something else.”

To be sure, there are gems here, and Weise’s publication record as well as mainstream reviews in places such as *Publisher’s Weekly* certainly speaks to her burgeoning reputation as a poet to watch. When a lover asks, “What does it feel like?” in the poem, “Abscission,” she responds:

“I think of the wives/of the  
twenty-thousand masons/who  
raised the Taj Mahal/...the  
emperor ordered a mass  
amputation of thumbs/so the  
craftsmen could never build/a  
more perfect mausoleum. Did  
their/wives ask questions while  
playing/with the remaining

fingers of their/husbands hands?  
Did they ask, Can/you feel my  
hand here? How about now?”  
(pp. 9-10).

There is great imagery and depth there, certainly enough to keep the interest of disabled and non-disabled readers alike. Likewise, her poetry, at times, exhibits an attention to plain language reminiscent of a Sharon Olds. There's nary a moment where a reader might ask, "Now, what was that poem *about*?"

But why did this book tire me out initially? Mostly, because for a book supposedly about sex, the sex is often cold and sterile. Consider these lines from the title poem: "Mobility shows confidence. Think for/two people. Know where your limbs are at all times; know/where your partner's limbs are at all times" (p. 3). Where is the passion or desire in that? Now, it is quite possible that Weise is saying to the reader, "Hey, look at how medicalized our bodies are. What's wrong with that?" In fact, one could hear these lines as a voiceover of some bad sex training film in rehab or a Veterans Affairs hospital. Indeed, if that is what Weise is doing, forcing a hard look at the medicalization of disability sexuality for either the medical professionals or the general disability reader of this book, then it is a neat hat trick.

In *New York Times* article ("Clearly, Frankly," 2007) Weise is quoted as saying, "I'm hoping that there's a middle ground, that this [disability] is just another kind of difference." Perhaps, Weise has achieved that goal too well. That is, the disability, and the sex therein, becomes not only too procedural, too antiseptic, but also too common, like having sex with any other non-disabled person. As a colleague of mine who was also, coincidentally, reading this book commented, "Surely, there were encounters where people did not know she was an amputee, or perhaps people who even fetishized it?" Where are the poems about those unexpected moments?" The sex here is often rather pedantic. On the whole,

this collection is worth reading for both the breadth of the coverage of its themes, and the detail embodied in Weise's poetic eye. Just do not expect to leave it feeling particularly...uh...passionate.

**Johnson Cheu, Ph.D.**, is a visiting assistant professor in the Department of Writing, Rhetoric, and American Cultures at Michigan State University. Recently, he was the poetry/fiction editor of *Disability Studies Quarterly* and is currently on the editorial board of the *Journal of Literary Disability*. He may be contacted at: [cheu@msu.edu](mailto:cheu@msu.edu)

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## Book Review

**Title:** *Deaf in Japan: Signing and the Politics of Identity*

**Author:** Karen Nakamura

**Publisher:** Cornell University Press, 2006.

**Cloth, ISBN:** 978-0-8014-4350-3, 226 pages

**Paper, ISBN:** 978-0-8014-7356-2

**Cost:** Cloth \$59.95 USD, Paper \$19.95 USD

**Reviewer:** Patrick Kermit

If you look into discussions related to deafness in the western world, you are bound to encounter the distinction between cultural and medical D/deafness. This distinction often

serves as a key example showing how models of disability can be constructed either socially or medically. In most western countries, signing people have found it truly liberating to replace the medical notion of deafness with the notion of belonging to a linguistic and cultural community.

But, what do signing people do in a society where being a linguistic minority historically has been more difficult than being a disabled member of the majority community? Karen Nakamura's book *Deaf in Japan: Signing and the Politics of Identity* starts with this question. The book offers a historical account of the Japanese deaf community from the late nineteenth century until the present. The basis for this account is four in-depth interviews with deaf women from three generations. Their life stories give an abundant view into life conditions for deaf people at different historical periods. The author contextualizes these stories, analyzing both the specific Japanese deaf history (e.g., educational systems for deaf children, the foundation and development of deaf organisations, job opportunities, interpreter services) as well as the general development of the Japanese society.

This is, however, not primarily a historical account. It is a fascinating and groundbreaking anthropological study that should offer plenty of food for thought to anyone interested in the fields of disability research and Deaf studies. The focal point throughout the book is the question of identity. As a Japanese national, raised in the United States, Nakamura is well acquainted with the above mentioned tension between the different notions of D/deafness, and she frequently contrasts Japan with the west. Nevertheless, she never falls into the temptation of taking a normative stance in favor of one notion of D/deafness before the other. This might provoke those who think there is a strict dichotomy between the social and medical models. For the less orthodox ones, however, Nakamura's methodological approach is more compelling. For example, she presents the reader with recent discussions

in the deaf Japanese community about what "true" Japanese sign language is. Similar discussions have occurred wherever Deaf communities debate the implications of the linguistic discovery that signed languages are as full fledged and natural as spoken ones. On the basis of her thorough descriptions, Nakamura manages to contextualize this discussion and analyze it in a way that really grasps the complexity of the matter at hand. In this respect, I would recommend Nakamura to anyone venturing an ethnographic study. She insists on trying to understand and render her informants as they are and not as subjects that can be framed and fitted into certain models.

Nakamura focuses on Japanese deaf society, but I have found the way she deals with questions related to signing and identity highly relevant and challenging for me as a Scandinavian researcher mostly acquainted with Scandinavian deaf communities. There is also a stylistic bonus for those willing to pay the book's moderate price. I think even those with little more than a curiosity for deaf questions or disability studies will find the book easy to read. Nakamura writes in a very accessible style, mostly avoiding academic tribal lingo. I enjoyed reading it and have no reservations recommending the book to others.

**Patrick Kermit** is a doctoral research fellow at the Norwegian University of Science and Technology (NTNU) in Trondheim. He has a degree in philosophy and is also a sign language interpreter. Currently he is working on a project assessing ethical aspects related to paediatric cochlear implantation. He may be contacted at: [patrick.kermit@svt.ntnu.no](mailto:patrick.kermit@svt.ntnu.no)



## Book Review

**Title:** *(my) Dying Is Fun: A Comedy of Disabled Misadventures*

**Author:** Christopher Day

**Publisher:** Trafford Publishing, 2007

**Paper, ISBN:** 1-4251-0622-6

**Cost:** Paper \$19.99 USD

**Reviewer:** Mark F. Romoser

*(my) Dying Is Fun: A Comedy of Disabled Misadventures* is the chronicle of a Welsh eco-architect living with what the British call “motor neurone disease” – ALS. You are probably thinking that the concepts “ALS” and “humor” cannot possibly coexist, except possibly in a rejected episode of *Family Guy*. And you would be wrong. Day has the dry, droll British humor thing down cold. Much of the book reads like what would happen if Monty Python were to reunite and (inexplicably) perform a sketch based on ALS. And as if all this was not enough, Day adds several of his own illustrations. They are not easy to describe in a print review obviously, but suffice it to say that one is captioned “Many washbasins offer a complimentary crotch-washing service” (p. 112).

Do not get so wrapped up in Day’s daily travails that you miss the larger points. For instance, some of the funniest moments in the book come while Day is traveling to Spain for a seminar. That’s right: a guy with ALS, unable to speak and using crutches, is traveling to another country for a professional seminar – and doing so as a matter of course, without any fanfare or sobbing violins. He is also raising two teenagers, who view him as “a walking (in my case, hobbling) cash machine or instant taxi” (p. 67).

Of interest to many will be Day’s descriptions of various forms of therapy he has tried. When conventional medicine throws up its hands and says there is nothing it can do, almost

anything is likely to pop up to attempt to fill the void. And so, Day takes us through a series of treatment regimens ranging from science-fiction electronic devices, developed in the former Soviet Union, to herbal medicine (the required tests alone proved too stressful) to acupuncture (recommended, as long as the therapist is Chinese-trained rather than “new age”) to bee venom and on to stuff with names like “cranial osteopathy” and (I kid you not) “forgiveness therapy” (pp. 120-131). And at the end of the day, Day is rather exhausted, a bit poorer – and still dying.

Any book about the end of life, no matter how much it focuses on the humorous aspects of daily living with a disability, must eventually come around to philosophy. This is no exception: “If life makes any sense, so must dying, for it will almost (?) certainly be part of every life. Life is a terminal condition – we’re all dying, some faster than others. Anyone, therefore, who feels miserable about dying, must feel miserable about living” (p. 167). *(my) Dying is Fun* is definitely not the work of someone who feels miserable about living. This is highly recommended for anyone dealing with end-of-life situations. It offers a rare and surprisingly lighthearted glimpse of the end of life from the point of view of the person whose life is ending.

**Mark Romoser** was diagnosed with autism at the age of 4, by the renowned Dr. Leo Kanner. After attending eight different schools and two colleges, he became a *cum laude* graduate of Yale in 1985. He is employed as the Policy and Program Analyst at Hawaii Centers for Independent Living in Honolulu. He may be contacted at: [markr@pacificil.org](mailto:markr@pacificil.org)

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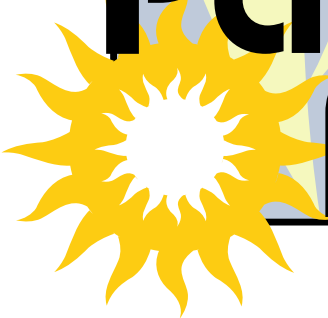
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