

Copyright
by
Chris Anne Strickling
2003

**The Dissertation Committee for Chris Anne Strickling Certifies that this is
the approved version of the following dissertation:**

Re/Presenting the Self:

Autobiographical Performance by People with Disability

Committee:

Ann Cvetkovich, Supervisor

John Slatin

Carol Mackay

Stacy Wolf

Joni L. Jones

Laura Ham Griebel

**Re/Presenting the Self:
Autobiographical Performance by People with Disability**

by

Chris Anne Strickling, B.S., M.A.

Dissertation

Presented to the Faculty of the Graduate School of English

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degree of

Doctor of Philosophy

The University of Texas at Austin

May 2003

Acknowledgements

It took the efforts and support of many friends and colleagues to bring this project to completion, and I want to thank every one of those people. First, I thank Ann Cvetkovich whose intellectual prowess and deep heart guided me through every step of this process. She fought for my admission to graduate school when I was told emphatically by the graduate advisor that I was “not what UT is looking for.” I thank graduate coordinator Jackie Rabinowitz for running out into the hallway that day and catching me by the arm, urging me to ignore what I had just heard. Jackie, I would never have made it without you. Special thanks to Dr. Lisa Moore, who put me in touch with Terry Galloway in 1998, wisely counseled me to make *Actual Lives* the focus of my dissertation and assured me that I could finish. I owe a debt of gratitude to Dr. Rosa Eberly and Dr. Sabrina Barton, who, along with Dr. Cvetkovich, nurtured my nascent formulations into a dissertation prospectus that seems to have stood me in good stead. My fellow graduate students Casey McKittrick and Jodie Sherman Egerton have read drafts for me, asked great questions, and thought through the difficult issues of dissertation

writing. My work reflects and incorporates their generous and intelligent feedback. Thanks to faculty members Carol Mackay, John Slatin, Joni Jones, and Stacy Wolf, as well as my dear friend and colleague Laura Griebel, for serving with such enthusiasm on my committee.

All of my writing arises from the creative work of other people, people I now hold dear. I thank David Roche for showing me what it means to face the world every day with courage, to look prejudice right in the eye with a measured dose of cynicism and an always ready sense of humor. I thank Terry Galloway for the most exhilarating, frustrating, intriguing, moving, mind-expanding, heart-opening, exciting, hilarious, soulful adventure I've been on in a long time. Through our work together with *Actual Lives*, and through the hard-fought friendship that we now enjoy, I have come to know myself and a whole group of adults with disability in ways I never knew were possible. Terry, there really aren't words for it. And to the members of *Actual Lives*, people who have turned my whole head and heart upside down, people who taught me to be suspicious of inspiration and joyful about difference, I extend my deepest gratitude. Those people are: Joyce Dawidczyk, Terri Stellar, Danny Saenz, Meg Barnett, Laura Griebel, Adam Griebel, Celia Hughes, Mike Burns, Rand Metcalfe, Katherine Ann May, Olivia Whitmer, Cheryl Green, Elizabeth Barber, Joby Dixon, Kathleen Juhl, Tori January, Diane Yoder, and Terrell Johnson.

Three friends have come to me as the unexpected gifts of graduate study. Gina Siesing helped me stay in school when I felt like leaving and led me to Tai Chi. Even though she's gone off to Harvard and I'm still braving this darn Texas heat, she's still with me. Alyssa Harad has read chapter drafts, held my hand when I felt bad, laughed with me through the good things, criticized my work when it hurt to hear it (and always been right), struggled with me to start *Grrl Action*, shared holidays and insights for many years and taught me to love high femme. She taught me the difference between "the body" and "my body," and it would have been such a harder road without her. And Susan Somers-Willett, a talented slam poet and creative writer, has been so close sometimes it's been hard to tell whose feelings and thoughts were whose, but we haven't really tried to make those kinds of distinctions anyway. We've fluffed each other up regularly, lovingly shared a tiny space well, and recognized and enjoyed an incredible connection that includes everything from the pure geek joy of thinking about the body in performance in ways that only graduates students can, to the simple tranny pleasures of MAC cosmetics. Tweedles, thank you so much.

Long-time friends who live far away have helped more than they will ever realize. I thank my childhood friend Katie Williams Johnson for being the familiar, forgiving voice on the other end of the phone, 24-7, for years. She teaches me to think about life as art, freely offers incredibly insightful ideas and makes me laugh so hard I lose my breath. Katie, you may be in Colorado, but

you're always here with me. My friends Frank Stovall and Genie Pritchett never stopped believing that I would finish this, never stopped telling me I could do it, and never hesitated to tell me to stop whining and get back to work. Debora Schreiber's cheerful and consistent offer of a listening ear has helped me at several strategic moments along with way, and our continued friendship reminds me how valuable history can be.

Close friends here at home, too, have held steady through my unavailability, my surliness, my disappointments and fears. I have to thank Holly Bell for sustaining the continuity of our friendship and for all those walks on the Barton Creek Greenbelt. Holly, you've refreshed my mind, my spirit (and my pocketbook!) over and over again. "Dr. Jan" Gilbreath has blazed a trail in front of me and showed me that us older women can actually complete a Ph.D. if we are willing to scratch and claw, hold onto each other, and laugh on our way there. Beck Runte and Ann Syptak have seen me through each tiny step, and the Bank of Ann relieved financial pressures this last semester so that I could write. Sometimes I can't believe that I still have the luxury of their friendship. My friends Klaus Koch and Gary Plakias, men who have taught me about wheelchair design and true human kindness, have shown amazingly active interest in *Actual Lives* and in this dissertation. Guys, it's been wonderful to have your input and your interest. And Chester Lyssy, thanks for looking out for me and for *Actual Lives*.

I extend grateful thanks to David Kramer, the best ex-husband anyone could ask for. David helped me believe that it was possible to change careers, and took on extra child care responsibilities when I first returned to UT to pursue graduate education. He's been there every day, all the way, offering solace, constructive criticism, friendship, financial support, whatever it took. David, I owe you big time. Cindy Phillips, the sister I will never deserve, has done everything from run the concession stand at *Actual Lives* performances to mopping up emotional messes that nobody else even understood. Cindy, my successes are yours, too. My daughter, Willa Kramer, came along with me for this whole journey. Maybe that's because if she was going to know me, she pretty much had to. Still, I recognize that she made a choice, and I appreciate what it took to live with a graduate student mom. We've studied Shakespeare together, learned how to read and write critically together, held each other's hands during the hard parts and celebrated all of the little victories, too. Willa, thank you for giving up so much of me for the past eight years. I'm going to make sure you never regret it. And to my partner, Kathleen Claps, I want to say thanks for all the mornings when we sat in our huge bed and drank coffee and thought big thoughts, and felt big feelings, made big plans. I thank you for your creative eye, your willingness to get excited about what I'm doing, for all those late night trips to the office to tell me to stop working and come to bed, for wanting to actually read my dissertation (while, of course, you were doing the formatting on it!). And for

listening to me cry when I felt like it was absolutely impossible to read another book or make another revision, you should be canonized. Thank you for years and years of support and help, and always, always, the encouraging word.

**Re/Presenting the Self: Autobiographical Performance
by People with Disability**

Publication No. _____

Chris Anne Strickling, Ph. D.

The University of Texas at Austin, 2003

Supervisor: Ann Cvetkovich

Representations of people with disability, whether in print media and literature, film, television, or theatre, have traditionally been produced by non-disabled people with varying degrees of exposure to, and knowledge of, the lived experience of disability. The resultant tradition of misrepresentation effectively reduces disabled people to the specificities of their physical or cognitive differences, erasing or rendering invisible the disabled self. Written autobiography by people with disability offers a productive counter-dialogue to this pervasive misrepresentation. Yet, written autobiography is constrained by its very materiality. The body exists outside the text, in much the same way that the disabled body, for many Americans, exists in an imaginary political and social space, devoid of corporeality.

It is into this (relative) void that I place my study of autobiographical performance by people with disability. I argue that in these performative moments, moments in which the self as constructed through narrative competes for recognition with visible difference and disability and the cultural meanings assigned to the marked body, the disabled performer has an opportunity to construct a self capable of a level of agency, integrity and complexity unavailable to disabled people in every day social encounters. This autobiographically constructed and theatrically conveyed self works as a corrective to the long tradition of misrepresentation of disability, literally re/presenting the self of disability to general audiences. Representations of people with disability, whether in print media and literature, film, television or theatre, have traditionally been produced by non-disabled people with varying degrees of exposure to, and knowledge of, the lived experience of disability. The resultant tradition of misrepresentation effectively reduces disabled people to the specificities of their physical or cognitive differences, erasing or rendering invisible the disabled self. Written autobiography by people with disability offers a productive counter-dialogue to this pervasive misrepresentation. Yet, written autobiography is constrained by its very materiality. The body exists outside the text, in much the same way that the disabled body, for many Americans, exists in an imaginary political and social space, devoid of corporeality.

It is into this (relative) void that I place my study of autobiographical performance by people with disability. I argue that in these performative moments, moments in which the self as constructed through narrative competes for recognition with visible difference and disability and the cultural meanings assigned to the marked body, the disabled performer has an opportunity to construct a self capable of a level of agency, integrity and complexity often unavailable to disabled people in every day social encounters. This autobiographically constructed and theatrically conveyed self literally re/presents the self of disability to largely non-disabled audiences.

In separate chapters, I examine facially disfigured performer David Roche's *The Church of 80% Sincerity*, deaf performance artist Terry Galloway's *Out All Night and Lost My Shoes* and performances by disabled performers in the *Actual Lives* Performance Project of Austin, Texas to identify the ways in which the autobiographical self is constructed and performed. I theorize each performance's ability to meaningfully re/present the disabled self. As examples of disability-identified autobiographical performance emerging from vastly different social and cultural positionings, these works have specific utility for the study of autobiography, for performance studies and Disability Studies, and for cross-over into ongoing medical and social discourses of disability. I argue for the inclusion of issues of disability into theoretical works on identity and the body and for the centrality of Disability Studies as an important area of inquiry in the humanities.

Table of Contents

Introduction, Setting the Stage	1
Misperceiving Misbehaving Bodies	2
(Mis)Representation	3
Re/Presenting Disability	4
From Stereotype to Trope.....	6
Making a Self Through Autobiography	10
“Autobiographical Self”	11
Presenting the Autobiographical Self through Disabled Performance.....	16
A “Courtesy Member”	20
The Performances.....	22
Art and the Autobiographical Self.....	28
Chapter 1 <i>Actual Lives</i> : Cripples in the House	37
Art and the Autobiographical Self in <i>Actual Lives</i>	39
Defining Disability	41
The Body's “Meaning” and Social Drama.....	42
Confronting Issues of Spectacle	46
Constructing Content	48
Performance of Disability as Identity	49
Managing Interactions	51
Twice Behaved Behaviors	54
Commenting on Cultural Attitudes: Talking Back	57
Resexing the Disabled Body	62
The Body/Self on Stage	65

Life Beyond “First Stories”	70
Chapter 2 <i>The Church of 80% Sincerity: from Stigma to Stigmata</i>	72
The Art of <i>The Church of 80% Sincerity</i>	70
Embodying Metaphor.....	75
The “We” of Collective Identity.....	76
Fear and Loathing: “Igor” and Other Body Anxieties.....	79
The Body as Psychic Aspect	82
Facing the Corporeal Body.....	84
The Freckle Lady and the False Self	86
The Risks of Metaphor	89
Memory as Meaning-Making: “Instances of Cruelty” and “Moments of Grace”	93
From Catechism to Communism.....	96
The Universal Experience of Embarrassment	98
Modeling Accommodation.....	100
Troubling Transformation	103
Erasing Difference.....	105
Representing Disability	107
Chapter 3 <i>Out All Night and Lost My Shoes</i>	113
Galloway's Art of Autobiography	117
A Fake Mistake.....	119
What Happened to You?	123
“By the Time I was Twelve, I was a Freak”	125
People Love Their Freaks.....	129
Jake Ratchett: Short Detective.....	133
The Etiquette of Suicide	138
Moments of Near Suspense.....	141
Mr. Handchops	143
Africa.....	150

Strategies	151
Cultural Capital: It's Not All About Money	154
Epilogue.....	157
From Here, Where?	163
Bibliography	166
Vita	174

Introduction

Setting the Stage

Not long ago, my friend Joyce had a disturbing experience on a city street. Joyce is a white woman with cerebral palsy, in her late forties, who uses a power wheelchair. Sometimes she sits perfectly still in her wheelchair, but there are times when just the jostling of the chair on the sidewalk, or the bounce of her wheelchair on the bus lift, can send her limbs flying. It was one of those days.

On her way to catch a bus, she approached an intersection and slowed to a stop, and then heard the sudden honking of a car horn. She looked up to see a middle aged white woman in a white sedan gesturing toward her, honking the car horn loudly and repeatedly. Joyce checked her own position on the sidewalk and stayed put. When the traffic began to move again, the woman in the car went on her way. Joyce crossed the street to her bus stop, and didn't think much more about it.

Moments later, she began to hear a distant siren, and as it grew louder, she could see that the sound was coming from an ambulance. Where was it going? It pulled up right at her bus stop, and a medic got out, walked toward her and put his hand on her shoulder. "You ok?" he asked. "Me?" Joyce questioned. "Yes, you," he said, "a lady called and said there was someone out here who needed an ambulance."

A long 20 seconds went by, then Joyce began to explain that she was just fine, but her speech impairment made it difficult for the medic to understand her. She did finally make herself clear, and insist that she was not going with him in the ambulance. When she called me later that day to relay this incident, she said, "Well, I guess I'm not a person at all anymore, I'm a medical emergency."

MISPERCEIVING MISBEHAVING BODIES

In this encounter, a disabled woman's simple act of independently accessing public transportation is misperceived as the dangerous exposure of an unruly body that is out of place on the street. To the woman in the car, Joyce's body "belongs" inside, away from public view. Viewing Joyce solely as representative of the socially abject, the driver uses Joyce's disability as a sorting mechanism which separates her own culturally acceptable body from the different, deviant, disabled body she sees before her, putting Joyce in her "proper place" in the body politic.¹

In an instant, Joyce's disabled body accrues social meanings over which she has no control, and her body imagined as "other." Butler argues that "from this belief that the body is Other, it is not a far leap to the conclusion that others are their bodies ..." (*Variations* 133). Butler is speaking about disembodiment in terms of gender in this passage, but I believe that her idea about the easy slippage from viewing "the body" (as a materialized perceptual construct) as "other" to viewing cultural others primarily as bodies has particular resonances with the

¹ See Sidonie Smith, *Subjectivity, Identity and the Body*, page 10 for a description of this process of sorting by physical characteristic.

process whereby people with disability are stigmatized. If the bodies of disabled people are considered culturally “other,” and I believe they are, it is easy to see how disabled people come to be viewed *as their bodies*, a process that takes place at the cost of subjectivity for people with disability.² Living with atypical embodiment carries with it, at least in contemporary American culture, the very real risk of being mis-identified on a daily basis and reduced to the cultural meaning (and value) of difference. When the disabled body stands in for the “self” in a cultural context in which the disabled body is negatively valued, the disabled self risks similar devaluation or even erasure.

(Mis)Representation

Of course, no one can rob Joyce of her sense of self, but the act of misperceiving her so completely means that the actual disabled person in this scenario has been displaced by an *idea* about disability. And that idea arises from a misperception that is fueled by misrepresentation and persists because of the very real social disconnect between disabled people and their non-disabled fellow citizens. In his book *No Pity*, journalist and disability advocate Joseph Shapiro discusses the gap between the way disabled people view themselves “and the way others insist on seeing them” (vii), a gap that produces this kind of encounter. This gap originates from social distance and unfamiliarity. The disabled body, for many Americans, exists in an imaginary political and social space, without

² I use the term “disabled people” interchangeably with the more politically correct formulation, “people with disabilities.” I am influenced in this decision by my colleagues in Disability Studies who recognize “people with disability” and “person first language” as a euphemistic device employed by professionals who are uncomfortable foregrounding disability as it relates to identity.

corporeality. Take, for example, the case of modifications to public buildings designed to insure access to the disabled. The ramped entryways are in place, the bathroom modifications have been made, but the disabled body is often not present. Non-disabled Americans have made physical accommodations for people who are still largely invisible to them, while continuing to retreat from personal relationships with disabled people.

Social disconnection allows stereotypical images of disabled people to go largely unchallenged, since for many Americans representation replaces relationship when it comes to disability. Representation is how we come to “know” about people in our society with whom we have little actual contact. And that knowing through representation is particularly troublesome in the case of people with disability because most representations of disability are produced by non-disabled people and fail to reflect or reveal the complex realities of living with disability.

RE/PRESENTING DISABILITY

In this project, I examine three works of autobiographical performance by people with disability in terms of how each performance constructs and deploys an autobiographical self, and to what ends. I use the *Actual Lives* Performance Project as an example of ensemble work by disabled adults, and examine facially disfigured performer David Roche’s *The Church of 80% Sincerity* and deaf performance artist Terry Galloway’s *Out All Night and Lost My Shoes* as solo

works. I argue that autobiographical performance by disabled people constitutes a corrective to the long tradition of mis-representation in literature and theatre. Or at least it has that potential. As America's freak show tradition has shown us, the simple act of putting the disabled body on stage does not necessarily produce representation that reflects the complex subjectivities of the people who inhabit such bodies. In the performance of autobiographical narrative, however, disabled people have the opportunity to represent themselves, an opportunity that offers the possibility of exceeding the socially imposed identities that accrue to them because of their embodiments. The ability to re-narrate lived experience through the construction of autobiographical narrative allows the disabled performer to create a performative self that is empowered to talk back to medical and social discourses that so often silence people with disabilities.

In the act of combining autobiographical narrative with the physically available disabled body in performance, two important effects are achieved. First, the specificity of performed autobiography creates a representation of a living person, which works against the kind of displacement that Joyce experienced on the street. The voice and presence of the "real person," speaking from the disabled point of view presents a radical alternative to stereotyped images of the disabled. In the introduction to *O Solo Homo*, lesbian performance artist Holly Hughes discusses the fact that in solo performance work, the audience knows that the performer is also the writer, and that what happens onstage is likely to have

“really happened.” This “realness,” which is also an aspect of solo and ensemble autobiographical performance, decreases the emotional distance between performer and audience, and a certain level of safety is lost to the audience, since they “can’t hide behind ‘It’s only art’” (4). This increased intimacy works to the advantage of the disabled performer by reducing the already substantial social distance that must be negotiated in encounters between disabled and non-disabled people. And, just as significantly, performers have the opportunity to own their disability in a situation of relative empowerment, instead of denigration. In all of the works I examine here, performers report that by enacting their autobiographical narratives through performance they try on new identities and experience an increased awareness of their own agency. What they do in performance has a positive impact on their daily lived experience.

From Stereotype to Trope

To understand the importance of these claims that disabled performance can counteract a tradition of misrepresentation that so captures the imaginations of those who are unfamiliar with disability, it seems useful to briefly explore the mechanisms through which disability is misrepresented. In her important work, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, Rosemarie Garland-Thomson illustrates how misperceptions about disabled people move into the cultural imagination through literary representation.

Disabled figures in literature are routinely presented “as fashioned corporeal others whose bodies carry social meaning,” instead of people with “atypical bodies in real-world social relations” (15). In the absence of more realistic depictions, disability is constructed in the non-disabled imagination more by received knowledges about disability than by actual interactions with disabled people. In this way, “the discursive construct of the disabled figure” circulates in culture and “finds a home within the conventions and codes of literary representation” (9). The constructed image stands in for, and often displaces, the embodied disabled subject in literature, just as it does in “real life.” Further, “stereotypes in life become tropes in textual representation,” creating and preserving literary figurations of disability that move from perceptual category (disabled) to stereotype (unable, ineffective, morally reprehensible, demonic) to caricature (Dickens’s “Tiny Tim” from *A Christmas Carol* or J.M. Barrie’s “Captain Hook” from *Peter Pan*) (*Extraordinary* 11).

Representations of disability in American film have added to this fund of cultural misunderstanding. Martin Norden, in an essay entitled “The Hollywood Discourse on Disability,” provides a brief history of disability film depictions divided into three periods. He characterizes images of disability in films made between the late 1890s and the mid 1930s as “exploitative” – with disabled men configured as “comic misadventurers,” and disabled women and children viewed as docile innocents (Smit 22).³ From WW II until the 1970s, film images of disability became more “exploratory” in that disability became a major life issue

³ As examples, see D. W. Griffith’s *Orphans of the Storms* (1921), *The Unknown* (1927), and Tod Browning’s *Freaks* (1932).

to explore and “overcome.” Disabled vet films such as *Pride of the Marines* (1945), and *The Men* (1951), and “civilian superstar” films such as *The Other Side of the Mountain* (1978) explored the tragedy of disability and celebrated triumph over it (23). Norden describes film images of disability since the late 1970s as “incidental,” offering characters with disability who go about the business of their daily lives. I would add that since the mid 1990s, especially in films targeted for teenagers and young adults, disability has become commodified and exploited for its visual reinscription of the unattainable normative body. Farrelly Brothers films such as *Me, Myself and Irene* (2000) and *Shallow Hal* (2002) use racially marked or otherwise “othered” disabled figures in a return to a freak-show level of display and spectacle as a way to redefine white, male heteronormativity. Norden notes that many people formulate their ideas about disability based on images they have seen in movies, and that moviemakers also get their ideas about disability from movies, which perpetuates a cycle of misunderstanding (2).⁴

At least in theory, since theatrical narratives are predominantly fictive, it would be reasonable to expect that theatre might allow for the construction of liberatory representations of disabled people. Yet theatre has its own limitations and vulnerabilities. Unlike the relatively fixed texts of film and literature, the performed theatrical text can disintegrate at any moment; there are no re-takes or edits. There is always the risk of failure, a risk that the disabled body, present in the performing moment, has already come to signify. Theatrical performance is a

⁴ See Norden, Martin, *The Cinema of Isolation: A History of Physical Disability in the Movies* for a detailed account of images of disability in film.

way for audience members to experience, in some small measure, the kind of vulnerability and risk that disabled people face routinely, on and off stage.

Theatre, however, has a tradition of using disability primarily for its cultural meaning-making potential. According to Victoria Ann Lewis, founder of the Mark Taper Forum's *Other Voices* project, the problem of disability representation in theatre is not that disability is under-represented, but that most depictions of disability reinscribe an outdated "dominant narrative of disability" that rarely attempts to portray disability as a real lived experience (Lewis 93).⁵ Instead, traditional theatre uses disability to signify everything from moral depravity (Shakespeare's *Richard III*) to saintly innocence. Lewis identifies the equation of physical difference with evil or moral shortcoming and/or with saintliness as "dramaturgically useful," which partially explains why "the twisted body, twisted mind" approach to characterization has become a stable element in American theatre (94). And because this kind of metaphoric association is such a stable element of theatre practice, whenever the disabled body takes the stage it *already* has a meaning – a meaning that the performer must confront in order to creatively re-invent a subject.

Performance art, as theatrical performance partially unleashed from traditional theatre constraints, makes space for the kind of self-representation that people with disability need. Grounded in identity politics, performance art developed as a public platform for working out issues of sexuality, gender conformity and sex role expectations. It has been an important aspect of AIDS

⁵ As well as outlining specific dramaturgical strategies for disabled theatre, Lewis provides a useful short history of plays and performances by disabled people in this essay.

activism, and offers a mechanism for developing performative selves that speak directly to the institutions and practices that affect performers.

MAKING A SELF THROUGH AUTOBIOGRAPHY

My work assumes that autobiography has to do, most basically, with constructing and conveying a “self” through a literary text which can exist as written or oral text and/or performance, and it is this re-narrated self which has the potential for disrupting and dislodging old and untenable stereotypes about disability. In fact, over the last ten years, written autobiography by disabled people has brought new models of disabled selfhood to the cultural mainstream. Singular autobiographical narratives like Stephen Kuusisto’s *Planet of the Blind*, Nancy Mairs’ autobiographical essays in *Carnal Acts*, Lucy Grealy’s *Autobiography of a Face*, and reporter John Hockenberry’s *Moving Violations: War Zones, Wheelchairs, and Declarations of Independence* have focused critical attention on disability and received significant readership. Anthologies such as Kenny Fries’ *Staring Back: The Disability Experience from the Inside Out* and *With wings: an anthology of literature by and about women with disabilities*, edited by Marsha Saxton and Florence Howe, assemble autobiographical narratives from people living with disability which present complex and well articulated narratives explaining their various class, economic, physical, medical, social, emotional, sexual and interpersonal experiences.

Disabled writers produce autobiographies as a way to narrate themselves into the cultural imagination, despite the difficulties of the process. Thomas

Couser, author of *Recovering Bodies: Illness, Disability and Life Writing*, theorizes that what compels a person with disability or illness to write about their life is a disruption of “the apparent plot of one’s life” (5). The expected “comic plot” of autobiography, comic in the sense that all the big, thorny issues are resolved through a narrative of triumph over adversity, may not be available to disabled people. Bodily dysfunction and difference, especially chronic, life-long disability or illness, “tends to heighten consciousness of self and of contingency” and urge autobiography (5), yet many who have significant illness or disability cannot produce autobiographical narratives because of the real constraints on their bodies (including not being physically able to write or use a computer keyboard, having insufficient energy to sustain long periods of mental focus, or scheduling writing time around work, medical procedures, and appointments).

The production of an autobiography also requires material resources. The very embodiment that prompts autobiography can also prevent its production. As Couser admits, “In cases of severe impairment living a life may be hard enough; writing a life may prove impossible” (182). Yet people with disability do write autobiographies, producing self- representations that contribute to a more complex representation of disability and participating in what Jerome Bruner, in “The Autobiographical Process,” calls a “general and perpetual conversation about life possibilities” (41).

“Autobiographical Self”

Autobiography is written with the belief that there is a self to be represented, a self constituted as a speaking subject. I want to trouble the familiar notion of a singular, cohesive, autonomous self of autobiography by exposing three aspects of the “autobiographical self” revealed through autobiographical performance by people with disability.

First, the autobiographical self should not be viewed as stable and autonomous, but emergent and relational. The idea that the self is continuous over time is a fiction, one that autobiography often perpetuates through the use of the first person “I,” which places the here-and-now speaker in an assumed continuity with past selves, which “masks the disruptions of identity produced by time and memory’s limitations” (Eakin 93). Because “disruptions,” such as changes in physical or cognitive function as a result of disability, or shifts in social position, can actually be productive in terms of identity, creating space for discontinuities of the self as part of autobiographical practice seems important to disabled autobiographers. Additionally, much of autobiography privileges what Paul John Eakin, in *How Our Lives Become Stories*, calls “the myth of autonomy,” or the idea that individual autobiographers possess their own lives (and certainly their narratives about them) in a kind of “possessive individualism” that denies the individual’s involvement with, even dependence on, others (61). This kind of individualistic narrative positioning has important ramifications for disabled people because it belies the positive dynamics of interdependence that disability advocates are struggling to make visible.

Second, working against the Cartesian model of disembodied subjectivity in which the autobiographical “I” is seen as equivalent to “mind,” I view the autobiographical self as necessarily embodied, whether the autobiographer is disabled or able bodied.⁶ We commonly consider our “selves” to be comprised of a loose association of physical properties (such as height, weight, skin color, biological gender) and psychological or mental characteristics or experiences (intelligence, the emotional experience of compassion, the auditory experience of hearing music).⁷ Even in this relatively simple configuration of the physical and mental aspects of the self, it is hard to ignore the connections between bodily and mental or psychological experience. Consider the physical basis of hearing and vision, and the complex ways in which the brain turns sensory information into perception, which drives bodily action and cognitive interpretation.⁸ Using information from our sensory systems, we develop an awareness of bodily experience, which is the beginning of self-awareness.⁹ The body, then, could be considered as “the neural substrate of self-hood” (Eakin 30).

This idea of a neural substrate for selfhood finds fuller expression in the work of neurologist Antonio Damasio, in his *The Feeling of What Happens: Body and Emotion in the Making of Consciousness*. Damasio develops a

⁶ Elizabeth Grosz offers a well-articulated response to the Cartesian dualism of mind/body in Chapter 1, “Refiguring Bodies,” of her book, *Volatile Bodies: Toward a Corporeal Feminism*. She insists that bodies “have all the explanatory power of minds” (vii) and comprise “the very stuff of subjectivity” (ix).

⁷ See “Self-Consciousness and the Body: An Interdisciplinary Introduction” by Naomi Eilan, Anthony Marcel and Jose Luis ú in *The Body and the Self* for an extended discussion of this model of self.

⁸ See Damasio, *The Feeling of What Happens*, Chapter 8, “The Neurology of Consciousness” for more on the body and perception.

⁹ See Damasio, Chapters 1 and 2 for more on bodily experience as the foundation of consciousness.

neurobiological account of selfhood that hinges on creation and deployment of an “autobiographical self.” In Damasio’s model, the autobiographical self is the self linked to identity, and it consists of awareness of relatively stable “facts” of an individual’s life: who you were born to, where, when, likes and dislikes, usual reactions to a problem (17). The autobiographical self relies on a type of autobiographical memory, which he defines as the brain’s “organized record of the main aspects of an organism’s biography” (18), to help us formulate a self that makes sense to us. Damasio’s autobiographical self mediates between the lived past (through memory) and the anticipated future (by constructing expectations for the future from the memories we have), helping us decide how to respond to the present (224). It is this autobiographical self that makes decisions in the moment, evaluates previous actions and events, and allows us to imagine new possibilities.

I am drawn to Damasio’s work not because I want to privilege the voice of neuroscience (though I admit to a certain fascination with a biologically based paradigm of autobiographical selfhood), but because it is the most coherent explanation I have discovered of the ways in which the body constitutes, or at least substantially contributes to, the “autobiographical self.” To establish an autobiographical way of knowing that is essential to the self and based on knowledges and processes of the body is to posit that all autobiography is inflected by embodiment. It leads us to the notion that people who live their lives in atypical bodies may have something interesting to share with nondisabled people in terms of written and/or performed autobiography, that disabled

subjectivity is not only determined by social and cultural paradigms, but by the experience of living-in-the-world in a specific body.

Third, the self of disabled autobiography is a narrating self, which exists long before a single word is written. In fact, written (or performed) autobiography is only a small part of the self-narrating process in which we engage daily. In the daily act of self-narration, by which I mean the making of a narrative or the constructing of a “story” from the events or feelings of the day, we form our identities – we make meaning out of the random (and not so random) events of everyday life. Identity takes shape in the purposeful inclusion and specific exclusions of that story making, and allows us to present ourselves to others, exchanging identity narratives as a way of knowing each other. Self-narration seemingly confirms that identity is in working order, and this performance “easily becomes a primary criterion for normalcy” (Eakin 11). For those who cannot narrate themselves into identity, the autobiographical self is not accessible.¹⁰

When faced with the task of writing and/or performing an autobiographical narrative, we arrange and modify those self-stories we have told ourselves and others in much the same way that our body does in the act of remembering, creating new narratives of identity.

¹⁰ Eakin, responding to Sidonie Smith’s work on the subjectivity of non-verbal children with autism, states that “It may well be the case that the narrative model of identity that forms the bedrock of interpersonal relations in human communities is more like a piece of necessary cultural equipment than an ultimate psychological reality, something we need in order to get on with the business of living as we have been socialized to understand it” (127).

PRESENTING THE AUTOBIOGRAPHICAL SELF THROUGH DISABLED PERFORMANCE

I am specifically interested in performed autobiographical selves because in performance the self-narration of autobiography is translated into public disclosure when the emergent, relational, embodied self takes the floor to speak and perform. Unlike the textually produced autobiographical self, this performative self has a voice, a narrative, and a body that is present in the moment and difficult to deny. The autobiographical self of disabled performance enacts its multiplicity, demonstrates its complex relationships to people and to social paradigms, and insists on a recognition of the body.

Performance is a way to breathe the life of the body into the word, to create or re-create a self capable of representing the lived experience of the performer. It has to do with “liveness,” which refers to the body being present in the moment (Auslander 196). For the purposes of this discussion, “live performance” refers to an embodied, present-in-the-moment person intentionally performing some act before an also embodied, present audience. Live performance art allows a performer to take up space, and privileges the performer’s voice and/or point of view. Live autobiographical performance emanates from and responds to personal experience, expresses longings for new or different ways of being, or critiques the cultural myths and practices that delimit personal experience. For disabled people, performance – as a site of subjectivity in which the disabled point of view is privileged and through which the disabled body, voice and narrative assumes center stage – can be transformative. My formulation of performance does not preclude the use of

written scripts, or theatrical techniques, but specifically excludes the practice of “acting” as fictional characters in traditional plays. Autobiographical performance, as I use it here, means “refusing the conventions of role playing” (Diamond 3), choosing, instead, to present your *self* on stage, however imaginatively.

Disabled performance art puts the bodies and the voices of disabled people front and center before an audience without apology, which is quite an accomplishment in itself, considering the current cultural investment in physical beauty. Garland-Thomson theorizes that the disabled body in performance is a reenactment of “the primal scene of disability in which the normative viewer encounters the disabled body and demands an explanation” (*Staring* 334). When the disabled body presents itself, according to Garland-Thomson, it is “not only the medium, but the content of performance”(334). The exchange between audience and visibly disabled performer takes the form of a “stare-and-tell ritual” in which the presence of the disabled body functions as visual spectacle and evokes the stare. That stare indicates that the primary function of the disabled performer is to answer the viewer’s question: “What happened to you?” (*Staring* 334).

It has been my experience that autobiographical disabled performance art is indeed compelled to provide an answer to the “What happened to you?” question, a question with which all of the performances I examine quite consciously engage. However, as I see it, performance of autobiographical material by disabled people goes well beyond answering that pervasive question,

and the body is not always both the “medium and the content.” Instead, the body (as medium) shapes the content, but the content also carries with it the possibility of a self-narration that exceeds the confines of the social meanings assigned to disabled bodies. Through the kind of re-narrating lived experience that autobiography requires, “performative selves” are generated. I hope my work here will illuminate the cultural impact of producing these performative selves, which have (at least) the potential to exceed the confining narratives of alienation, isolation, abjection and lack of agency that determine identity for many disabled people in current American culture. It is the goal of this project to add to Garland-Thomson’s formulation of the cultural function(s) of autobiographical performance by disabled people by identifying and specifying narrative strategies and performative outcomes in the works I examine.

There is a “tradition” of autobiographical disabled performance art, though the field is small. Neil Marcus’ autobiographical play *Storm Reading*, which premiered in 1988, is recognized as a benchmark in disability-identified performance art. Marcus, who calls himself the “fantastic spastic,” performs his work in two acts with Rod Lathim, assisted by Roger Marcus, all of Access Theatre.¹¹ *Storm Reading* has been performed over 200 times in the US and England since then. Disabled poet and activist Cheryl Marie Wade produced her signature performance *Sassy Girl: Memoirs of a Poster Child Gone Awry* in 1994 at the Brava Theater Center in San Francisco. Wade continues to perform autobiographical prose and poetry. Irish performance artist Mary Duffy travels

¹¹ *Access Theater* of Santa Barbara, California was a leading force and pioneer in making the arts accessible to people with disabilities. It closed in 1996.

extensively in the US and abroad performing an autobiographical piece that critiques the medical and social scrutiny that her “sensationally abnormal body” (*Staring* 335) receives. Other artists include Julia (Dolphin) Trahan (performing *Julia’s Body*), Bob DeFelice (who proposes an exercise video entitled *Crip Sluts in Spandex*), Jaehn Clare (*Tail Tell Tale*), Greg Walloch (*White Disabled Talent*), Steve Parks (*Fucking Handicapped Guy*), and David Roche (*The Church of 80% Sincerity*), the focus of Chapter Two. I am interested in the way in which Roche, who is facially disfigured, negotiates membership in the group of “disabled performers” (since his disability is primarily aesthetic), a line of inquiry that I pursue in my treatment of his work.

All of the autobiographical disabled performance art that I have reviewed emerges from the desire to educate and communicate, and to narrate a self into existence that has the kind of complexity, agency and potential that disabled people are often denied in day-to-day experience. Their performances are a way to imagine a new world.

Performance also draws audiences who share a similar desire to re-imagine. As theatre theorist Jill Dolan explains:

I go to theatre and performance to hear stories that order, for a moment, my incoherent longings, that engage the complexity of personal and social relationships, and that critique the assumptions of a social system that I find sorely lacking. (456)

If spectators come to autobiographical performance by disabled people looking for critiques of social practice, ready to hear about desire, to expand their ideas about disability and the body, or pause for a moment to consider the meanings of their own embodiments, they will not be disappointed.

A “COURTESY MEMBER”

I am what Erving Goffman in *Stigma: Notes on the Management of Spoiled Identity* has called a “courtesy member” of the “stigmatized group” known as people with disability (28). Since I do not have a disability, I “belong” in disability culture by a process not of identification, but affinity, or “conscious coalition,” a term I borrow from Donna Haraway.¹² I came to this dissertation project as a result of working with deaf performance artist Terry Galloway in a course at the University of Texas at Austin during the 1998 Fall semester. Galloway entitled the course “Actual Lives: Aging, Gender and Disability.” Just the title set my head on fire. From the course description, I imagined a community of people with and without disability, who could share experiences with aging, disability, gender and sexuality and learn how to perform those stories.

After twenty years as a clinical occupational therapist, I needed that community. Discomfort with my relationship to disability made me eager to share a more personal process with disabled people, and I already knew many people whose self-narrations had enriched my understanding of how disability affected their position in culture, and mine. In my identities as queer and aging, I was intrigued by the possibility of meeting others who shared my interests and concerns. As it turned out, though, there were no “aging” students except for me, and nobody who claimed disability as an identity, but the class prompted an

¹² See “A Manifesto for Cyborgs,” page 182.

extended discussion with Galloway about the possibilities of offering *Actual Lives* to disabled people.

To fulfill the class requirements, I wrote and performed a 20-minute monologue that re-narrated deeply troubling events in my early life through the sometimes comic lens of memory and in the position of speaking subject, instead of silenced child. Performing this revisionary version of my life experience before an audience, putting my body behind those words and rendering public what had so long been private, made me even more certain that I wanted to bring that experience to people with disability. The whole process changed my life.

And it almost ended my graduate career. By the spring of 1999, Galloway and I were scheming long distance from our respective homes in Florida and Texas, to make this opportunity available to people with disability. For the next year, most of my time was spent raising money, recruiting performers and finding non-profit sponsorship for our *Actual Lives* project in Austin. I was finished with coursework, all of my advising faculty members were on sabbatical out of state, and I was almost literally out the door of the academy, focused on getting this project (and a similar one for young girls from different socio-economic and ethnic backgrounds, called *Grrl Action*) up and running. In August of 2000, Galloway and I held the first *Actual Lives* Performance Project summer workshop. Designed to be a one-week project, it continues to develop and change, and the group has become a de facto performance ensemble. I decided to make autobiographical performance by people with disability the focus of my

dissertation, knowing full well that if I didn't, I was never going to write a dissertation at all because *Actual Lives* had taken over most of mine.

Dividing my time between community based work with *Actual Lives* and a serious intellectual inquiry into the issues that it raises has proven to be a much richer experience than doing either exclusively. My academic coursework prepared me to imagine this dissertation project, gave me the theoretical tools to pursue it, and has informed the work with *Actual Lives* every bit as much as *Actual Lives* has informed my dissertation project. By analyzing the solo works of Roche and Galloway, I have expanded my understanding of autobiography, of disability, and certainly of performance, and developed productive working relationships with them along the way.

THE PERFORMANCES

All of the performers I study here have self-identified as disabled, using their own criteria for what constitutes disability and expressing a range of identificatory practice. All of them declare their work to be autobiographical, though autobiography takes different forms in their performances. I am interested in how their self-stories come to be constructed, what their stories tell us about their lived experience of disability, and what happens to them and to their audiences when these stories are expressed through live performance.

In Chapter One, I examine the *Actual Lives* Performance Project of Austin, Texas as an example of ensemble performance by people with disability that creates an onstage disability community and articulates the process of

assuming (or refusing to assume) disability as an identity. My reading of *Actual Lives* is fundamentally optimistic, and my personal involvement with it creates both a breadth of knowledge about the work and an undeniable bias. *Actual Lives* uses performance as a vehicle for identity politics, while continuously striving to be good art. The performance material emerges from a page-to-stage workshop format in which participants write from their experience and then translate those writings into performance. I argue that these performances, arising out of the experiences of living in the world in atypical bodies, create the possibility of talking back to dominant discourses of disability that impact their daily lived experiences. *Actual Lives* also demonstrates the tension inherent in attempting to locate disability in the culture (instead of define it as a personal, medical tragedy or problem) through performance of resistant narrative, while simultaneously presenting the disabled body onstage, available as visual spectacle. I identify five performance strategies that shape the individual works of *Actual Lives*, as a gesture toward development of an aesthetics of disabled performance art.

David Roche's signature autobiographical work, *The Church of 80% Sincerity* is the focus of Chapter Two. This monologue exemplifies autobiography's conventions of memory and re-narrating events. Roche, who has facial disfigurement, identifies and then envisions alternatives to the stigmatization he faces, figuratively installing himself as the head of a cynically revisionary humanist "church." Roche's work is controversial because of his precarious identification as disabled and his willingness to engage in metaphoric associations with the dichotomous concepts of monstrosity and sanctimony. That

willingness leaves him vulnerable to the trap of “personal canonization,” through which a disabled character’s personal identity is rehabilitated (or in Roche’s case, “transformed”), in a way that lets audiences off the hook for their complicity in disabling social prejudices which reiterate disability as a personal tragedy. I hope to make clear how autobiography intervenes in this problem of content to make Roche’s work useful as a contribution to disabled performance, and for what audiences.

Chapter Three presents deaf performance artist Terry Galloway’s solo autobiographical show, *Out All Night and Lost My Shoes*, as a work that incorporates multiple identifications and disidentifications to formulate a multifaceted autobiographical self that illuminates the interfaces of gender, sexuality, class and disability. Her performance is based as much on imagination as on memory, with less specific ties to actual events and more intentionally imaginative, or fictional, confrontations with gender roles and cultural expectations. This solo work comically “freaks” Galloway’s coming-of-age process to show the tensions inherent in both lesbian and disability identity, makes institutionalized violence visible, and questions medical paradigms of mental illness and disability. I examine issues of female masculinity and male toughness in Galloway’s portrayal of “Jake Ratchett, Short Detective,” and approach “Mr. Handchops,” Galloway’s parody of Shari Lewis’ “Lamb Chop,” as a multilayered disidentification incorporating masochism and parodic ventriloquism.

The epilogue addresses some of the material constraints on disabled performance and the noticeable absence of representations of working class, African-American, and other non-white, non middle-class voices in disabled performance. I identify important linkages between queer theatre and autobiographical performance by people with disability and comment on the difficulty of appropriating sexuality for people with disability in performance. I consider what future disabled performance might offer to “cripdom”¹³ and to the general public, and explore the pedagogical applications of my own work of identifying the strategies and stakes of disabled performance, calling for the inclusion of a disability studies perspective in the humanities.

In selecting these pieces, I consciously chose to include solo and ensemble works because of their different risks and effects. Solo performances by people with disability risk reproducing isolated, singular, disabled protagonists, which reinforce the already pervasive idea that disability is inherently alienating. Alternately, solo performance offers an extended exposure to the audience, creating the possibility of a fuller engagement and the development of a more complicated voice and presence (as well as the risk of a more noticeable failure to engage). Solo performance is somewhat more accessible than ensemble work to people with limited financial resources, since it can be done with almost no

¹³ “Cripdom” has come into common usage among my colleagues in *Actual Lives*. It imagines a social and cultural domain exclusively defined by disabled people. We appropriate the words

budget. As Hughes reminds us, solo work is all that many performers, disabled or not, “can barely afford to produce” (Hughes 2).

Ensemble performance at least *feels* less risky at times, because the responsibility for performance is shared, though it also requires a strong sense of trust between performers. Ensemble autobiographical works by disabled people allow for a broad range of perspectives to be voiced, which is useful in the political sense, because the disabled community is not always perceived in its diversity. Our work with *Actual Lives* has made it clear that it is also easier to draw an audience when there are several performers onstage, since each performer draws a certain number of interested friends or family members. The major drawback in producing ensemble work with disabled performers is that the logistics can be overwhelming. Dealing with transportation needs, with accommodations that will insure access (both environmental and technical, such as audio description or real time captioning), and with personal attendant care is both expensive and labor intensive.

The order in which I examine these three performance pieces is not intended to establish a particular hierarchy of performance skill or “success.” The three performances that I have chosen to analyze represent distinctly different ways of performing an autobiographical self, and raise fruitful questions about the nature of disability and its representations. I chose to analyze *Actual Lives* based on my interest in determining what was at work in the process of generating

“crip” and “gimp” in much the same way that my gay and lesbian colleagues own the word “queer.”

autobiographical narrative that produced such intense personal reactions from the members of *Actual Lives*. Though each member of *Actual Lives* has a personal story to tell, and individually they articulate many different experiences of disability, their goal as an ensemble is to educate non-disabled people about what it means to be disabled. They want to make the point that disability has been constructed not by their bodies, but by the culture, and move audiences to take responsibility for complicity in that process. They want to represent themselves, as they are, or long to be. Theirs is activist performance with an agenda, and their disabilities are quite obviously the motivating factor for performance.

I include David Roche's *The Church of 80% Sincerity* because, though he is thoroughly disability-identified, his identification as disabled, based on facial disfigurement, is debated within the disability community. Roche bills himself as a disabled performer, and as such he can access a certain envied cultural capital. I find his unique and difficult position fascinating, especially in terms of the ways in which his work generates discussion about the meaning of disability, the "authority" of autobiography, and the burden and privilege of representation. I include Terry Galloway's *Out All Night and Lost My Shoes* because, as a person with a physical disability who is not specifically disability-identified, she produces a performance that is not "about" disability, but informed by it. By including her work, I extend the category "autobiographical disabled performance art" to include much more than narratives of disability identity. I also want to archive this work, and mark it as an early example of disabled performance art. Galloway began performing this show long before autobiographical accounts of

disability were imagined as viable cultural products. Additionally, I am interested in Galloway's work because her attitudes about disability and performance productively influence the collaborative work we do with *Actual Lives*.

I think of these three performances as constituting a richly varied body of work that, taken together, give broad exposure to the issues facing disabled people in contemporary culture. I know and appreciate what is at stake in that exposure. Each raises questions of disability identity, agency and subjectivity in its own way. Obvious in its absence from this discussion is the "typical" disabled autobiographical performance. With so small a field, I do not consider any autobiographical performances by disabled people to be typical. My role as critic here is mediated by my desire to preserve these performances and their momentary accomplishments, while theorizing their continued usefulness to audience and performers alike.

ART AND THE AUTOBIOGRAPHICAL SELF

I want to pose two central questions that can frame this discussion of autobiographical performance by disabled people and establish connections between these three performances, questions to which I will return in each chapter. First, what does it mean to create an autobiographical self and present it, through performance, as a work of art? And, what does art have to do with disability? I want to answer these questions through a brief discussion of the fabric and functions of art.

Art is expression. As Erving Goffman asserts in *The Presentation of Self in Everyday Life*, every social encounter is a performance, and individuals desire both to express themselves to others as a way of establishing social identities and impress themselves on others in the most favorable light possible (7). Expressions of identity, of belief, of hope or despair, of the full range of human experience, all have their place in autobiographical performance by people with disability. In *Actual Lives*, performers come to the project of constructing and performing an autobiographical self as novices who know little about writing or performance. The *Actual Lives* workshop asks for autobiographical narratives from people with disability, and then translates those narratives through public performance to develop a new kind of cultural voice for performers. Re-narrating life events in acts of autobiographical meaning making, *Actual Lives* performers express the disability experience from the inside out.

Roche's artistic expression enables him to transact a public transformation of the socially assigned meanings of his face. His performance constitutes a "coming out" story of sorts, in which he "outs" himself as facially disfigured. Like many of the individual pieces in *Actual Lives*, Roche's public declaration of his difference allows him to own that difference and envision alternatives to the stigma he has confronted because of it. For Galloway, artistic expression is a conscious act of "stacking the deck" (*Answers*). Guiding the audience to see things from her point of view, Galloway admits that, in performance "I contrive to rope people into my argument using the same dynamics that always rope people into an argument – energy, charisma, humor, and something else – emotion ..."

(*Answers*). Galloway is concerned about asserting herself as someone who is authorized to express herself, to take up the cultural space of performance. “Why listen to me? I’ve done nothing, I have no money, I have no fame – I have nothing but the argument of my own worth,” she wonders, “And that’s an argument disabled people often lose, on many fronts” (*Answers*). *Out All Night and Lost My Shoes* is Galloway’s opportunity to win the argument of her own worth.

In many ways, the success of artistic expression depends on reception. Who receives these performances? *Actual Lives* draws audiences that reflect the diversity of the Austin community. Friends of performers sit next to university faculty members, computer programmers meet lawyers at these performances. Theatre students, engineers and Ph.D. social workers, women who clean houses for a living, and disabled activists all share the crowded alternative theater spaces in which *Actual Lives* performs. What brings audiences to *Actual Lives* performances, and what keeps those audiences coming back, is a desire to hear and see disabled people represent themselves. Yet, audiences appreciate the social distance of performance, because it allows them to come into comfortable confrontation with disability. They know what to expect. People who attend *Actual Lives* performances are not required to have personal conversations with disabled people, or deal with any awkward silences, or wonder what to do when someone with a shortened limb offers her hand in greeting. Clearly, though, audiences want to hear about the experience of disability. They stay afterward for “talk backs” and ask questions, and days later they write letters informing me that

the next time they're in the elevator with "the quadriplegic guy at work" they will know how to start a conversation with him.

David Roche's *The Church of 80% Sincerity* does not usually draw audiences of theatre-goers that would choose to see Galloway perform, or the varied audiences that attend *Actual Lives*. He performs *The Church of 80% Sincerity* before audiences that have been assembled for him, audiences that already know he will be addressing issues of disability and difference. Whether he is serving as an inspirational keynote speaker or conference entertainer, performing at public schools, or addressing civic groups, his audiences expect to see a disabled person who has triumphed over disability. Roche delivers this narrative of overcoming without apology, and with an unexpectedly cynical sense of humor. His reception by the audiences for whom he most often performs has been positive enough that he has been able to make a modest living from his work.

Out All Night and Lost My Shoes plays for many different audiences. Galloway's reputation as a performer brings many people to this play, including audience members who are motivated by curiosity about deafness and performers and those who are not even aware that Galloway is deaf. Theatre critics and students, writers, local performers, long-time fans, scholars, poets, queer activists – these are the people who attend Galloway's plays. She performs in small theatre spaces, at various theatre and other professional conferences, at universities and a wide variety of other small venues. For many of these people,

disability is a relatively unexplored territory, which makes *Out All Night and Lost My Shoes* an important contribution to disability awareness.

Art and politics inform each other, regardless of intention. Whether political context, content or motivations are obvious, disguised, or specifically denied, the very nature of performance art by people with disability makes it a clearly political forum. As promoters of a recent art and politics forum at Cornell University have claimed, “By re-thinking authorship, ownership, and power, art transgresses the boundaries of personal taste and aesthetic pleasure. By opening up, revealing, and constructing meaning within the milieu of the global political landscape, artistic practice and discourse has allowed voice to emerge from silence, political agency from dormant social opposition” (*Art*). Not only does art energize political life, political and social realities are sometimes “as politically charged as the enlightening encounter with a provocative piece of art” (*ibid*).

Public performances of autobiographical, identity-based work rely on a cultural context in which these works can be intelligible. As David Román explains in the introduction to *O Solo Homo*, performance art is “enabled by a larger cultural collaboration not just of presenters, directors, and tech artists, but also of spectators and the political movements that make this work possible in the first place” (Hughes 12). Just as queer theatre developed in tandem with the gay rights movement, disability-related performance emerges out of a larger political and cultural discourse linked to the development of the independent living movement and the passage of the ADA. If the queer theatre examined by Hughes

and Román advocates for “queer public culture,” it is fair to say that all of these performance works advocate for a visible, viable public culture of disability.

Holly Hughes asserts that performance artists rarely set out simply to entertain, but rather, “they mean to provoke, to raise questions, to implicate their audiences,” always attempting to “mediate differences” without erasing them (Hughes 9). Producing autobiographical performance art by disabled people constitutes a political act, in that it renders public what has long been considered a private matter, simultaneously enacting difference and mediating across physical and cognitive difference to effect connections with the audience. Hughes discusses the blurring of the distinctions between private and public in queer performance by pinpointing the “performative nature” of queer identity and the importance of the experience of “coming out” (7). Autobiographical work by queer performance artists not only “bring[s] into representation the diversity of queer life,” but also “provides a space where queer people can themselves rehearse key issues and concerns” (7). Similarly, disabled performance creates public spaces in which disabled people “rehearse” issues of concern to the disability community while also educating the public about the ways in which disability is performed on a daily basis.

According to Hughes, this awareness of the public nature of their private lives leads performance artists to take Audre Lorde’s idea that “the personal is political” to heart (8).¹⁴ Certainly members of *Actual Lives* enact this connection between personal and political. Expressing the values and concerns of the

¹⁴ Audre Lorde uses this phrase in her essay “The master’s tools will never dismantle the master’s house,” from *Sister Outsider*.

disability rights movement through the vehicle of their own personal experience, members of *Actual Lives* politicize the personal, and personalize their social and political identities. By highlighting issues such as the need for improved social and personal services, by resisting medicalized paradigms of disability and actively re-sexualizing the disabled body, *Actual Lives* makes its politics clear. Roche's work, too, reinforces the notion that the personal is political. Though it is difficult to find a specifically political statement in David Roche's work, he crafts an intensely personal re-appropriation of experiences and interactions that have been denied him, and develops a social and political "solution" to the "problem" of his body in *The Church of 80% Sincerity*. Roche's work has also sparked a discussion of the politics of performance art among disability studies scholars and the disability rights community who are invested in evaluating and policing disabled representation. Like Roche's work, Galloway's *Out All Night and Lost My Shoes* is not overtly political, except in the ways that art is always political. Staking out representational territory for a "deaf, queer, and female" character (who happens to be crazy, at least part of the time) has its own political implications. Insisting on critiques of socially and politically charged issues such as gender role expectations, medical professionalism, and psychiatry establishes Galloway's work, depending on where and to whom she performs it, as political statement.

Art is also a kind of cultural and personal power. Fundamentally fatalistic, Galloway's *Out All Night and Lost My Shoes* envisions a scenario in which we all end up in the belly of the beast, the silent motion of our bare feet kicking at the

crocodile's jaw our only impotent protest. Yet, just the act of performing *Out All Night and Lost My Shoes* expresses Galloway's deep faith in the power of art. Art, after all, is what makes her tough. "Art saved me from self-oblivion," Galloway admits, "... it saved me and gave me some power over my own life that I had never had before" (*Interview*). Galloway believes that the construction of an autobiographical self as a performed identity can "give you the guts to live the life you can live. So that you can fool yourself into approaching your own life with the courage that the character you've created has shown" (*Interview*).

David Roche's performance has given him, on and off stage, this kind of power to "live the life you can live." The power of artistic expression renders Roche a representative of a larger community, while still allowing him to make his own personal statement. His autobiographical "true" self manages to release him from the social meaning of his body into a more complex subjectivity, at least during the performance, and provides audiences with a model for accepting and valuing difference. For members of *Actual Lives*, the power of art may well reside in the process of creating and enacting autobiographical performative selves that talk back to discourses and practices that shape their identities and limit their possibilities. These performed selves demonstrate a necessary, longed-for shift in power.

Finally, art is risk and vulnerability. There are fiscal risks. Disabled performance art does not make you rich, or even financially stable. And emotional ones. Offering personal stories for public consumption can leave a performer feeling emotionally exposed. There is always the risk of failure. In *Actual Lives*,

there is a constant vulnerability to others in the cast, upon whom each performer depends for support and cooperation. In both solo and ensemble performance, success depends on the ability to exceed the underlying narcissism of self-disclosure and achieve an intellectual, aesthetic and emotional connection with the audience.

Still, David Roche, Terry Galloway and members of *Actual Lives* all agree that the greatest risk is *not* performing these autobiographical selves. As Galloway says, “It takes guts to ask for attention from a culture that doesn’t value you” (*Answers*), to get out there and “toot your own horn,” but without that, nothing changes.

Chapter One

Actual Lives: Cripples in the House

In the early morning hours of the 11th day of November, 1989, my buddies and I were partying, without a single thought of the frailty of these mortal lives that we are all participating in.

At approximately 3:30 a.m. we entered the intersection of 6th and Lamar, through a flashing yellow light, only to be broadsided by a speeding car with no consideration of a flashing red, westbound on 6th. Things started making sense again about the 20th of January, 1990. Now, going on eleven years post head injury, I understand that our lives are tottering like dew drops on the petal of a lotus blossom.

Adam Griebel
Actual Lives, 2000

Since August of 2000, I have worked with deaf writer and performance artist Terry Galloway, Celia Hughes of VSA arts of Texas, and a group of disabled adults to create the *Actual Lives* Performance Project. *Actual Lives* consists of simply staged, autobiographically-based solo and ensemble pieces that critique cultural and medical attitudes toward disability, reassert the sexuality of disabled people, trouble the reduction of disability to metaphor, and attempt to engage the imagination of audiences in re-envisioning what it means to live with disability. This community based performance workshop designed for adults with and without disability fits into an aesthetic tradition of what Marvin Carlson calls “socially engaged performance” which is “performance work based primarily upon autobiographical material and frequently dedicated to providing a voice to

previously silenced individuals or groups” (Carlson 165). Much as early feminist and queer performance helped establish a cultural voice for members of those groups, *Actual Lives* engages the specific concerns, desires and needs of disabled people and puts those issues front and center before largely non-disabled audiences.

Galloway’s experience as a deaf performer working in predominantly hearing environments prompted her to develop a theatrical tool that could give voice and presence to people with disability. She first used the format for the *Actual Lives* workshop in 1993 in Manchester, England and has since conducted similar workshops that range in length from one day to one week. She uses a process of writing from memory to elicit the raw material of actual life and then turns that writing into performance by teaching participants how to use their bodies, and/or simple props and staging, to convey their stories. Though Galloway has concentrated for most of her career on work with hearing, non-disabled theatre groups, the recent productions of her Tallahassee, Florida theatre company, the *Mickee Faust Club*, reflect a conscious effort to integrate disabled and non-disabled performers. I was motivated to develop and produce *Actual Lives* in Austin after writing and performing an autobiographical narrative as part of an *Actual Lives* class that Galloway taught at the University of Texas in Austin in 1998. My exposure to issues of disability through my work as an Occupational Therapist, combined with my experience as a writing instructor at the University of Texas at Austin, put me in a good position to facilitate the writing process (the “page” part of this page-to-stage project). Our third partner was Celia Hughes,

Executive Director of VSA arts of Texas. She was intrigued by the project because it offered a way to provide disabled adults access to the arts as more than patrons, as performers. As an affiliate of VSA arts, an international nonprofit organization founded in 1974 by Jean Kennedy Smith and affiliated with the John F. Kennedy Center for the Performing Arts, her organization is dedicated to reducing barriers between the cultural arts and people with disability.

Through our collaboration, we brought fifteen adults with disability together for one short week in August of 2000 to write and then translate those writings into a standing-room-only public performance that became *Actual Lives: Cripples in the House*. Since that time, the group has continued to write and perform, most recently at the Tillery Street Theater in Austin, Texas in November of 2002, as part of a celebration of Disability Arts Month in Texas. Writing from memory gives narrative structure to lived experience and performing reconstructed narratives in the current moment gives performers a chance to theatrically re-present their actual lives to audiences that, for too long, have depended on culturally constructed images and myths for their knowledge of disability.

ART AND THE AUTOBIOGRAPHICAL SELF IN *ACTUAL LIVES*

Why do people with disability create autobiographical selves and present them through performance? Clearly, what motivates the expression of autobiographical self in *Actual Lives* is the desire for voice. Many *Actual Lives* performers have already established themselves as disability advocates and

activists, and know what it means to exercise a dissident political voice. They come to the experience of artistic voice with a similar desire to make themselves heard and they use artistic voice to formulate expressions of identity that will complicate and disrupt stereotypes of disability. The expressive voice developed through the performance of personal stories lays claim to a certain kind of authenticity, and offers performers the chance to personalize their resistance to social practices that impact their daily lives. “Actual Lives” seems to insist that these stories are “true,” and that they express the “actual lives” of performers. My analysis of the process of self-narration complicates that connection between autobiographical narrative and “truth.” What is perhaps most true about these stories is that they are based on lived experience and they privilege the point of view of the disabled narrator, a point of view that is too often denied in the actual encounter.

What does art have to do with disability? Like more direct forms of political action, art has the potential to create change - change of heart, change of mind. *Actual Lives* succeeds when audience members receive these self-representations of actual life with disability, however creatively re-imagined, and allow them to displace pre-conceived notions of disability, effecting a changed perspective. The political positionings of these autobiographical selves are revealed through the strategies they use in performance, strategies that I identify and examine in this chapter. If art is cultural and personal power, *Actual Lives*

realizes that power through the use of personal narrative to highlight disability issues, accomplishing both an individual and a collective voice. This chapter examines the risks of disability-identified ensemble performance as located in the paradoxical tensions produced by putting “visible cripples”¹⁵ on stage in an effort to unhinge notions of disability from the body and relocate them in culture.

DEFINING DISABILITY

We created *Actual Lives* as a means of resisting a longstanding tradition of misrepresentation of disability in the media, the arts, and in the culture at large. To assemble a performance company comprised of disabled people, we needed a working definition of disability, but just as there is no identifiable “African American,” no monolithic “feminist,” or even “woman,” and no easily defined “queer” subjectivity, there is no static, all encompassing definition of disability. The simple discursive act of creating the category “people with disability” is fraught with social and political tensions. In defining physical disability for the purpose of recruiting participants for *Actual Lives*, we acknowledged an interest in working with people whose bodies would visibly demonstrate difference in order to confront an aesthetic tradition that has refused space and presence to the disabled subject on stage. That emphasis risked unnecessarily limiting our invitation. We realized that foregrounding visible bodily difference might also be suspect, since such an emphasis potentially essentializes the disabled person,

¹⁵ I take this term from disability scholar Mark Jeffreys’ essay “The Visible Cripple (Scars and Other Disfiguring Displays Included),” published in *Enabling Humanities: A Disability Studies Sourcebook*.

reducing the complex person to the corporeal character of the body. It also risked erasure of the experience of people with invisible disability. This discomfort weighed against the efficacy of assembling a disability-identified performance group to speak for and represent themselves.

Instead of resolving these tensions, we sidestepped them. The final printed application form simply invited “adults with physical disability” to participate, which left the field of applicants open to include people with both visible and invisible disability. For subsequent workshops, the promotional material omitted the qualifier “physical,” and invited “adults with disability.” Those who applied all *identified themselves* as disabled, according to their own criteria. There were those who actively claimed disability as an identity, and those who primarily experienced physical or mental disability as just another aspect of their always complicated lives. Some purposefully defined disability as a social construction, and were active in trying to dismantle that construction. We did not question their assertion of disability as an identity, but rather attempted to engage them in dialogue about the ways that disability contributed to their experience of daily life.

THE BODY’S “MEANING” AND SOCIAL DRAMA

Actual Lives has the potential to effectively complicate the cultural meaning of disability by adding privileged personal narrative to the visible presence of disabled bodies on the stage. In myriad social encounters, as well as on stage, the disabled person, recognized as a disabled body, often becomes what

Susan Wendell, in *The Rejected Body*, has called the marked “other”(61). Disabled actors and performers remain almost invisible to mainstream culture, with most parts calling for disabled characters offered to able-bodied actors. These alienating images and ideas, which circulate in the culture, and emerge through literature, film, theater and other cultural productions, shape perceptions that eventually drive political and social policy and behaviors.

At stake in this tradition of misrepresentation is the continuation of a pattern of social stigmatization and marginalization. We visualized *Actual Lives* as a way to intervene in this damaging cultural miscommunication in much the same way that Victor Turner in *From Ritual to Theatre: The Human Seriousness of Play*, theorizes performance as a possible “mode of redress” for “social drama”(11). According to Turner, “social drama” begins with a “public breach” of the “normal workings of society.” It was clear to us that the atypical or disabled body constitutes such a breach, especially in a society that highly values physical beauty and superlative athletic prowess. In Turner’s model, the breach “slides into crisis” once individuals and groups take “sides” on the issue. Disabled activists claim that they occupy the “side” of self-advocacy, independence and integrity, in opposition to a whole milieu of medical and social service “professionals” and the general public, who appear to be on the side of institutionalization, stigmatization and enforced segregation. “Redressive machinery” is then employed to “mend broken social ties” and “seal up punctures in the social fabric.” Theatre and performance by disabled artists can serve as modes of redress to critique the

dominant culture, “portray its characteristic conflicts and suggest remedies for them” and “desacralize” entrenched ideas about disability (Turner 10, 11).

Disability is a “social drama” in the sense that the appearance of the disabled body in public life interrupts the “normal workings of society.” Disability has been medicalized in American culture and traditionally enacted privately. We were hoping that *Actual Lives* would erode some of the boundaries between personal and public and that self-representation, even the simple confident presence of disabled bodies on the stage, might disrupt previously stable images of disabled people that Simi Linton, in *Claiming Disability*, describes as “self-loathing, docile, bitter, or insentient fictional versions” of the real people they are (3). Linton describes people with physical disability coming out from behind the material and institutional screens that have separated them from mainstream society, not with “brown woolen lap robes over our withered legs or dark glasses over our pale eyes but in shorts and sandals, in overalls and business suits, dressed for play and work - straightforward, unmasked and unapologetic. We are, as Crosby, Stills and Nash told their Woodstock audience, letting our ‘freak flag fly’” (3).

We were not exactly sure what it would mean to let the “freak flag fly,” but we all agreed that we did not want to produce another “special theatre” event. We were careful not to privilege inspirational stories of overcoming disability over less tidy narratives, and instead tried to confront audiences with their own complicity in constructing a physical and social environment that converts physical difference into disability. We hoped that participants would feel free to

deal with sexuality, to articulate desire. We wanted to encourage free expression of a whole gamut of experience and emotion, not just the pretty ones, but thornier issues of social critique, anger, ambivalence, resistance, isolation, poverty or grief; in short, the stuff of “actual lives.”

We knew of the existence of other disability-identified performance projects that negotiated imaginative spaces divorced from spectacle and were confident that *Actual Lives* would occupy a unique position among them. Victoria Ann Lewis began the *Other Voices* Project of the Mark Taper Forum more than two decades ago. The National Theater Workshop for the Handicapped, the longest running disability-specific theater group in the country, has been producing works by and about people with disability since 1977 (Tolan 18). Both of these projects continue their focus on providing disabled performers with the skills to pursue professional theatre careers, while *Actual Lives* privileges the non-professional. We felt resonances with the *Wry Crips*, a disabled women’s theater ensemble that began in the San Francisco Bay Area in 1985 and continues to bring disability issues with a feminist twist to the stage.¹⁶ Like the *Wry Crips*, *Actual Lives* is a segregated, disability-identified ensemble, but our group is not gender restricted and is much less homogeneous in political stance and narrative content. Joan Lipkin’s *DisAbility Project*, part of *That Uppity Theater Company* in St. Louis, Missouri, incorporates autobiographical material in performance, but instead of emphasizing individual personal narratives the group develops topically

¹⁶ Their 28 minute video, “No Apologies,” a compilation of performance footage and interviews with members of *Wry Crips*, was produced in 1994 by Penni Hall with associate producer Pandoura Carpenter. Available from *Wry Crips*, PO Box 21474, Oakland 94620.

focused performance pieces that deal with issues such as underemployment or the meaning of physical difference and plays to venues that include churches, synagogues, public school classrooms and civic groups. There was conceptual room for our specific theatrical endeavor and reason to believe it would make a contribution to the cultural dialogue about disability.

Despite our ability to historically contextualize *Actual Lives*, several key questions emerged about the project. The cultural risks are obvious. Could the articulation of personal stories about the lived experience of visible (and not-so-visible) disability through the vehicle of performance prevent the kind of spectacle associated with the 19th century “freak show”? And, considering the struggle to fashion a new definition of disability as located in the culture and not in the individual body, how can the materially realized disabled body-in-performance advance the cause of disability advocacy? And that question led us to issues of subjectivity. Would *Actual Lives* become an experience of “talking back” to hegemonic discourse about disability? In what ways is it feasible to theorize such a resistance? And what are the benefits to performers, and to their audiences? What theatre practice(s) would be required to insure that *Actual Lives* participants would find and exercise their voices?

CONFRONTING ISSUES OF SPECTACLE

Assembling a cast of performers whose bodies are so often the objects of fascination poses a very real risk of creating a spectacle that could erase the power of their narratives. In the twenty-first century, Americans still do not know quite

what to do with people whose bodies won't behave. Disabled bodies still "function as magnets to which culture secures its anxieties, questions, and needs at any moment" (Thomson, *Freakery* 2). This was certainly the case in the 19th century freak show. People with physical anomalies were paraded in front of audiences, mute and meant to perform as bodies only, as objects of a privileged and scrutinizing gaze. Narratives of embodiment derived from this spectacle helped shape and define the "average" citizen's perspective on their normative bodies. As the freak show popularity waned in the 1940s, and social attitudes began to shift in response to other changes in the culture, the disabled body became a medical project. Through the discourse of medicine, disability was located in the body and considered a personal tragedy, and the goal was to "cure" or "fix" it. By locating disability in the body, and viewing it as a personal tragedy to be overcome, medical discourse has helped the culture dodge responsibility for constructing and imposing disability as an identity. As disability activists begin to make clear the ways in which their bodily differences have been *made into* disability by means of hostile physical and social environments and attitudes, they attempt to relocate disability away from the body, and introject it back into social and cultural practice.¹⁷

We wanted to shape a materialist performance paradigm that would treat disability as a culturally constructed identity derived from a specific set of power relationships (wielded through pathologized medical and social discourses) and

¹⁷ For a more thorough discussion of the ways in which disability theorists and activists are reconfiguring disability to locate the disadvantages of disability in "exclusionary institutions" and "prejudiced social attitudes" see Thomson, "Redrawing the Boundaries."

then use the body-in-performance to expose those power relationships, and resist them, to whatever extent that is possible. We hoped that writing from personal experience to develop performance personas would not only re-present the experience of disability in the lives of the performers, but offer an opportunity to explore “alternative, imaginary and even mythic selves” (Carlson 152).

CONSTRUCTING CONTENT

In order to produce the performance script, participants in the *Actual Lives* workshop write from memory and then review their writings together, looking for thematic connections or useful disjunctions between them and considering which narratives might best make the translation into performance. Writing from personal experience means that there is never any dearth of material. The group selects individual pieces for inclusion in the script based on how interesting, creative or compelling they seem, how well each piece represents the concerns of the group and how each “talks back” to the world outside the group.

Performers acknowledge two primary concerns related to content. First, they agree not to perform material that others in the group find objectionable. In fact, much of the writing from the workshop never makes it to the stage because it is too raw or too controversial to be acceptable to the group. Second, they agree that they will not edit or censor content to insure audience comfort or to conform to notions of the “good cripple” that audiences may expect. This insistence on relatively unrestricted expression shapes the tenor of the performed material and

has resulted in performances that employ several different strategies for addressing disability.

PERFORMANCE OF DISABILITY AS IDENTITY

Not everyone who has a disability takes on the identity of “being” disabled. For example, many older adults who acquire disability in the process of aging have difficulty seeing their personal or political commonality with disability rights advocates, many of whom have disabilities that have branded them as cultural outsiders since birth. Those who experience disability as an unavoidable fact of life, and define disability as a condition of the body, are less likely to be invested in disability as an identity than those who have lived with longer term disability and its impact on identity formation. For some participants, *Actual Lives* constitutes the first opportunity to publicly acknowledge disability as an identity. For Galloway, the workshop process enabled a public repositioning relative to disability culture. In her introductory remarks in the moments before “*Actual Lives: Cripples in the House*” begins, Galloway “outs” herself as a disabled person who has “passed” in a non-disabled theatrical world. “This has been one of the most remarkable weeks of my life. I’m deaf and I was mainstreamed. And I’ve been primarily with hearing theatre groups, and...” after a pause, “I feel perfectly at home.” Identifying herself as part of this specific disabled community seems to resolve some of Galloway’s tension between *having* a disability and *being* disabled and creates a sense of “home” for her.

Disability as an identity marker is not so comfortable for others in the group. As performer Nathan May, a disabled visual artist, walks slowly to center stage to deliver *Double-Edged Sword* dressed in a painter's smock and holding his cane, he insists that, "As a visual artist, I want to be known for my ability, not my disability." Though "disabled" and "artist" both describe him, he refuses disability as a primary identity, and states that disability "is only half of who I aim to be." May shows a willingness to acknowledge that he *has* a disability, but not that he *is*, in any fundamental sense, disabled.

Joby Dixon uses *Which is Worse?* to place himself quite specifically in disability culture by asking whether mental or physical disability is more debilitating. Dixon is a doctoral student in sociology at the University of Texas. His scholarly style of speech reflects the southern white gentleman drawl he acquired growing up in North Carolina. His cerebral palsy primarily impacts his mobility. His boyish face and easy laugh put people instantly at ease. As he struggles to rise from his position on the floor (a position he chose in order to allow audiences to see his movement transitions) and approach center stage using crutches, he begins his story. "She was an all-state soccer player. A goddess by society's definition and her beauty was stunning." He takes a moment to make eye contact with the audience, then continues: "However, she was dyslexic and had a really tough time processing written words. I was the guy with cerebral palsy and crutches for whom most college courses were child's play." He poses the question as much to himself as to the audience, "Which was worse?" The answer is easy. "I was a cripple, but I could think, and read. And," he adds with

great enthusiasm, “I could spell California!” By reinscribing a hierarchy of disability in which people with cognitive disabilities are considered “more disabled” than people with physical disability only, Dixon performs his prowess, instead of his powerlessness (just as he does on stage by highlighting his physical strength and agility through his movements) and allies himself with other intelligent, articulate, physically disabled people (always at the risk of alienating those with cognitive disability).

MANAGING INTERACTIONS

Dixon’s *Which is Worse?* provides an example of an awkward social encounter between two people with different kinds of disability, but much of the social difficulty disabled people deal with has to do with face to face encounters with non-disabled strangers. In many such interfaces, the disabled person is charged with the responsibility for putting the non-disabled person at ease. Rosemarie Garland Thomson describes this process of “managing interactions” “To be granted fully human status by normates, disabled people must learn to manage relationships from the beginning. In other words, disabled people must use charm, intimidation, ardor, deference, humor or entertainment to relieve non-disabled people of their discomfort.” Further, she asserts that when these “...efforts at reparation are successful, disabled people neutralize the initial stigma of disability so that relationships can be sustained and deepened” with each person emerging as “multifaceted” and “whole”(Extraordinary 13). The most common question asked of disabled people in public is “What happened to

you?” Answering this question (or deciding not to answer it) is a predictable part of the everyday experience of meeting new people. Thomson asserts that in social interactions with “normates,” the “disabled body demands a narrative, requires an apologia that accounts for its difference from unexceptional bodies” (*Staring* 334.) In *Actual Lives*, however, this question arose from a desire to establish links of commonality between members of a group of people who had all self-identified as disabled. The group members quickly became engrossed in articulating the nature of their disability and establishing their shared, and their unique, experiences.

What Happened to You? developed from those early workshop conversations and comments on how that particular question impacts people with disability on a daily basis. It serves as the show opener. Danny Saenz comes on stage first, followed by Adam Griebel, and they begin an onstage conversation that expands to include new performers as each takes their place on the stage. Saenz begins by registering a complaint with Griebel. “When people asked what happened to me, I usually don’t mind, but sometimes they go on and on, wanting to know details and I don’t want to get that involved. Because it’s like, I just get tired of explaining.” Griebel responds briefly, then Belinda Lane joins the conversation, intentionally missing the point of the question, and answers:

When people ask what happened to me, I say, I grew up in San Antonio. I went to public school and took music lessons. I went to college and changed my major a couple of times before graduating with a bachelor's degree in liberal arts. I married the kindest, sweetest and most loving guy in the world and had three beautiful children. I divorced the meanest, most inconsiderate, self-centered and selfish asshole on the planet!

Then, after an exaggerated pause, she adds: “*Oh, what happened to my eyes?* I have glaucoma.” Nathan May, a visual artist who had a brain injury as a child, lays it out with a dose of hostility and impatience: “What do you want to know first? The frontal lobotomy I suffered, or the crushed lower back that I endure?” As she takes her seat upstage, Cindy Massey, disabled from a traumatic brain injury, offers the kind of straight forward answer that many people expect, but without the attendant shame: “I used to be a wedding photographer, fast running, fast thinking, ran my own business. Now, I think slow, move slow, and I’m easily confused. I can’t do two things at once.” Laura Griebel refuses to answer, posing a question of her own: “Don’t you think you should get to know me a little better before you get so personal?”

Diane Domingue, the vocalist in the group, employs a similar dodge. Instead of commenting on her blindness, she offers: “I tell them I’ve been a brunette since I was born! Then they get very quiet as I twirl my hair and smile ruthlessly.” Terri Stellar’s response shows the ambivalence she feels at being asked to explain her body: “The good girl in me says ‘Well, what do you want to know?’ The bad girl in me doesn’t say.” Terrell Johnson responds with a list of physical ailments which is aimed at increasing the questioner’s discomfort, complete with a Tiny Tim ending: “an organ that does not work, no toes on one leg, no foot on the other, eyes that bleed, eyes with high blood pressure, ...Pinched nerve in my head – nobody look. But, I’m always happy, I never cry.” Finally, Joyce Dawidczyk responds by asking the assistance of another cast member to form the hand gesture that goes with her verbal response: “Fuck you!”

What Happened to You? serves as a proactive tool for managing the initial interaction with the audience. By establishing an onstage conversation among cast members about difficult interactions with strangers, the piece solidifies their group identity. A mixture of complaint and apology, it establishes the audience as spectator, as the “other” to a group of speaking subjects who occupy the discursive space of the stage. Several responses to the question draw privacy boundaries that most cannot draw in real encounters. By appropriating this important question and orchestrating responses to it, the cast of *Actual Lives* inverts the usual power dynamics of that situation.

TWICE BEHAVED BEHAVIOR

In fact, *What Happened to You?* does more than simply manage the group’s initial interaction with the audience. Like several other pieces, it creatively re-envision and re-narrates lived experience. Far from claiming that these performances reproduce actual life in any mimetic fashion, the autobiographical writing and performance in *Actual Lives* constitutes the re-writing or re-performing of lived experience. The bulk of this performance material is generated from and comprised of what Richard Schechner, in *Between Theatre and Anthropology*, has called “restored behavior” (35). Schechner imagines the restored behavior of performance as similar to “living behavior treated as a film director treats a strip of film,” in that these behaviors can be “rearranged or reconstructed, they are independent of the causal systems (social, psychological, technological) that brought them into existence. They have a life of

their own” (35). In performance, “the self can act in/as another; the social or transindividual self is a role or set of roles” which become symbolic and reflexive restored behaviors. In fact, he asserts, “Performance means: never for the first time. It means: for the second to the nth time. Performance is ‘twice-behaved behavior’”(36).

This “twice-behaved behavior” is at the heart of *Actual Lives*. For example, Laura Griebel’s humorous *Occupational Therapy* is a vehicle for talking back to the kind of erasure Griebel experienced at the hands of medical professionals as a child, to an audience that might be tempted to effect that same kind of erasure. Griebel has congenitally shortened arms and has had multiple surgeries to reconstruct her legs. She walks with metal braces. Griebel’s body disrupts the usual flow of casual social intercourse on first encounter, a disruption mediated by her conventionally attractive face and excellent social skills. Still, her presence on stage recreates what Rosemarie Garland-Thomson labels the “primal scene of disability” (*Staring* 334), in which the normative viewer confronts the disabled body and demands information about that bodily difference. Garland-Thomson theorizes that the “disabled body summons the stare” in our ablist society, and “the stare mandates the story” (*Staring* 335). In short, once Griebel is on the stage, she is initially compelled to speak about her body, in order to talk back to the questioning gaze of the audience, something she is well equipped to do. As performance artist Deb Margolin has observed, for every woman, “standing up in front of people is a radical political act, expressing, as it does, the desire to speak” (qtd. in Dolan 473). But for this woman, it also

represents a desire to see and be seen. Griebel presents herself to be looked at, but also to be heard, which reverses the power dynamics of the many instances in which she has been the silently unwilling object of critical scrutiny. Though the audience is caught between “staring at” Griebel because of her bodily difference and “looking at” her as a desirable white female, her ability to clearly and confidently articulate her story enables her to exceed visual spectacle.

Griebel tells the story of an interaction with an occupational therapist following one of the many surgeries she had as a child. Moving slowly downstage, she assumes the stance and voice of a young girl to deliver her lines. She explains that when the first OT appointment was scheduled, rather than ask questions of Griebel and her mom about what had been effective in maximizing Griebel’s independence, the therapist proceeded with her own “treatment plan.” After several such sessions, the OT appeared with a pair of Velcro underpants designed to provide independence in toileting. But to use them, Griebel would have needed to be able to reach parts of her body that her shortened arms simply could not reach. Aside from the fact that the OT had totally misperceived Griebel’s physical capabilities, “It was the most obnoxious contraption I’d ever seen,” she says in a commanding adult voice. “And besides, if I could have reached my crotch to use that Velcro, I wouldn’t have needed an OT to teach me how to drop my drawers!” And then, with a slight turn of her head, and a shift in body posture that allows her to visually survey the audience, Griebel offers: “My mom and I listened politely (she was new at this and we didn’t want to hurt her feelings), and then proceeded to laugh so hard on our way to the car that we

nearly peed in our pants.” Then she adds, as she turns away from the audience, grinning widely, “No pun intended.”

The remembered actual life experience of *Occupational Therapy* was one of being essentially unrecognized and subjected to an inappropriate professional “intervention.” The performed narrative turns the tables to highlight the therapist’s entrapment in a discourse of professionalism that prevented her from being helpful, and allows Griebel to assert her agency.

COMMENTING ON CULTURAL ATTITUDES: TALKING BACK

There are moments in the show when instead of recreating or reenacting an event, cast members choose to lodge a more direct complaint, or make a more direct comment on social expectations and practices that impact their lives as an exercise of cultural power usually denied to people with disability. One such complaint has to do with language. G. Thomas Causer points out in *Recovering Bodies: Illness, Disability and Life Writing* that because “one element of the oppressive culture is discursive –the ways in which the disabled are talked about, written about, portrayed in electronic media – ” disabled writers have responded by challenging the prevailing terminology, specifically euphemistic terms like “physically challenged” or “differently abled” (179). *Special Shit*, by Danny Saenz, openly resists not only the ways that language about disability glosses over and “sugar coats” the very real difficulties that disability can bring, but also the expectation that disabled people should “overcome” their “tragedy.” Saenz is a

middle aged Mexican American man, a disability rights activist with ADAPT,¹⁸ who uses a wheelchair for mobility. He has cerebral palsy. In performance, he dresses the way he normally would, in jeans and t-shirt bearing an ADAPT logo. His shoulder length hair is pulled back in a neat ponytail; his beard is trimmed. He drives his wheelchair to the front of the stage, and begins to talk in a smooth baritone voice.

Remembering a childhood full of hospitalizations during which he was separated from his family, he articulates the problem of “being told that I was just like everyone else, but being treated so differently.” Everything about him was “special.” He says, with a sardonic smile, “When I was a kid, I went to a special day care. I went to special kindergarten, and when I was sick, I went to special hospitals. I even went to a special college where I learned special skills.” Then, moving to the other side of the stage, he leans forward in a gesture of intimacy, to add:

I learned how to load a pipe for a quad. I learned special techniques of abusing Valium, because that’s what they gave *everybody* for spasms. You could practically get it for dandruff. I learned that you could trade Valium for the pot you *really* wanted, and that Medicaid would pay for it. It was a very special experience of drug and alcohol abuse. Followed by a special decade of being a devout Catholic, then an extra special episode of suicidal depression. This special shit was killing me.

¹⁸ ADAPT stands for American Disabled For Attendant Programs Today. Attendant care services (help with daily living functions such as eating, dressing, toileting, moving from wheelchair to bed) are the cornerstone to community based services for people with physical disabilities that impact mobility and other daily life activities. ADAPT has been instrumental in moving disabled adults out of nursing homes and into their own homes through extensive lobbying and direct political action. See the ADAPT homepage at www.adapt.org.

Saenz employs a wry sense of humor to make the point that separating his experience from anyone else's on the basis of his physical difference (by designating him as "special") has a negative impact on his life. His criticism of the patronizing label "special" calls attention to the ways in which language betrays people with disability, reducing the complicated experience of disability to a sentimentalized fiction of otherness.

The Good Cripples' Oath, an ensemble piece, is another comment on cultural practice that takes the form of a darkly comic critique of sentimentalized literary images of disability that circulate in American culture. Like Saenz' *Special Shit*, it addresses issues of language, but it goes beyond language to take on misrepresentation and cultural expectations. Use of the word "cripples" is a purposeful reappropriation of a derogatory term, one that only the performers are allowed to use with impunity. It signals their membership in disability culture. The oath begins as a dialogue with Galloway, who has been conspicuously absent from the stage until this moment. Stressing the fact that Galloway is also "a crip," Joby Dixon challenges her to take her place among the cast on stage, to perform her criptom along with group.

As Galloway makes her way up onto the stage, cast member Terri Stellar begins the recitation of *The Oath*. Stellar speaks to the performers from her wheelchair, "Raise your right hand, or whatever you can raise, and repeat after me: I promise, on my honor, to be a good cripple." Anyone who can stand comes to their feet from their various places on the stage; they face the audience, and raise their right hands. As though they were reciting the Girl Scout Promise by

assigning each girl one line, cast members take turns supplying the remaining lines of the *Oath*. A good cripple is “polite all the time.” Good cripples learn early “to be *neither* seen nor heard,” and to “speak only when spoken to.” They learn “to never cuss, to *definitely* never say ‘Fuck,’ to never have sex,” and, even worse, “to never even know about sex.” Skilled at saying “please” and “thank you” at all the right times, good cripples never complain, never “have to go to the bathroom, ever” when it’s inconvenient. A good cripple has a job, “but not too good of a job,” so that non-disabled people are not threatened. Most of all, to be a good cripple, you “always serve as an inspiration to others,” are glad to be alone, and “happy forever” with whatever comes your way. The entire group speaks the closing line of *The Good Cripples’ Oath* together, conjuring Charles Dickens’ Tiny Tim: “God bless us, every one!”

This piece uses a unified group voice to launch a full assault on the worn out image of the inspirational cripple. *The Good Cripples’ Oath* is an audience favorite because it allows the audience to feel let in on the joke by virtue of the disdain they share with performers for the ridiculously outdated assumptions and social expectations that are the brunt of this piece.

Joby Dixon’s *Spilled Blood* comments on the ways in which peer attitudes toward him were influenced by his physical difference. Dixon revisits the final week of high school, when friends got together to “remember the milestone’s of each other’s lives.” They “ran through first unrequited loves, first kisses, football games and then earlier parts of our lives – scout trips, sleepovers and other events of normal life.” His friends “remember all the places I had spilled blood: the rock

in the driveway when I was seven, the concrete step in fourth grade,” he adds with a low chuckle, or “ the thorn bush on a hiking trip.” Then, in a strong and edgy voice, he laments this erasure of the other aspects of his personality: “Forget past friendships, stupid pranks (for which I was famous), forget everything! I was the walking NASCAR crash of the senior class!” The narrative turn from humor to complaint prevents *Spilled Blood* from becoming oversentimentalized, but still allows Dixon to state his clear resistance to being reduced to his physical difference.

Cindy Massey’s *Ford Econoline* shows her own process of re-imagining “normal life” after her head injury. Massey shares the story of a cross-country trip she took in a brand new 1995 Ford Econoline, three years post-injury, traveling alone except for her dog. Late on a Saturday evening, in a campground in the mountains of New Mexico, she locks her dog and her keys, in the van. Her story pokes fun at the difficulty she has problem solving in this situation, and takes pleasure in her eventual success at freeing the dog. She ends with a concise comment about the way her adventure talks back to cultural expectations about disability. “My mission in taking this trip,” she asserts, was to show a disabled friend that “disability should never make you a shut in.” Massey wants audiences to know that disability is something to live with, not something that should prevent life from unfolding in meaningful ways and she uses herself as an example: “Here I am with traumatic brain injury, traveling across country with my little dog, Star.”

Meg Barnett's *Growing Pains* comments on material conditions of culture that resulted in her disability. "When I was a child and I cried at night about the ache in my legs, I was taught to call it growing pains." A youth lived hand-to-mouth without proper medical attention to the bony deformity in her leg led to "pointlessly difficult challenges of simple everyday life" as she grew older. "By 42, I had pushed through all the cartilage and meniscus we get in one lifetime. Standing meant bone on bone." She ends by asserting her willingness to face disability, and her friends, "They have to face their own terrors." No humor saves the audience from the seriousness of Barnett's comment on poverty's link to disability.

RE-SEXING THE DISABLED BODY

In perhaps their boldest political move, *Actual Lives* makes a point of commenting on the myth of desexualization of disabled people. Explicit sexual material is a prominent feature of *Actual Lives* performances. Sexual innuendo, flirting and sexual jokes are prevalent in the workshop process as well. The cast insists on the right to include adult sexual material in their performances, and they resist efforts to "clean up the act" when they are invited to perform in more traditional venues such as public schools, or civic groups. This insistence, which constitutes a militant resistance to the many ways that disabled people are desexualized, determines and to some extent limits the audience for their performances.

In her solo piece *Torch Song*, Diane Domingue asks, “So, why is it men can't relate to me? They always see my blindness first.” Domingue comes center stage, but refuses to stay put, preferring to demonstrate the ease with which she negotiates physical space. Strutting confidently toward stage left, with cane in hand, like the accomplished diva that she is, she continues: “They treat me like a child. They want to help me, guide me, they don't want to fuck me.” Domingue was married until retinitis pigmentosa caused her low vision to become functional blindness, at which point her husband left because he “could never imagine a blind wife.”

In her late thirties, divorced and totally blind, dating isn't easy. Turning sharply on her heel and moving toward stage right, she describes a man she met at a party: “Oh yeah, then there was the guy I met at the party who tried to pick me up, and was successful at it until I stood up and used my cane. ‘Oh!’ he exclaimed, as if he made a terrible mistake, ‘I didn't know!’ As he slid away, I wondered to myself, He did not know *what* exactly?” Dominique laments the idea that disabled people should “keep to their own kind.” “According to my Latino gay transsexual hairdresser,” she quips, “I should stick to my own kind. Maybe I could get a blind man, but a sighted one will always feel sorry for me.” Getting more to the point, she moves into the spotlight of center stage and directly addresses the audience with the question, “What does being blind have to do with sexuality anyway?” She lets the question reverberate through the house, then says in a raucous voice, “Once it's in your mouth, you don't need to see it do you?!”

Other individual pieces, like *Sex Education* by Danny Saenz and *Mom Worries to God about Sex* by Joyce Dawidczyk, deal with the common assumption that people with disability are not sexually active or knowledgeable. *Sex Education* parodies an informational sex class offered through a local clinic. The Occupational Therapists who conducted the class supplied erroneous and highly medicalized information that Saenz renders hilariously funny in his brief monologue. Using handouts and overheads and a battery powered vibrator, Saenz mocks the “Master’s and Johnson Sex Ed Program” and those who tried to teach it to him. And as a corrective to that misinformation, he tells us “the real reason they invited those LaBac reclining wheelchairs.”

Dawidczyk’s *Mom Worries to God About Sex* re-enacts a confrontation with her mother when Dawidczyk was 32 years old. “This was the sex talk that my sister had gotten. Probably back in her teenaged years.” Her mother expresses concern about the consummation of Catholic marriage vows through “the real deal, penis and vagina,” for her disabled daughter. “She didn’t think she’d ever be having this conversation with me. I was disabled. In my younger years, she had planned that I would be a nun. I never went to the convent — I went to college instead.” The obvious irony is that the possibility of an ongoing sexual relationship between Dawidczyk and her fiancé is explicitly denied because it is inconceivable to her mother, or her priest, that a woman with a disability would be sexually active. To Dawidczyk’s amazement, her mother says to her, “I realize that you have *normal organs*. But, I’ve been to the priest. We’re concerned. Does Jim have normal organs?” Dawidczyk tells us that she played the dutiful daughter

role and listened politely to her mother, but adds, sarcastically, “I really wanted to say, ‘It works just fine, Mom. We thought about this very issue, so we decided we’d practice. We’ve got it down just right!’”

THE BODY/SELF ON STAGE

In the context of *Actual Lives*, the specificity of the disability experience emerges by placing oneself in relationship to disability culture, demonstrating ways to manage social interactions, re-performing lived experience to reinterpret the self, talking back to social and cultural constraints on the lives of disabled people and reasserting sexuality. The disabled body is the site of these negotiations and the physical presence of the body is of paramount importance to the work. Still, the presence of the body does not necessarily produce the performer as a subject. This risk and vulnerability of autobiography as art are related to the delicate balance between body and self on stage.

It may prove useful to examine two examples of *Actual Lives* performances by people whose physical embodiment makes it difficult to exceed what Sidonie Smith in *Subjectivity, Identity and the Body* refers to as the cumbersome “drag of the body” (17). Smith refers to nineteenth century discourses of race, class, and sexuality that posited women as either “angels in the house,” or “fallen women.” Since both literary and social repression of the female body was “proper,” enacting desire and autonomy made women into “a cultural grotesque.” Conceptually “framed through embodiment,” women negotiated the “tremulous private body” as a discursive problem, and female autobiographers

had to struggle to escape “the drag of the body” and write themselves into literary tradition as speaking subjects (16). The disabled body is also discursively framed through a problematic embodiment, especially on stage where the visual reality of the body is accentuated. Repression of the disabled body continues to be proper, and exposing the materiality of the disabled body continues to risk producing the cultural grotesque. When disabled people perform autobiographical material, the body is placed in discursive competition with the narrative, and subjectivity depends on escaping, or at least complicating, the “drag” of the disabled body on those narratives of autonomy and agency.

In her piece entitled *Just What the Doctor Ordered*, Joyce Dawidczyk offers a glimpse into a visit with one of her many doctors in which she experiences a debilitating condescension. Dawidczyk is a performer with cerebral palsy who has significant dysarthria (speech articulation difficulty) and diminished physical coordination. She begins by moving towards center stage in her motorized wheelchair to explain, through the voice of a cast member serving as narrator, that “major misconceptions sometimes arise about who I am, based on how I look and how I speak.” People are so distracted by her “very horribly disabled” body that “all meaningful communication is lost.” When she seeks help “from the special doctor to simply sign a special doctor form,” the physician is unable to recognize Dawidczyk’s considerable cognitive ability. Though we never hear the doctor’s actual words, since his speech is rendered in gibberish, a voice-over narrator tells us that the physician is all too willing to make decisions about Dawidczyk’s life without consulting her. He refuses to sign the “special doctor

form” she has brought, which makes her question whether or not the doctor might have a disability. “His task seems simple enough,” she muses as she moves her wheelchair downstage to more directly face the audience, but he is having “an awfully difficult time picking up that pen” and signing his name. She ends the piece with an ironic inversion of the advice she so often hears, suggesting to the doctor that “Perhaps more training might be in order?”

Dawidczyk wrote *Just What the Doctor Ordered* to be performed by two cast members whose speech is clearly intelligible. Making the physician’s voice unintelligible robs him of the customary power position that physicians often enjoy in encounters with disabled patients, and allows Dawidczyk to *speak for* him. This textual reversal of the doctor/patient power dynamic constitutes a radical reassignment of value and agency from physician to disabled subject. Unfortunately, much of that critique is lost in performance. On stage, Dawidczyk primarily pantomimes the actions of the piece, but never speaks her own lines. The audience hears the disembodied voices of two offstage narrators, one speaking for Dawidczyk, the other performing a voice-over that fills in the narrative line of the story. Dawidczyk occupies the stage, but her movements are not completely intelligible without prior knowledge of the scripted plot. We allowed this piece to be performed as written, not understanding that instead of achieving the critique that was *in the text* of Dawidczyk’s piece, substituting the voices of others for her voice effectively re-silences her. In subsequent performances, she has performed her own narratives using a microphone.

Creating an opportunity to literally give her a voice has allowed her to command the full attention of the audience and be understood.

Actual Lives offers the *potential* for agency on the stage, but there is no guarantee that the disabled performer, by sheer bodily presence or through the force of autobiography, will necessarily achieve it. Terrell Johnson, whose diabetes has necessitated amputations on both legs, generated performance material about her daily personal care routines, including Insulin injections and applying her prosthesis. Like many of the other performers whose bodies are visibly disabled, Terrell's spoken narrative is at risk of being eclipsed by the visual spectacle of her body on stage. She was also the only African American cast member at the time, which served to doubly accentuate her bodily difference to a primarily white audience. In order to project her full complexity to the audience, to become more than a disabled and marginalized body, she needs to be able to forcefully articulate her critical and insightful narrative.

In rehearsal, *Terrell's Morning Routine* bristled with satire and liberal doses of criticism of everything from attendant care (or lack thereof) to the high cost of prosthetic care. However, she was not able to memorize or "fix" the text that she produced orally in rehearsal and glaucoma has made it impossible for her to read from the text onstage. Because performing before an audience makes her nervous, she tends to ad-lib. At one point in performance, Johnson strains vocally and physically to demonstrate how hard it is to put on her left leg prosthesis and loses track of her scripted narrative. Disconnected from the focus of her narrative, she performs the laborious details of her daily routine without her

powerful words to mitigate its visual impact. This performance of disability generated sympathy for her condition, but sympathy was not the goal.

Two tensions produced by Johnson's performance of *Terrell's Morning Routine* are worth examining. First, this piece highlights the tension between distinctly different models of disability. Johnson's intended spoken narrative employs what Michael Oliver, in his *Understanding Disability: From Theory to Practice* has called "the social model of disability," which locates disability primarily in the social and cultural environment (32). Johnson's clear intention was to identify not her body, but inadequate social services and medical practices, as the disabling factors in her life. Her actual performance more nearly exemplifies the "individual model of disability" because performing her physical struggle with the prosthesis, without the accompaniment of her critical narrative, locates the "problem" of disability within her individual body (Oliver 32). Performing her body's complex difference in the absence of the complicating force of well articulated autobiographical narrative highlights her dependency and isolation instead of "talking back" to a repressive system that keeps her trapped in her house. Second, the critical and comic aspects of the piece are muted when she loses track of her narrative. Thomas Couser argues that when physical impairment "deprives someone of the appearance of autonomy and potency," narratives of disability become "unwritable and unreadable," and I would argue unperformable, unless the writer or speaker can "claim some compensatory power and freedom" and shape the narrative to "assume a comic plot" that eases

audience tension about disability (Couser 185). Effective communication of a message depends on disabled performer's command of both body and narrative.

LIFE BEYOND "FIRST STORIES"

These "first stories" told in *Actual Lives* represent the first level of personal story, in which the subject advances a carefully constructed narrative of the self in an attempt to be seen and heard. Though *Actual Lives* offers the opportunity for self-identification, a practice that is often denied to disabled people in social interaction, this kind of performed autobiography has its limits, too. Members of the ongoing *Actual Lives* troupe have begun to strategize about ways to continue writing from personal experience so that their unique viewpoints can still be heard, but structure the shows so that their performances are less like monologues and more fully developed as performance pieces. After two years, they are ready to move beyond self-disclosure, which can verge on narcissism, to examine more collaboratively the interfaces between disability and issues of religion, work, sexuality and many more. Currently, they are engaged in the process of writing a mission statement that should help them decide when and from whom to accept performance invitations, how to promote the troupe and how to shape future performances. The goal appears to be the same as it was for that first performance in August of 2000: They want to get in the way.

Sometimes I get tired of being out there.
So I go where it's safe. I go with other people with disabilities.
Sometimes I just want to go someplace without all this hassle.
Physical barriers and lack of accessibility keep me out.

Out of society.
Out of the way.
What can I change?
What can I do?
I want to get in the way!

(Danny Saenz)

Chapter Two

The Church of 80% Sincerity: from Stigma to Stigmata

David Roche's autobiographically based one-man show, *The Church of 80% Sincerity*, presents a multi-dimensional self derived from his experiences as a person with facial disfigurement immersed in a culture committed to physical beauty. This signature piece is an exploration of identity in which Roche attempts to transform the "false self" presented by his problematic body into a "true self" that transcends bodily limitation. *The Church of 80% Sincerity* goes beyond expressing the experience of embodiment or the specificities of the lived experience of disability to critique institutionalized powers that come to bear on the excesses of the unregulated, outlaw body.

Because he is unable to escape the physical facts of his embodiment, or access a "cure" or prosthetic that might allow him to pass unnoticed in social encounters, Roche engages daily in the work of transforming the cultural meaning of his marked face. His performance re-enacts that daily process. Confronted with the negative impacts of the institutionalized power of organized religion, cultural constructions of masculinity and demands for physical and ideological conformity (or, perhaps, most specifically to his inability to enact that conformity), Roche attempts to transform, not altogether obliterate, these institutions through the vehicle of *The Church of 80% Sincerity*, which models a utopian accommodation

to the complexities of the human body and spirit and exists to validate a wide realm of human experience.

I first saw Roche perform *The Church of 80% Sincerity* in March of 2000, as part of a statewide conference on non-traditional theatre held in Houston, Texas. Roche's commitment to illustrating disability as a social construction in which audience members are complicit, his creative imagining of alternatives to the stigmatized position of disabled people, and the way in which he effected the cynical recovery of a Church that had repudiated him, all caught my attention immediately as fruitful elements for analysis. In writing about *The Church of 80% Sincerity* I have two specific goals. I see myself as both advocate and critic in relation to this work. As advocate, I present the work itself in great detail as a gesture of preservation. There is precious little disabled autobiographical performance about which to write, and I want readers to appreciate and understand Roche's work based on a certain level of familiarity with the text.¹⁹ As critic, I theorize how this performance contributes to a cultural understanding of disability, how Roche develops an alternative self through this show, and how autobiography and disability inflect this performance.

THE ART OF THE CHURCH OF 80% SINCERITY

What does it mean for David Roche to make art out of his facial disfigurement, to construct an autobiographical self and perform it on stage?

¹⁹ Roche does have a video of *The Church of 80% Sincerity*, but it is not in distribution. I work from a transcription of the videocassette.

Accepting my previous claim that Roche's artistic expression is a vehicle for transforming the socially assigned meanings of his facial disfigurement leads immediately to a discussion of the politics of appearance. Roche's spectacular body, which prompts a stare-and-tell ritual that risks erasure of his selfhood, requires powerful self-narration if the autobiographical self is going to become visible. Through performance, Roche takes what is usually an involuntary level of visual inspection and turns it into what Rosemarie Garland-Thomson refers to as an "artistic engagement with self-display" (*Staring* 335). His narrative self-expression captures the self that is often denied and re/presents it to his audiences.

What does art have to do with facial disfigurement? Roche's disfigurement is played out on the level of visual spectacle, and live performance is an opportunity for him to control the terms of that visual encounter. Unlike many members of *Actual Lives* who engage in political activism in addition to artistic expression in order to effect change, Roche cannot lobby legislators for legal remedies for his social stigmatization. He has to use face-to-face encounters to do that work, and performance greatly expands the number of encounters he can use to get his message across. Performance is also a way to reduce the stakes of the encounter for audiences, to put them at ease with difference.

In terms of audience for *The Church of 80% Sincerity*, Roche has the definite advantage of performing in front of audiences who have been assembled for him, audiences often already sympathetic to and interested in exploring his

embodiment and the social situations it produces. Yet, some of those audiences are still hard to win. The success of this work relies on the audience's willingness to be led into self-examination as a result of Roche's self-disclosure and to make empathetic identifications with him. When either of these fails, so does *The Church of 80% Sincerity*.

EMBODYING METAPHOR

The setting for *The Church of 80% Sincerity* is a small stage, with just enough room for the single chair, a folding table on which select family photographs rest, and a small podium. The simplicity of the set creates an expectation of intimacy. "Darkness," both actual and metaphoric, is the condition of Roche's introduction to the audience. He identifies himself through his physicality, the problematic body serving as the base of identity. With the house lights down, he speaks of the experience of facial disfigurement as a place in the dark:

We who are facially disfigured are children of the dark. Here, in the dark, we keep our faces hidden away. Here we can get relief from the stares and the comments. Here, in the dark, we can keep our secrets.

In this introductory passage, Roche insures that his body is not visually available to the audience. The facially disfigured body here described and performed is the object of "stares and comments," hidden away to avoid the incriminations of critical scrutiny. No euphemisms are employed, no reference is made to "facial difference." Roche knows that visible difference on the face constitutes disfigurement. The protagonist "self" who speaks here claims a metaphoric and

discursive space for the stigmatized body that, through its absence, is silenced. Discursive displacement of the body introduces the split between body and self. Locating the performed self in psychic “darkness” heightens the association of physical difference with moral or spiritual disturbance. By willfully occupying metaphoric darkness imposed on him by social prejudice about his bodily difference while physically absenting himself from the stage, Roche emphasizes his claim to both metaphor and marked body.

There are times when this “radical dissociation from the body” serves as “a strategy for psychological survival” (Eakin 41). Like Lucy Grealy, facial cancer survivor and author of *Autobiography of a Face*, Roche longs for the fulfillment of a “body plot” that would resolve the social conflicts produced by his face: “fix my face, fix my life, my soul” (Grealy 215). As an adult, Roche realizes that no such miracle will occur, and is left to effect the dissociation of his body from his “true self” in order to establish a viable social identity.

THE “WE” OF COLLECTIVE IDENTITY

This opening passage also incorporates concomitant references to both an individual and a collective self. Theories of the self now emerging in social psychology posit that the self is “fundamentally interpersonal” (Tice & Baumeister 71). The individual self is accomplished by differentiating self from others (“I know I am me because of the specificity of my physical and emotional traits, my responses to situations, etc.”). The self is “defined by the network of relationships in which it exists,” and is actually “for” relationship since it is

“...constructed, used, altered, and maintained as a way of connecting the individual organism to other members of its species” (71). The interdependence of individual and collective selves is theoretically demonstrated through “integrational” models of the self (Sedikides & Gaertner 18). In these models, the individual self is seen as “the experiential (i.e. emotional and motivational) home base” (19). The individual person may temporarily abandon the home base of individual self to join a group, since “groups serve important functions and satisfy many critical needs” (quoted from Hogg, 19). Collective self is achieved by inclusion in large social groups (which are then contrasted against other groups) and based on impersonal bonds derived from common and symbolic identification with the group.

For Roche, claiming a collective identity reinforces his symbolic, metaphoric function by minimizing his individuality. Evoking a collective identity seems prudent since basing individual self-concept on the physicality of facial disfigurement could produce negative consequences. Through conscious alliance with other facially disfigured people, Roche highlights his position as a representative of a collective stigma and shame. His minority position is rendered less painful, and perhaps more powerful, by identification with others.

Roche highlights his identification with other facially disfigured people while simultaneously commenting on their segregation into private worlds that limit acceptance by and access to the larger public society. As Susan Wendell explains in *The Rejected Body*, the public world, which is so often hostile to people with atypical bodies, is “the world of strength, the positive (valued) body,

performance and production, the non-disabled, and the young adults. Weakness, illness, rest and recovery, pain, death, and the negative (devalued) body are private, generally hidden, and often neglected” (40). For Roche, the simple act of going out into the street and showing his face makes public what has been a private matter. Standing alone on stage before an audience of unfamiliar constitutes a confrontation with the body in which Roche has to convey a self that exceeds his individual marked body in order to connect with the audience. To insure that his audience is not alienated by his disfigurement, and to effect their consciousness of the ways in which his bodily difference conveys metaphoric meanings, he initially enacts his membership in the “we” of collective identity.

Safe in this collective identification with other facially disfigured people, Roche enacts their collective status as not only objects of the critical gaze, but as people with the power to recognize the sources of discrimination against them. As a pinhole light opens on his face, and then broadens to light the stage, Roche continues:

We keep *your* secrets, too. Because we can see in the dark. From the shadows, *we* stare out at *you*. And we understand your darkness. *We know that you turn away, not from our faces, but from yourselves.* From your own fears.

(Italics mine)

Reversing the critical gaze so that he is now the one who *looks at*, Roche sees the psychic interiors (not the bodies) of his audience members, and this psychologizing maneuver amounts to a displacement away from the body. Asserting that “We keep your secrets,” and “...we can see in the dark” imputes a psychic dimension to Roche’s performed self, and locates “the problem” in the

psyches of unfamiliar others instead of in the bodies of people with facial disfigurement. Those who are facially disfigured have been contained in the shadowy domains of imagination because they personify the psychic darkness of people who cannot see them for who they “really are.” It is not the bodily difference, but the turning away from what that physical marking “means” in social interaction that disables Roche. Asserting that this revulsion is based on fear, Roche locates disability in the perceptions and fears of nondisabled people instead of in his own body. This works to establish an important distance between his body (which is flawed) and a self assumed to be intact and whole and ostensibly, outside the bounds of social meaning.

FEAR AND LOATHING: “IGOR” AND OTHER BODY ANXIETIES

Roche immediately implicates cultural (mis)representations for fostering these fears. He knows that facial disfigurement is “something very scary to people, it brings out a primal fear.”²⁰ He understands the facially disfigured person to be “the most hackneyed symbol in cinema and theater, commonly standing for something that has gone dreadfully wrong,” and blames cinematic and theatrical representations for contributing to an already pervasive discomfort in interactions between people with disability and/or physical difference and “normal” people.²¹

²⁰ From an unpublished interview, 10/12/2001, Austin, Texas.

²¹ Roche, David. “My Face Does Not Belong To Me.”
<http://www.davidroche.com/my%20face.htm>

Despair is the message of *The Phantom of the Opera*, a character totally defined by his disfigurement, forced by the playwright to live forever in the dark. Evil is conveyed by Freddy Krueger and his slasher film counterparts—barely human, driven insane by deformity, constantly lurching out of the bushes to exact revenge upon the cute.

(*Face*)

“We know that you’ve read all the fairy tales,” he says after naming fear as a primary component of the “darkness” of soul that prevents people from accepting him, “you’ve seen all the movies that invariably portray us as evil, sub-human monsters.” As an example of damaging associations between moral evil and physical difference, Roche performs a familiar image of monstrosity. “Igor!” he yells in a powerfully dramatic and masculine voice, “Igor, the brain, you cretin!” And with that, he takes a short step upstage, purposefully distorts his face by closing his right eye, and assumes the hunchbacked position and character of Igor, with his right shoulder elevated. Raising his left hand in a gesture of sycophantic supplication toward an imaginary overlord, he makes a low guttural noise from the back of his throat, lurches forward, and says in a growl, “Yes, master.” Roche performs “Igor” as a fictionalized, villainized, emasculated, disfigured male whose body is an albatross, pointing out how easily “normal” people associate physical disfigurement with the classical grotesque ²². By making this association between his own facial disfigurement and Igor’s spinal deformity, moral depravity, and mental incompetency, Roche enacts the process of projection and leaves the audience feeling uncertain whether to laugh at the visual

²² Although associated with Mary Shelley’s *Frankenstein*, Igor does not appear in Shelley’s work. His character is an invention that was added to Frankenstein lore when it was adapted into screenplay, a character whose origins are difficult to pinpoint but who circulates in popular culture through various cinematic productions beginning in 1931.

spectacle or gasp in nervous recognition of their complicity in prejudicial stereotyping.

Having provoked discomfort in his audience, Roche narrows his exploration of fear from the general to the specific in a move that returns the focus to the body. Naming the fears that he has aroused, Roche attempts to build an emotional bridge between his still un-named metaphoric “self” and the individual “selves” in the audience by illustrating the ways in which he and his audience members share body anxiety and physical flaws, a move which equalizes their differences and emphasizes their sameness. “Tell me,” he implores, “when you stand naked in front of the mirror, where does your gaze fall? On the parts of your body that might be a little obnoxious, even disgusting, to other people? That are imperfect?” The fear to which Roche refers comes “lurching up out of your unconscious.” He names it as “That deep fear that maybe you, also, are disfigured.”

This emphasis on bodily stigma is followed immediately by an attempt to locate disfigurement in the inner dimensions of the self. Disfigurement can reside “on the outside,” or be comprised by “something on the inside, some character flaw,” or even “something that was done to you, something you had no control over.” No matter its origins, disfigurement must be kept hidden. If it is exposed “it will mark you, too, as unacceptable, unlovable, to family, to village, to species, even to God.” With this universalizing gesture, Roche opens the category of “disfigurement” to include problems not only of the body, but also of the psyche or spirit. Then, returning to a purely metaphoric position, Roche goes on to name

himself as the embodiment of unconscious fears. “In that hidden part of you, that’s me. I have a voice now. And I’m ready to talk.”

THE BODY AS PSYCHIC ASPECT

From that complete dissociation between body and self, in which Roche’s “self” is redefined as a psychic aspect of others, he is free to further explore the process of projection (an exploration that he began with his performance of Igor.)

I’m a walking Rorschach test.²³ When we meet in the light of day, all your fears are pushed onto me in a millisecond. That’s my job. Carrying the weight of that fear for you, so that you can pretend that you are normal.

Here “normal” is exposed as a pretense that depends for its validity on the attribution of “abnormality” to any body marked by difference,²⁴ and the process of projection is exposed. Projection has been defined as: “the attribution of one’s own ideas, feelings, or attitudes to other people or to objects; *especially*: the externalization of blame, guilt, or responsibility as a defense against anxiety (Merriam Webster). Roche uses it to reference the process in which other people’s fears are “pushed onto me.” Projection is a way to address the tensions between what people actually see when they look at him, which is his face, and what they often perceive (metaphoric associations) and feel when they look at him.

²³ The Rorschach test is a psychodiagnostic test that relies heavily on perception as a projection of psychic phenomena. See Rorschach, Hermann. *Psychodiagnostics - A Diagnostic Test Based on Perception*. Berne, H. Huber: New York, 1942.

²⁴ Lennard Davis, in his essay “Constructing Normalcy,” explains the development of the concept of “normal” bodies through a set of “practices and discourses that are linked to eighteenth and nineteenth-century notions of nationality, race, gender, criminality, sexual orientation, and so on” (10). From Davis, Lennard J., ed. *The Disability Studies Reader*. New York: Routledge, 1997.

But Roche is not satisfied to simply expose the process of projection. Claiming the acceptance of such projections as “my job,” Roche implies that his body is not only *for* him, it serves an important social function that has nothing to do with his actual identity. Here Roche actively takes on the metaphoric associations that are imposed on his body, as a way to exercise some kind of control over the meaning of his physicality. As acknowledgement of the social function of his individual body, Roche asserts that “My face does not belong to me, it belongs in a catalog of symbols” (*Face*). Roche’s face suggests to others that something has gone terribly wrong.

At the deepest level, a distorted face can signify that God or the universe may be quirky and careless, or at worst, vengeful and punitive. When others judge a face to be marred, it serves as an unconscious reminder to them that the whole human experience, including their own, is one of being flawed.

(*Face*)

Awareness of this flawed human condition, according to Roche, provides the foundation for profound personal growth. And because of its value in reminding others of their own flaws, Roche redeems his facial difference by claiming it as “an elaborately disguised gift from God,” albeit the kind of gift that, “when you open it, you say, “Oh, you *shouldn’t* have.” He names “the gift” specifically: “My shadow side is on the outside, where I have had to learn to deal with it.” This return to the metaphoric space of disability equates his disfigured face with his “Shadow,” and configures the body as a reflection of the psyche. Roche takes the term “shadow” by which he means “my difficulty and challenge” from Jungian psychology, who first used it to describe the repressed or denied

part of the Self. The shadow is all those parts of ourselves we have split off, repressed or denied.²⁵ The “gift” of disfigurement is that in his dealings with himself and with others, Roche has been forced to confront parts of himself that might otherwise have remained unconscious. To survive emotionally and spiritually, he has been “forced to find [his] own inner beauty.”²⁶ This process entails recognizing that he cannot be reduced to the metaphoric darkness and chaos that his face suggests, that he exceeds his marked body.

FACING THE CORPOREAL BODY

Having insisted that he cannot be reduced to metaphor, Roche moves from the shadows into “the light of day” by bringing the house lights up. This simple move establishes that the body, or at least his body, is “real” and can be seen. Admitting that he is still shy about speaking about his face in public, Roche asks for “encouragement” from his audience, and instructs them to join together, on the count of three and ask him collectively, “What happened to your face?” After a long pause, he responds by offering a clinical explanation of his facial disfigurement. “On the left side of my head and neck is an extensive cavernous hemangioma. Basically, a hemangioma is a benign tumor consisting of blood

²⁵ Jung also referenced a “collective shadow,” projections of psychic or social qualities onto certain groups (as with projections regarding nature-based spirituality of Native Americans). The shadow is not necessarily negative, either collectively or individually. The primary marker of shadow material is that it is unconscious. “In the projection of ‘darkness’ and inferiority, in violence and oppression, in romantic projections, in the invisibility of current suffering, in the denial of current responsibility, we find the collective shadow” (“Facing the Collective Shadow,” *ReVision*, Summer 99, vol. 22, issue 1, p. 1.).

²⁶ Unpublished interview, 10/01.

vessels.” What is visually discernible from the audience is that the entire left side of his face is a purplish color, the left jaw line is uneven.²⁷

“Then, as an infant and child, I had multiple surgeries. My lower lip was removed, and parts of my face. I had very heavy radiation. This,” he says as he points to his left eye, “is a radiation burn, hopefully the last one you’ll ever see.” Invoking the spectre of his victimization by medical technology (not by the hemangioma), and displaying the horrors of radiation and the mutability of nature itself, Roche highlights the vulnerability of his own body while reminding audience members of the potent threat of nuclear annihilation. Again, here Roche moves quickly into humor so that the audience only briefly inhabits that awkwardly morbid moment.

What follows is a short but biting diatribe that shows Roche’s resistance to public scrutiny. He describes what I call a “hierarchy of hostility” in response to the query about his face. “People do ask me about my face. I don’t always feel like giving them a nice, educational answer.” At times, he tells interrogators that instead of having a “bad hair day,” he’s just having a “bad face day.” Other times, he’ll snarl and retort “Read my lip!” But his most hostile and wittiest response is one he has never used. “I’ve never done this, but I’d like to do this to some kid who’s acting really obnoxious. I’d say, ‘No, my face doesn’t hurt. My face is like this because when I was a little boy like you, I touched my wee-wee.’”

²⁷ Writer Ann Lamott describes Roche’s speech as “strangely like a brogue; like that of a Scottish person who just had a shot of Novocain,” emanating from “a crazy mouth, a jumble of teeth, only one lip and a too-large tongue.” (<http://www.davidroche.com/lamott.htm>)

When Roche returns the scrutinizing gaze to which he has just subjected himself, he takes the opportunity to look at the physical bodies of those in the audience, and to comment on their faces. In that moment of the gaze, they “become” their bodies, since their “selves” are not visible. “I see that you all have normal faces. You’re all very attractive, in a boring sort of way. The legion of the same.” Looking closer, he continues. “You have no scars! How do you people tell each other apart? Get a Face!” Not only is this a reversal of the gaze, but it approximates a verbatim reversal of the kind of unspoken hostility he sometimes elicits in public encounters. That unspoken dialogue might take this form: “I see you have a disfigured face. You’re unattractive, in a very specific way. You have so many scars! You’re a freak. Fix your face!” The effect of this reversal is that the audience gets a taste of what it means to be the object of the critical gaze. Aware that as individuals they exceed the “sameness” Roche attributes to them, “sameness” is revealed as a construction, which makes it easier for audiences to question Roche’s “otherness,” which is based on an assumption of (now tenuous) “difference.”

THE FRECKLE LADY AND THE “FALSE SELF”

Roche tells the story of the first time that he gave a talk about facial difference before a large audience. Afterward, “this very lovely woman” approached him and said, “David, you are so courageous. Oh, thank you so much for what you do. And, I really understand,” she adds, “because it was terrible for

me in high school, too. As a matter of fact, I'm still afraid of my freckles." His sardonic retort, addressed to the audience, is "Oh, yea, the heartbreak of freckles."

The comic aspect of the story depends on audience outrage at The Freckle Lady's preposterous assertion that she and Roche share equivalent social stigma. Initially, Roche totally resists that idea. He steps forward slightly, slams his right fist into his left palm violently, raises his voice and yells out that he wanted to "slap the freckles off her face!" Moments later, however, Roche tells the audience that he managed not to say anything at all to The Freckle Lady in that situation. He goes on to articulate an awareness that they share "the fear of disfigurement, or abandonment, or being unworthy." He follows with, "I submit to you that there is the *real* disfigurement."

What disables The Freckle Lady, then, is not the irregular pigmentation of her skin, but the fear that her body is unacceptable. Similarly, Roche's facial difference constitutes disability for him primarily in terms of the social processes, which come to bear on his body. The visibly flawed body (configured as the outer, apparent "self") belies the intact inner, invisible "self."²⁸ Because the body represents the self to those with whom we come into contact, the visibly flawed (devalued) body conveys a "false self," essentially misrepresenting a (positively valued) "true self" that has yet to be experienced in interactions. As Roche puts it, the "My shadow self is on the outside, where I have had to learn to deal with it." With the story of "The Freckle Lady," Roche relocates

²⁸ Elizabeth Grosz, in *Volatile Bodies*, discusses this body/mind or inner self/outer body dichotomy at length, resolving it by employing the mobius strip as an illustration of the interrelation of body and mind, vii-xii.

disfigurement from its position on his body onto the fearful psychic landscapes of his audience members. The “false self” of his body is exposed, his “true self” remains unexplored.

Erving Goffman’s theories of “actual” and “virtual” social identity can be usefully applied to Roche’s construction of his disfigured face as representative of a false self. In *Stigma: Notes on the Management of Spoiled Identity*, Goffman theorizes the construction of a “social identity” in which we develop ideas about what attributes are acceptable in those we meet. According to Goffman, we categorize unfamiliar people and set up the “complement of attributes felt to be ordinary and natural” for people in each category, which results in specific social settings predetermining, to some extent, the categories of persons likely to frequent them (2). Then we establish (largely unconscious, but sometimes quite arbitrary and consciously imposed) routines for interactions, in order to minimize surprise and avoid having to bring an analysis to bear on the situation. When an unfamiliar, a “stranger,” comes into our presence, then, first appearances are likely to enable us to anticipate her category and attributes, or to automatically impute her “social identity.” We give this person a social identity based on our expectations and anticipations, which are shaped by our social settings. Without really knowing this person, we assign a *virtual social identity* (Goffman is speaking before the term “virtual” came into common use, but it conveys a similar ethereal sense) – which means we “give” or impute to the stranger some attributes based on what we want or expect. The attributes a person might possess, which can only be known after more exposure to and interaction with the individual,

comprise the *actual social identity* (2). Stigma occurs when there is a discrepancy (a negative one) between virtual and actual social identities (3). This discrepancy effectively “spoils” the stigmatized person’s identity and has “... the effect of cutting him off from society and from himself so that he stands a discredited person facing an unaccepting world” (19). Goffman offers this explanation of the origins of the word and the concept of stigma.

The Greeks, who were apparently strong on visual aids, originated the term stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal or a traitor – a blemished person, ritually polluted, to be avoided, especially in public places. Later, in Christian times, two layers of metaphor were added to the term: the first referred to bodily signs of holy grace that took the form of eruptive blossoms on the skin; the second, a medical allusion to this religious allusion referred to bodily signs of physical disorder. Today the term is widely used in something like the original literal sense, but is applied more to the disgrace itself than to the bodily evidence of it (1).

According to Goffman, then, stigma relies on metaphoric association, and has from its inception. Instead of representing his “actual social identity,” Roche’s disfigured face, the source of his stigma, belies the “inner beauty” of his “true self.”

THE RISKS OF METAPHOR

Boldly embodying a metaphoric association of disability or disfigurement with psychic and emotional otherness leaves Roche open to criticism by those in disability culture, and others who actively resist the production of such characters and images. This resistance stems from the fact that there is a profound

difference between the lived experience of people with disability and disabled figures that populate literature and film. Ideas and images that circulate in the culture, and emerge through literature, film, theater and other cultural productions, shape perceptions that eventually drive political and social policy and behaviors.²⁹ Literary and filmic figures of disability range from “...extraordinary individuals whose lonely struggles against incredible odds” insure heart-warming stories of triumph to “saintly sages who possess the gift of second sight,” or “violence-prone beasts just asking to be destroyed” (Norden *Cinema* 3). Reducing the complicated experiences of people with disability to sentimental images and characters whose value is primarily metaphoric potentially hinders the development of awareness of the issues facing the disabled. Also, by rendering disability as metaphor, the specificity of the actual disabled body is at risk of erasure.

Kathleen Tolan’s article entitled “We Are Not a Metaphor,” in the April 2001 issue of *American Theater* magazine, shares a conversation between several disabled performance artists and writers. Lynn Manning, a disabled Los Angeles based poet, playwright and actor who is currently associated with the Mark Taper Forum, admits that he chooses not to use disability as a metaphor in his writings because “ ... disabled characters are too often used to represent some broken aspect of the human condition” Instead, Manning consciously writes disabled characters as fully individual, “...not a metaphor for something else” (Tolan 20).

²⁹ For a discussion of the ways that literature impacts society, and how public discussions of literary texts reflect political and social values, see *Citizen Critics: Literary Public Spheres* by Rosa Eberly, Illinois University Press, Chicago, 2000.

Cheryl Marie Wade, who began her theatrical career in San Francisco at the radical disabled women's theater *Wry Crips*, acknowledges that she resists the idea of "...the damaged soul who is often represented through a damaged body." Her response to the problem of metaphor is to "...tap into that compelling emotion that draws you into that kind of metaphor, but make it a real disabled person. We have to make our characters so compelling, and their emotional journeys so rich and so full, that we demolish some of those metaphors, and those kind of simplistic and narrow views of what it means. That's a damned hard job" (20). Still, Wade's comments hint at the possibility of a disabled performer effectively using metaphor as a tool, specifically through the development of a "real disabled person" or character.

Roche seems motivated to use metaphor in *The Church of 80% Sincerity* as a way to dialogue with the audience about imperfection. He understands that in many of his social encounters his facial difference refers to an assumed inward imperfection, and knows that imperfection is also a reality of all corporeal bodies.

In my work on stage, I acknowledge and play upon that universal sense of being flawed. Then I introduce a different, more powerful metaphor—one that is more true and more healing. One that is defined by its true owners, those who live it.

(Face)

This "more powerful metaphor" that is "more true, more healing," refers to the paradox of wearing your "inner darkness" on the outside. Living with facial difference has motivated his personal work so that his "imperfection" has made him whole. His clear intention is to claim bodily imperfection and shame, both for himself and for the audience.

I believe that seeing and accepting one's "flawed" condition is a core spiritual growth experience, an essential step in developing emotional maturity for all people, disabled and otherwise.

(Face)

Roche seeks to transform the metaphoric connections between facial disfigurement, fear and "darkness."

And in my work, the artistic metaphor of the scarred face conveys not fear but wholeness. This is a basic task for all of us in the culture of disability, to reclaim our own metaphor by using our best tools to stir the imagination of the audience.

(Face)

If occupying the metaphoric space of disability were Roche's only narrative device, *The Church of 80% Sincerity* could certainly join the ranks of plays such as *The Phantom of the Opera* that function as maudlin, mystical misrepresentations of disability, associating physical difference with moral and emotional deviance. As I see it, however, Roche uses metaphor initially as part of "managing interactions" with audience members. Like performers in *Actual Lives*, Roche is initially compelled to explain himself physically (to mitigate the stare) and then use his considerable verbal skills to put the "normate" audience at ease and insure that the audience can move from visual inspection (looking at him), to perceptual recognition (receiving what he has to say).

After his first few performances of *The Church of 80% Sincerity*, Roche realized that audiences did not "warm up right away" (*Interview 2*).³⁰ The feedback he received about that slow start with the audience was that "It takes

³⁰ The citation "Interview 2" represents material taken from an unpublished interview with Roche, conducted on October 12, 2002. "Interview 1" refers to an unpublished interview conducted on March 12, 2001.

them about ten to twelve minutes to get used to you.” He realized that audiences “want to look at me, physically look at me, to get used to my face” (*Interview 2*). Interestingly, Roche spends approximately the first thirteen minutes of the show engaging the audience through these metaphoric associations and putting them at ease in order to maintain an interaction.

Roche sees himself as wielding metaphor, not succumbing to it. “I feel like I’m trying to seize the metaphor of disability and bring it into our purview,” he states in a recent interview, and “Yea, I’m inspirational. And yea, you know what, I *am* fucking courageous. If you don’t think so, then put on a David Roche mask and try living inside of it. And see how you do getting up on stage and being a comedian. I claim that and I use that and that’s part, to me, of being seen as a whole person” (*Interview 2*). Clearly, Roche highlights the audience’s complicity in the process of projection of fear onto his body through his performance of “Igor,” and demonstrates through The Freckle Lady anecdote that all bodies have meaning, and that everyone falls short of the ideal. All of his maneuvers into metaphoric associations take the focus off of his body, play with relocating and redefining disfigurement, and give audience members a chance to get used to his face so that they can hear the autobiographical material to come.

MEMORY AS MEANING-MAKING: “INSTANCES OF CRUELTY” AND “MOMENTS OF GRACE”

Once Roche completes the work of illustrating the ways in which the flawed body conveys a “false self,” he moves away from metaphoric association and collective identity and employs autobiographical narrative to establish a “true

self” that transcends his problematic body. Because there is no viable resolution for his problem body, Roche’s autobiographical protagonist relies for acceptance on his ability to “follow the rules” of an ideological system that rewards conformity with acceptance, or avail himself of what he calls “unconditional love.” The family, the Catholic Church, and radically engaged Communism are all implicated in this war between forces that regulate the outlaw body (usually to no avail) and the power of loving acceptance (which can be transformative). Roche’s autobiographical anecdotes locate and make meaning of “instances of cruelty” which exemplify his inability to regulate his body or negotiate interactions across the boundaries of facial disfigurement and “moments of grace,” which instantiate unconditional love.

Family stories offer the first foray into this troubled terrain. Denial, or perhaps more correctly de-emphasis, of the facts of his physical difference allows family members to fully accept him. Denial becomes one of the major tenets of the “dogma” of *The Church of 80% Sincerity*. Raised in an Irish Catholic family, Roche learned early to deny his bodily desires and control his behaviors. His strict Catholic mother organized all seven children’s daily activities, regulated their bodily functions as much as possible, and held them accountable for every assigned task. Yet, her household rules “... were a comfort to me. I could follow them to win approval.”

Roche partially attributes his difficulty with self-acceptance to indoctrination by the Catholic Church. Catholicism contributed to his stigmatization through the idealization of the regimented and regulated body,

which he could never achieve. Sanctity was a product of self-control. The nuns of Our Lady of Grace enforced the regimentation of the bodies of their charges in the service of godliness. As school children, “We learned that God wanted us to march, single file, into church together. God wanted us to be in order by size. God wanted us to look holy.” Added to this denigration of the flawed body, is Christian dogma which asserts that humans are “innately evil, born with the birth defect of original sin.”³¹ This deep subtext of fear and shame was compounded by the guilt of accepting Christ’s sacrifice. At one point Roche quips, “If Jesus could take our sins, why not our guilt, too?”

Much of that guilt has to do with guilt over carnal desire. As a way of staking out some sexual territory for people with disabilities, Roche purposefully introjects the topics of masturbation and erotic desire. It was clear that “being raised Catholic meant being obsessed with sex,” and being required to repress it. “The priests conducted a war on masturbation” while Roche was in his adolescence. As his resistant gesture, he “learned to speak Latin and masturbate, simultaneously.” And, he learned to “pray.” In order to escape the damning consequences of “moments of carnal pleasure,” his ritual “prayer” became a cycle of “masturbate/confess/say a few Hail Marys, masturbate/confess/say a few Hail Marys.”

Perhaps the most profound “instance of cruelty” that Roche relates *in The Church of 80% Sincerity* was the Catholic Church’s decision to deny him a position in the priesthood because of his appearance. Instead of offering a safe

³¹ From “My Face is Not My Own.”

haven from the stigma he faced day to day, the church underscored the unacceptability of his body. Roche allows no “moment of grace” in his portrayal of the Church. Instead, he reveals his deep cynicism through a serious indictment expressed as a joke. When asked in an interview whether Catholicism or facial disfigurement had been harder to survive, Roche admits “They’re both in the top ten, I would say, in my life. I think that the effects of Catholicism probably run deeper.” Onstage, quoting an acquaintance who says to him, “Hey, Dave, that thing on your face. It must have had a really bad effect on your sex life,” Roche’s response is, “Yeah, but I tell you, it’s not nearly as bad as being raised Catholic. I call myself an *incense survivor*.” This allusion to incest, with its implied sexual violation by a trusted familiar, indicts Catholicism for spiritually violating him through a kind of piety that stunts sexuality and spontaneity, and impedes meaningful social relationship.

FROM CATECHISM TO COMMUNISM

Citing them as the “two least fun cults,” Roche traces his transition from Catholicism to Communism as a continuance of his “grim struggle” to gain acceptance and make the world a better place by following the rules. “I went from being a Catholic to spending a good deal of my life as a communist. I barely noted the transition.” As a good Catholic, he had become accustomed to “authoritarian hierarchy, rigid dogma, humiliation rituals, infallible leaders and,” he adds with a smug smile, “rampant alcoholism,” all of which were equally

operative for him in Catholicism and communism.³² Communism demanded total selfless commitment, of mind and body. “It was easy to be selfless when I had no sense of myself.”

It is in this secular world of ideological, instead of religious, commitment that Roche identifies an instance of cruelty that brought with it an important “moment of grace.” Standing terrified at the front of the #14 bus one day in San Francisco, dutifully speaking his own brand of Communist propaganda, he is abruptly interrupted by the strident voice of a white, middle class businessman, who yells to the driver, “Hey, get this disgusting, deformed faggot off the bus!” When Roche moves to the back of the bus to avoid further humiliation, an older white woman extends her hand to him, saying, “Son, you did a grand job, and,” turning to the businessman and pointing a harsh finger, “you’re the one who should be getting off the bus, you damn bully.” Two Latino youths also make a point of comforting him.

Here Roche performs his minority status, his vulnerable singularity, with the specific aim of eliciting audience sympathy. This “minoritizing” maneuver critiques a straight, white, middleclass masculinity that he cannot achieve and simultaneously makes it possible for him to ally himself with members of two other groups that he perceives as disaffected: elderly (assumed white) women and

³² Roche makes only this one reference to the role of alcoholism in his life. In performance, he keeps “all references to alcohol deliberately vague” (*Interview 2*), though he is not reluctant to speak about his alcoholism, or recovery from it, in private. Recovery from alcoholism was part of a process of “physical, spiritual and emotional rebuilding” that Roche underwent when he ended his activism as a communist and entered the frightening territory of life outside the constraints of institutional rules (*Interview 2*).

young Latinos. Roche transitions repeatedly from minoritizing to universalizing strategies as he relates his autobiographical narratives.

“Minoritizing” and “universalizing” are terms I borrow from Eve Kosofsky Sedgwick’s *The Epistemology of the Closet*. As I understand these terms, a “universalizing” discourse is one in which a member of a denigrated minority makes claims to commonality with, or membership in, the dominant culture. “Minoritizing” refers to maneuvers that call attention to or invoke minority status with specific aims (44). Sedgwick’s discussion of the tensions between universalizing and minoritizing is related specifically to queer identity issues, but the concept is applicable to disability issues as well. Minoritizing his position demonstrates Roche’s vulnerability and victimization and allows him to expose some of the social attitudes and practices that disable him. Universalizing creates emotional connection with the audience by drawing attention to experiential commonalities and minimizing otherness. This balance between uniqueness and sameness is negotiated in every performance of autobiographical material by people with disability.

THE UNIVERSAL EXPERIENCE OF EMBARRASSMENT

Like Jesus, who “took on the sins of the world,” Roche claims to “...take on the embarrassment of the world” and in so doing, uses his minoritized status as a facially disfigured person to focus attention on the universal desire to avoid embarrassment. “I talk about things I’m embarrassed about,” he says at one point in the show, “because I think you like it. I know I do. In The Church of 80%

Sincerity we've learned that the basic motivating factor for all human beings is not sex, love or preservation of the species, but the desire to avoid embarrassment.”

These embarrassing moments are essentially “instances of cruelty” that do not produce “moments of grace.” He relates an experience of visiting a singles bar on the north side of Chicago when he was in his early twenties. Before he even got into the bar, “this huge, drunken bouncer grabbed me and held me pinned against the wall,” held him there on display and yelled out to everyone in the bar, “Hey, Everybody! Take a look! Take a look at what’s tryin’ to get in here tonight!”

Roche avoids telling personal stories that depend on the specificity of his unique embodiment in order to emphasize his emotional and experiential commonality with audience members. He consciously omits from *The Church of 80% Sincerity*, for example, one of his most painful stories about being “... attacked by a group of 4 and 5 year old boys, in a child care center, who were calling me a monster. And attacking me with karate, and they were yelling “Kill the monster!” (*Interview 1*). Instead, Roche uses “... the bouncer story because it’s a more universal story; entry into a room that’s filled with strangers and being on display, whether it’s by a drunken bouncer, or just in your imagination, everybody has that experience, or feels that experience, or has dreamed that experience. That’s why I chose that story, because it’s not just my story, it’s a universal story” (*Interview 2*).

These “universal” stories, however, maintain their personal significance for Roche. “I have to cop to the fact that, with that the story about being too ugly to be a priest....that is still not a fully healed wound, I just give the audience a little break with that. So there’s a place where I’m probably at the 80% sincerity level. It’s an artistic choice, I try to have a balance in there” (*Interview 2*).

MODELING ACCOMMODATION

From the base of shared experience provided by storytelling, Roche launches an optimistic exploration of alternatives, figuratively constructing the Church of 80% Sincerity as his attempt to accommodate for the messy, unregulated body/selves that we all are. When Catholicism and Communism failed to provide the redemption and social change that he had worked for, Roche realized that he still “couldn’t get along without a benign institution to give me rules, to tell me how to behave, to tell me what to believe,” so he created an alternative institution with “rules” that leave room for the atypical body and the nonconformist spirit. “Eighty percent sincerity is about as good as it’s ever going to get,” he asserts, “eighty percent compassion, 80% celibacy. And we believe that you can be 80% sincere 100% of the time, or 100% sincere 80% of the time, makes no difference. The point is, 20% of the time you get to be yourself.”

Central to the Church of 80% Sincerity is an insistence on accommodation, a practice that has profound implications for people with disability. In the Church of 80% Sincerity, “the church of choice for recovering perfectionists,” accommodation is a given. If dogma or doctrine interferes with

the demands of daily life, no need to change behavior, simply change the doctrine. “We adjust our beliefs and practices to conform to the reality of human beings.”

Perhaps the most fully developed accommodation made by the Church of 80% Sincerity pertains to meditation. It is not surprising that Roche would take on New Age Spirituality, and specifically meditation, since he is interested in alternatives to mainstream religious practice and he lives in Marin, County, the de facto headquarters of New Age spiritual practice in America.³³ As a member of the Church of 80% Sincerity, anyone who is “too anxious to mediate,” or finds it “impossible to meditate for more than 15 to 20 seconds,” will not be required to “memorize a mantra in a foreign language, you get to just say what you’re thinking all the time anyway.” The “Anxiety Meditation” allows expression of fundamental doubts about the process of meditation, and other anxieties like “I have so much to do. Why am I doing this? This is such a waste of time.” Once the anxiety meditation is mastered, practitioners progress to the “Panic Meditation,” which is expressed through hyperventilation. Advanced practice involves the “Sex Fantasy Meditation,” and the “What Will I Do When I Win the Lottery?” meditation.

Roche, as Reverend Dave, even makes accommodation for those who cannot practice unconditional love. “We do believe in unconditional love,” he insists, “but we understand that the true nature of unconditional love is that it only

³³ By “New Age Spirituality,” Roche refers to non-traditional (at least non-traditional in America) religious practices that have come into the culture within the last 20 – 30 years. Marin county is the home of Spirit Rock Meditation Center, founded in the early 1907s, and one of the largest centers for the study of Buddhism through Vipassana Yoga techniques. Instruction in TM, Eckancar and many other New Age spiritual practices is widely available in Marin County and surrounding areas.

lasts a few seconds at a time.” Church of 80% Sincerity members are encouraged to express unconditional love, no matter how transitory, saying to your loved one, “Honey, I’ve been having these feelings for you that last about 8 seconds” or, “I’ll love you ‘til the end of dinner.”

This accommodation extends to unconditional love for yourself. Church members, including Reverend Dave, are not even required to love themselves unconditionally. If self-acceptance is too great a demand, then something less divine is acceptable. “I can stand in front of the mirror,” Roche explains, “I don’t even have to make eye contact if I don’t want to,” and if self-love is not possible, then some lesser form of self-acceptance will do. “I can look in the mirror and say, ‘You’re a nice guy, you’ve got a good sense of humor and you try hard, but hey, man, I just don’t love you Maybe we can just be friends?’”

Through *The Church of 80% Sincerity*, Roche creates his own cynically liberating doctrines, and redefines prayer and meditation, sacred space, grace, and salvation. To explicate the conventions of the church, Roche steps behind his “pulpit” and takes on the persona of “Reverend Dave.” Bracing an arm on the pulpit, he occasionally raises the other in an imitation of evangelistic rhetorical style. Accommodating for the human inability to live up to religious ideals, Roche’s Church substitutes vows of abundance, sensuality and creativity for the traditional Catholic vows of poverty, chastity and obedience. Reverend Dave replaces the “faith, hope and love” of Christian doctrine with denial, resentment and short term memory loss, “the three greatest gifts of God.” Denial shields us from the bitter intensity of reality, and “without denial, nothing would ever get

done.” Resentment is for “those twelve-step program graduates who know they should not persist in denial,” and may be the only reasonable response to being in touch with reality. Short term memory loss, “most of what passes for forgiveness,” makes sure that we don’t remember our past, and cannot precisely envision the future, so it forces us, finally, to “live in the moment,” which is the goal of all New Age religion.

There is no need for a physical structure for worship in the Church of 80% Sincerity, so there can be no physical barriers that require accommodation. Reverend Dave identifies the mundane space of the shower as a sacred space in which he prays his “daily prayer of terror and confusion.” The Church is actually an inner sanctum, an expression of Roche’s rejection of the dogmatic requirement for regulation of the body and mind and his desire for a flexible humanist belief system that allows him to be fully himself.

TROUBLING TRANSFORMATION

The ultimate accommodation in this work is Roche’s attempt to change the meaning of his facial disfigurement. Ever seeking a “sign from God, during Chapel Roche would kneel and pray “with my hands open a little bit, pointed up toward Jesus on the crucifix” praying for “laser beams” to “shoot out of the wounds of Jesus’ hands into mine, thereby giving me stigmata – the wounds of Christ.” Stigmata, rarified “eruptive blossoms on the skin” would be “proof that I was chosen and special,” not marked and rejected, and that there was “a reason that I looked the way I looked. “But no,” he says sighing, “not a scratch.”

We come to know through his performance that Roche's transformation is to be an internal, psychic and essentially social one, not a matter of changing the body. Challenged to be "fully present" while caretaking a friend who is dying of AIDS, relinquishing the hope of cure and the desire to effect change, Roche is asked by his friend to "just be here." The request is that he give up hopes of miraculous accomplishment and affirm the power of the moment and the vulnerability of the body. When Roche is able to be emotionally available to his friend, facing the certainty of death and the mystery of that transition, his friend's praise, "Good for you," makes him realize that relinquishing the need to "do" or to achieve is the beginning experiencing your "inner beauty." These two prayers, "Just be here," and "Good for you," become the central mantras of *The Church of 80% Sincerity*.

In the closing moments of the performance, Roche explains that though there were times that " ... I prayed for stigmata, the wounds of Christ ... I see now that I've always had my own stigmata." Roche refers here not to a "new" self, but to a self re-imagined as blessed, rather than cursed. The "transformation" is a perceptual one, based on the realization that his facial disfigurement is a special marking from God, and that this marking has been the vehicle through which he has come to understand himself.

I have discovered that I am a child of God. I am whole. And my face is a gift, because my shadow side is on the outside, where I have had to deal with it. Paradoxically, I have been made whole through, and with, what originally seemed to be my flaws. (Face)

By embodying embarrassment for the audience, Reverend Dave attempts to release the audience from body anxiety and shame. Looking intently at the audience, Roche recognizes their flawed humanity, their pain: “Now that I’ve had a chance to be with you, I see that you do have scars.” He asks them to forgive him for not seeing them in their complexity, knowing all too well how difficult it is for most people to see him in this compassionate way. “Please, forgive me for not noticing earlier.” And then, in a final poetic gesture, he attempts a total unity with the audience by claiming: “We’re all children of the darkness, and of the light, and we’re all wounded, and we’re all blessed and finally, we are all exquisite.”

ERASING DIFFERENCE

This universalizing strategy, an inclusionary gesture that all but erases any significant difference between Roche and his audience, reifies “Reverend Dave” as the sacrificial lamb whose life is offered to relieve the audience’s fear of embarrassment, and establishes Roche as the seer, not the seen. It is possible to view the transformation of Roche’s negatively marked, stigmatized body into the positively marked body that proudly bears stigmata in terms of a narrative trajectory of identity formation that has specific applications to people with disability. Roche’s narrative process introduces his marked body as object of the gaze, employs personal story to transition to the status of a speaking subject, and eventually allows him to perform his body/self as a “body for others.”

Perhaps all bodies are “bodies for others,” in that they serve such fundamentally social functions. *The Church of 80% Sincerity* is concerned with what Arthur Frank, in *The Wounded Storyteller*, calls “the shared condition of being bodies” and how such embodiment “becomes a basis for empathic relations among living beings” (34). Frank’s work focuses on illness as it impacts story, but its application to disability, and specifically to Roche’s work, is potent since Roche is invested in probing the relationship of self to body. Quoting Albert Schweitzer’s now famous allusion to the “brotherhood of those who bear the mark of pain,” Frank defines the sense of “other-relatedness” of the body/self as reflective of a “dyadic body” (35). The person who understands herself to be a dyadic body recognizes that “my pain is mine alone – but also shared”(36). Roche seems to express himself as a dyadic body, especially in the process through which Roche/Reverend Dave realizes that his “disfigurement” is both unique to his body and a part of collective experience. Frank asserts that storytelling, “the privileged medium of the dyadic body,” is “one medium through which the dyadic body both offers its pain and receives the reassurance that others recognize what afflicts it” (36). Performing on stage or in daily life as the dyadic body, according to Frank, represents an ethical choice to “be a body for other bodies”(36).

REPRESENTING DISABILITY

I include *The Church of 80% Sincerity* in my analysis of autobiographical performance by people with disability based on its contributions to the ongoing cultural dialogue about representations of disability. I am especially interested in

this work because of Roche's contested claim to represent disability, and because of the critical reception of the work from within the academic disabled community.

Roche embodies the difficulty of defining disability. Because he does not experience the same kinds of problems with access to the physical environment and social intercourse as those whose physical disabilities more significantly limit their function, Roche's designation as a "disabled" performer troubles some disabled people. "If he is going to claim the name," says disability activist Joyce Dawidczyk, a quadriplegic, "he needs to live the label. He doesn't have a disability, he just has some scars." Not quite "disabled enough" to qualify as a physically disabled performer, he is also not quite "normal enough" to perform anything *but* disability in traditional theater and performance venues.

Others in the disability community welcome Roche as a performer because he is willing to take on the project of speaking for the abject. Cheryl Marie Wade says of Roche:

David Roche is a theater pioneer, a major contributor to the emerging culture of disability. His groundbreaking work is helping to create and define a much needed disability aesthetic in the arts. He gives voice to people who have been hidden and shamed, people who have been named freak, monster and been made invisible by a society that worships shallow beauty. David cuts into the deep heart of difficult matters with embracing and insightful humor, grace and charm. He is a truly gifted communicator. His disability, facial disfigurement, is the strength and driving force behind his work.

(Roche website, quoted from *Disability Rag*)

Wade locates Roche's contribution to disabled performance in his willingness to give voice to disability and to confront issues of social meaning of disfigurement. Roche makes his own strident claims for a position within disability culture based on his symbolic value. "I'm part of disability culture because I symbolize disability. I think that everyone who has a visible disability is highly symbolic, we know that." He refers to himself as "95% able bodied," yet fully qualified to represent people with disability because of his shared experience of marginalization. "You know the ADA mentions that part of being disabled is being perceived as being disabled. I never understood how that got in there, where that came from, but I'm a perfect example of that" (*Interview 2*).

What prompts this argument about whether Roche is or is not disabled stems, at least partially, from a struggle over cultural capital. Roche has been fairly successful touring *The Church of 80% Sincerity*, and quite a few of his venues are disability-focused conferences, where he is billed as a disabled performer. He has toured 17 states, as well as Canada and Australia, performed at the White House, and was invited to the 2000 Cultural Olympics in Sydney, Australia, based on his role as representative of disability. These performance opportunities are so rare and so desired, and the burden of representation is so heavy, that the struggle heats up when there is any question about whether or not that representative is disabled. Until disabled performance is more widely practiced, and more enthusiastically supported, this kind of tension is likely to continue.

The second representational difficulty with *The Church of 80% Sincerity* relates to what disabled performer and theorist Victoria Ann Lewis has called “personal canonization” (99). Disability scholars see Roche’s choice to contain himself within the institution of a church, and to lay claim spiritual powers in his act of “transformation” as a capitulation to the traditional expectation that cripples are saints. Lewis points out that when there is only one disabled character in a play or performance, that character will “inevitably acquire a metaphorical status” (98). Narratives that stress the humanity of the subject (the “Hey, I’m human, too!” model) are especially vulnerable to this. Canonization reinforces the idea that disability is the problem of the individual, not the culture.

I argue, however, that to infer that “Reverend Dave” is simply a sentimental device employed to gain credibility with the audience through association with this kind of metaphoric “goodness” ignores the complex cynicism at the core of *The Church of 80% Sincerity*. In this case, the fact that Roche’s performance is autobiographical does matter, enormously. Reconstructing an institution that has rejected him, and reappropriating ritual, meditation and church doctrine, is a radical act of autobiography, born out of his personal experience, and not an acquiescence to social expectations about morality for disabled people.³⁴

There are several other aspects to *The Church of 80% Sincerity* that make it especially useful in this examination of autobiographical performance by disabled people. First, as solo performance, it manages to exceed the predictable

³⁴ It amounts to an elaborate disidentification, a term that I elaborate in Chapter Three.

narrative of singularity and isolation. Disability scholar David Mitchell, in *Body Solitaire: The Singular Subject of Disability Autobiography*, makes an interesting distinction between disability as represented in literature and disability in autobiography. In literature, disability “functions largely as a metaphor of social collapse,” while in autobiography, “disability represents the coordinates of a singular subjectivity” (311). Mitchell is interested in exposing “the lie of the age-old masculine fantasy of singularity,” in favor of a “more usable definition of self” (315). Roche, too, is interested in troubling notions of singularity, a notion he complicates by claiming a collective identity and by focusing his work on establishing both his unique subjectivity and his experiential connections with audience members. Negotiating identity across the dualisms of singularity/collectivity is an embedded tension in autobiography, and particularly in autobiography performed by people with disability, since membership in an imagined “disability community” often provides a sense of empowerment and identity unavailable to a person who experiences disability as an individual, personal, medical tragedy. Roche uses his collective identity to ease his marginalization, and performs his singularity in ways that allow the audience to connect with his experience.

Second, Roche effects a reversal of the critical gaze in *The Church of 80% Sincerity* in which he (and by association, others with disability) becomes the wielder of that gaze. This is an important maneuver for the success of his autobiographical performance, since it allows him to represent himself as a speaking subject, and it exemplifies the kind of successful management of

interactions on which people with disability depend in order to be perceived in their complexities.

Third, Roche also wrangles with tensions between “self” and “body” in complex ways that intensify the cultural discussion about disability and the body. The self portrayed in *The Church of 80% Sincerity*, despite the transformational tropes, is not a new self, but rather represents a new awareness of “who I have always been” (Frank 129). A character “not so newly discovered as newly *connected* to its own memory” in a process that reinterprets the past in terms of the present and then “takes on an enhanced meaning” (129). The ability to make meaning from past experience and to proffer that newly constructed meaning to non-disabled audiences has potential for changing social attitudes toward people with disability. Dissociating from his body to present the marked body as the “false self” has powerful, and perhaps unpopular, ramifications, especially since the “true” or truer self is presented as an inner dimension and therefore disembodied. Instead of resolving the conflicts between his body and his “self,” Roche enacts the conflicts, and this very enactment raises the level of dialogue about the complicated relationship(s) between body, self and disability.

Fourth, Roche envisions alternatives to regimes of thought and practice that oppress him and others with, and without, disability and physical difference. Theatre critic Jill Dolan, in “Performance, Utopia, and the ‘Utopian Performance,’” theorizes that “Audiences are compelled to gather with others, to see people perform live, hoping, perhaps, for moments of transformation that might let them reconsider and change the world outside the theatre, from its

macro to its micro arrangements” (Dolan 455). Roche delivers this opportunity for reconsidering the possibilities. Describing a flexible, humanist, accommodating “church” that offers acceptance without the need for physical or ideological conformity, he models a social environment in which people with disability can thrive. He believes in performance as a vehicle for change. “I don’t think, after spending 10 years as a communist, that change comes about through information, intellect or through education,” Roche comments. “ It doesn’t happen that way. I think that there are two main ways that change happens; one is through violence, and the other is through a change in the imagination, or the heart. Hooray for the arts, in other words!” (*Interview 2*).

Finally, it seems important to remember, when everything is said and done, that Roche is still only 80% sincere. He introduces incredibly important, painful issues, but is careful to constantly infuse humor into them. He does things that a good, politically correct disabled performer should not, but he does it as a reflection of his own lived experience, from an autobiographical impulse, without apology. Yes, he toys with inspirational themes, and he admits to a certain persistent, driving spirituality, and his work straddles the borderline between the maudlin metaphoric and the sentimentally comedic. Just the straddling is worth it.

Chapter Three

Out All Night and Lost My Shoes

My disability is only one part of the whole shebang, and it is an essential part only in that it acts as a focal point for the rest of it – madness, warmongering, tragic accident, power play, arrogance, just plain old fucking fate.

Terry Galloway

2/12/03

To be out all night and lose your shoes is to return home breathless and barefoot, having narrowly escaped a kind of danger that only those who have wandered in the darkness can know. There is more than a hint of wildness in the phrase, of risk and vulnerability. Terry Galloway's signature autobiographical performance piece, *Out All Night and Lost My Shoes*, puts audiences in touch with the terrible vulnerability of being human, of being helpless to resist "the primal thing itself," expressed as the violent force of nature, and of culture, that threatens, always, to annihilate us. Galloway's work insists that art makes us tough enough to face the worst, and that laughter may well be the only real recourse to the threat of ultimate annihilation.

Galloway is a hearing-impaired writer, director and performer, who has performed professionally for more than two decades. Despite her deafness, she speaks intelligibly and is an exceptionally good lip reader, which enables her to access mainstream hearing culture and perform ensemble work with hearing performers. She was instrumental in establishing *Esther's Follies* in Austin,

Texas, one of the longest running musical comedy theaters in the Southwest. Beginning in 1976, she played *Esther's* every weekend, cross-dressing as parodic private eye character "Jake Ratchett, Short Detective," with a series of female partners. Drag Queen Toni Denise, who was always "a knockout in a tight red dress," was Galloway's leading lady when she first performed Jake for the *Mickee Faust Club*, the theatre ensemble she and partner Donna Marie Nudd started in Tallahassee, Florida. At *Esther's* and as a regular performer in Shakespeare at Winedale, an alternative summer Shakespeare festival held annually in central Texas, Galloway quickly developed a reputation in the late 1970s and early 1980s for playing comic male roles on stage. Galloway's plays and performance pieces, including *Out All Night and Lost My Shoes*, *Heart of a Dog*, *Lardo Weeping* and *In the House of the Moles* have been produced around the world in venues ranging from the Manhattan Theater Club in New York to the Zap Club in Brighton, England and her articles, essays and poems have been widely published.

She now divides her working life between Austin, Texas and Tallahassee, Florida, where she heads *The Mickee Faust Club*, a community based alternative theater most recently documented in *Performing Democracy, International Perspectives on Urban Community-Based Performance*. *Mickee Faust* productions include at least two explicitly queer skits in each of their cabaret style performances. As a lesbian performer who writes from a queer sensitivity, Galloway contributes to, and often performs in skits such as "The Gay Caballero" (a parody of "Zorro") and "Boot Scootin' Beauty" (Transsexuals at the Truck

Stop). In Austin, Texas she works with various theater groups including the *Rude Mechanicals* Theatre Collective and the *Actual Lives* Performance Project.

Out All Night and Lost My Shoes owes much of its content to a previous show entitled *Heart of a Dog*, which Galloway developed from two even earlier one-woman shows while she was living in New York City. The first was *A Texan in Berlin*, performed in 1981 at the WOW Café, an alternative performance space in Manhattan's Lower East Side that became known as the lesbian "home for wayward girls" during the mid 1980's (Carr xvi). Portions of *True Crime*, performed at the Limbo Lounge in 1982, where she performed frequently with a group that called itself "Bimbos from Limbo," also made their way into *Heart of a Dog*, which debuted at the American Place Theater in June of 1983, directed by Suzanne Bennett and produced by the Women's Project.

My approach to *Out All Night and Lost My Shoes* is both archival and analytical. Although Apalachee Press published Galloway's script in 1993, it is no longer commercially available and there is no videotaped record of the show. My work here is informed by a recent script draft on loan from Galloway. In much the same way that I attempt to partially archive and re-present David Roche's *The Church of 80% Sincerity* in Chapter Two, and for quite similar reasons, I include a substantial exposure to the text in this analysis of *Out All Night and Lost My Shoes*. Because I situate *Out All Night and Lost My Shoes* as an example of "disabled performance," an act that extends the category to include works not specifically disability-identified, I offer readers a familiarity with the text designed to assist them in deciding the merits of my argument. Additionally, I

hope that my inclusion of examples of identification-based moments, along with instances of disidentification-based performance, will make clear how Galloway establishes a performative self that is and is not disabled.

I approach this work thinking about the ways in which Galloway identifies, narrates and performs herself on stage. Two specific strategies seem to be at work here. Galloway uses the first few sketches of *Out All Night and Lost My Shoes* to produce what I am calling “identification-based performance,” in which she creates a multi-layered picture of an autobiographical self that spans from childhood to the present. This persona is historically situated, culturally shaped, inflected with queer desires, and somewhat determined by Galloway’s deafness. Having established her identity, and complicated it enough to keep her audience interested, she then produces a series of “disidentification-based performances.” In these disidentificatory personas, Galloway’s deafness either disappears or is infused in such a way that it subtly shapes the performance.

José Esteban Muñoz develops the term “disidentification,” in *Disidentifications: Queers of Color and the Performance of Politics*, as a way to discuss the process whereby a performer appropriates a phobic object and reconfigures it as valued, or manipulates a valued object (or person, or practice) to re-perform its sinister side. He sees disidentification as a survival strategy for marginalized, minority subjects in their attempts to “negotiate a phobic majoritarian public sphere that continuously elides or punishes” those who cannot conform to white heteronormativity (4). Muñoz is concerned with the cultural positioning of marginalized people – people of color, queers, queer people of

color – and discusses identification (which leads to cultural assimilation) as the usual response to dominant ideology, and counter-identification (an oppositional stance that demands cultural change from an outsider position) as its opposite. Muñoz is trying to stake out some conceptual territory that offers a third possibility – the possibility of disidentifying from practices or attitudes, while recognizing that these same practices retain some cultural use value, then re-imagining a way to replace or revise them. For doubly minoritized queers of color (or, possibly, for deaf queers), disidentification is a way to read and decode a mass culture that excludes them, and then perform alternatives. Muñoz locates that re-imagining in performance work by Marga Gomez, Carmelita Tropicana, Pedro Zamora and many others. I hope to usefully employ his theoretical framework in application to Galloway’s performance.

GALLOWAY’S ART OF AUTOBIOGRAPHY

When Terry Galloway approaches autobiography in performance, when she “narrates herself into existence” on the stage (*Answers*)³⁵, she leaves behind any notion of the singularity of the self and performs multiples “selves.” For Galloway, the question is not so much why she creates an autobiographical self and enacts it through performance, but why she chooses to create multiple characters in this autobiographical play, instead of narrate a singular (perhaps more intelligible) autobiographical self.

³⁵ “Answers” refers to e-mailed answers to questions, received on 2/12/2003.

Galloway's understanding of the multiplicity of identity drives the decision to present autobiography as *characters*, instead of presenting a cohesive "self" as the subject of autobiography. Each of the different characters she portrays speaks both for and about her in specific ways, enacting the complexity of her experience. Just as disability is only one of Galloway's identity markers, autobiographical narrative is just one of her tools for self-expression. And her performance "topics," too, extend beyond the traditionally autobiographical narratives evidenced in *The Church of 80% Sincerity* and *Actual Lives* to include characters who function as cultural critiques.

In terms of art as cultural power, Galloway has a distinctly different relationship to both art and cultural power than David Roche or *Actual Lives* members. *Actual Lives* members use expressions of the experience of disability, realized through their voices and bodies in performance, to create disability public culture, exercising a new kind of cultural and political power that emerges through artistic expression. For Roche, and for *Actual Lives*, artistic expression is always connected to disability. Not so for Galloway, who uses her already established reputation as a performer, her most potent form of cultural power, to authorize her expression of disability in this piece (her only performance piece that addresses disability and its effects). Like Roche and many of the performers in *Actual Lives*, Galloway believes in the transformational power of art, but for Galloway that power seems much more personal. She is as interested in the ways in which art can be transformative *for herself* as she is in transforming the audience, a point I illustrate in my discussion of the "Mr. Handchops" piece in

Out All Night and Lost My Shoes. Galloway presents these many facets of herself, these autobiographical selves, within a narrative framework that emphasizes mortality and vulnerability, not just of disabled people, but of all of us. Using identification-based performance, complex disidentifications, and personal stories, Galloway locates herself at the troubled borders of the identities of queer, deaf and female, and carves out public space for the kind of complex subjectivity she experiences in her daily life.

A FAKE MISTAKE

Out All Night and Lost My Shoes takes place on a stage that has been ravaged. In this back alley dumping ground, metal garbage cans and broken glass lie scattered on the floor, and amid them a broken toilet and a janitor's wheeled bucket and long-handled mop are visible. A small wooden table with a chopping knife embedded in it has landed on its side near a battered dining room chair. Early Elvis music plays in the background. The audience joins Galloway in an imaginary space that she has constructed, a space visually coded as culturally devalued, an outsider space. A designated "straggler" comes into the theatre as the lights fade down, shutting the door quietly behind her in a polite gesture of respect. As soon as the straggler is seated, Galloway bursts through a door at the back of the theater and then slams it loudly shut.

The deliberate slamming of that door breaks the formality of the theatrical conceit and may appear to audiences as an unintentional "mistake" made by a

deaf woman. This fake mistake makes it appear that the audience now knows something the performer does not, that they have caught her in the act of performing her own deafness, unaware that she's just slammed a door. Whether they respond to the loud noise or pretend to ignore it to spare her feelings, audiences must negotiate this unexpected event, a comment on deafness and theatricality, as part of their introduction to *Out All Night and Lost My Shoes*. This "trick" creates a kind of condescending tension, or distance, between Galloway and audience members who may be ready to forgive the mistake. Galloway recognizes that her audiences will allow her more intimacy if "I make a kind of small fool of myself" and "break the formality of the situation in which we find ourselves" (*Interview*),³⁶ so she is willing to create this illusion of error.

On her way to the stage, Galloway introduces herself to the audience quite casually, asserting as she approaches the stage that "this is not high church theatre, it's low rent performance,"³⁷ the difference being that high church theater would demand that she "pretend that you don't exist." Effacing the formality of theatre in this way confronts the complacent expectation that the audience is there to watch a seamless performance from their distance as onlookers. Galloway purposefully disrupts the convention through which she is required to be the "actor" and we are the audience because she wants us all to be in this thing together.

³⁶ The parenthetical citation "*Interview*" refers to an unpublished interview that I conducted with Terry Galloway on March 26, 2002.

³⁷ Quotations not followed by parenthetical citations are taken from the script text of *Out All Night and Lost My Shoes*.

Galloway is interested in placing herself within a family context, which she does through the story of “Snake Canyon,” a “bedtime story” that establishes Texas as a mythical space, only partly knowable, with “savage and unforgiving” parts. Snake Canyon is imagined “both as a place and a danger – as if it were a home to some primal Thing itself.” The story’s central image is of Grandmother standing one morning in the doorway of her baby boy’s room, “barefoot, still in her nightgown,” frozen in terror, watching the “little, blue last-breath bubble” come from his newly stilled body. Grandmother “didn’t say a word, didn’t make a sound,” just picked up the baby and ran. “She ran just as dawn was breaking. Barefoot. Through Snake Canyon.”

By introducing issues of accident, death, and loss, themes that prompt the audience toward an awareness of our shared vulnerability to forces beyond our control, “Snake Canyon” sets the emotional tone for *Out All Night and Lost My Shoes*, containing all of its essential thematic elements. It captures the melancholy of human vulnerability and loss. The wilderness of Snake Canyon prefaces the urban wildernesses that emerge in *Out All Night and Lost My Shoes* as the site of constant negotiations of identity and sanity. Granny Doris’s flight through Snake Canyon creates a character that is vulnerable to intense emotion, someone who may be a little crazy, but tough enough to take it. And, if “Snake Canyon” really was a bedtime story, then Galloway and her siblings had to be tough little children just to hear it. Toughness as a response to the consistent vulnerability we face as

humans becomes a major theme of *Out All Night and Lost My Shoes*, though getting tough is just one of Galloway's responses to that vulnerability.

Like Roche, Galloway consciously reverses the critical gaze and comments on the process of performing. Addressing the audience directly, she declares: "As a general rule, performing makes me sick." Pausing a moment to allow the inevitable laughter, or the frequent gasp elicited by this comment, she continues. "No, come on, think about it. How would you feel if I had the cultural authority to kick back and say, 'Not worth the ticket price'?" Galloway comments here on how performance creates a critical distance between performer and audience, referring directly to the distance she addresses surreptitiously in her opening. "But here I am again," she continues, "I think its because it's the only thing I've ever found in life that reminds me of being home with my mother's family." She remembers evenings when "the whole family crowded into one room, everybody stays up a little late, and it's kind of an 'occasion.'" During those occasions, the family would talk about "who lived, who died, what they wore. The important things." Here Galloway equates theatre (where people crowd into one room, stay up late, and create an occasion for listening to stories) with family, and thereby includes her audience in the category of "family," at least in a momentary, temporally bounded, site specific family (one type of family that many queers construct).

WHAT HAPPENED TO YOU?

Galloway engages the “What happened to you?” question in much the same way that *Actual Lives* performers and David Roche handled this query, using explication as a conscious corrective to the denial of disability that figured so prominently in her earlier life. “I wouldn’t want to do *Out All Night and Lost My Shoes* without that kind of explanation,” she explains, because “I hid [my disability] for so long, I tried to avoid it for so long, it embarrassed me for so long ... my own attempts to pass, to manage, to do without [hearing], it made me very angry” (*Interview*).

In order to answer the question, Galloway locates herself and her family in Berlin in the 1950s, her body a product of “reckless experimentation and doctoring that seems to characterize the fifties and sixties”(Nudd 29). For many audiences, this cultural and temporal location fosters associations with Nazi Germany and fears about annihilation, which serves her purposes well because she is working toward a recognition of the threat of ultimate annihilation, on which a large part of the show’s emotional appeal relies. Like Roche’s reference to radiation, Galloway believes that the fears engendered by “the accidents” of her own life are “shared fears because those kinds of accidents happened all the time, though often on a much broader scale” (*Interview*).

Born as a “perfectly normal child,” Galloway’s disability wasn’t “discovered” until later in childhood when her vision and hearing problems became more pronounced. Reproducing the exact medical terminology used to describe the etiology of her deafness, with a characteristic Galloway twist, she

explains that “a chemical imbalance caused by the introduction of drugs to the fetal nervous system” had left her “not quite blind as a bat but definitely deaf as a doornail.” Referring to herself not as a “modern medical miracle,” but as a “modern medical accident,” Galloway emphasizes the culpability of medical practice in creating her disability. “I wanted to put some things straight,” she explains when asked about her motivations for addressing this directly, “I want people who are culpable to be shown to be culpable” (*Interview*).

Her tone is not so much angry as melancholy, or resigned. Perhaps it is her understanding of the relationship between autobiography and truth that takes some of the anger out of her answer to that question. In the conscious act of constructing a “version” of the truth, the innocence of autobiography is lost. As autobiography scholar Leigh Gilmore asserts in her essay “Policing Truth: Confession, Gender, and Autobiographical Authority,” what we “have come to call truth or what a culture determines to be truth in autobiography, among other discourses, is largely the effect of a long and complex process of authorization” (55). Authorizing herself to tell a version of the story of her disability that omits the fact that the doctors who caused her disability were also “the people who saved my mother’s life” (*Interview*), Galloway entertains the more complicated reality in her mind, and that other truth mediates her anger. Galloway’s truth, and the “truth” of all autobiography, is constructed by consciously giving order and meaning to life events, privileging certain feelings over others, claiming and denying motives for actions (and failures to act), and sifting memories.³⁸

“BY THE TIME I WAS TWELVE, I WAS A FREAK.”

Galloway continues her confrontation with deafness as identity marker by performing the transition from childhood into adolescence as a site of traumatic identity formation through the introduction of a character I will call “Terry-as-12-year-old freak,” which she brings to life via memory and representation. In much the same way that Simone de Beauvoir posits, in *The Second Sex*, that one is not born a woman but becomes one, Galloway explains that she “became” deaf in late childhood, struggling to make sense of biological reality as it related to identity. She began losing her hearing “in chunks” just as she moved from childhood through adolescence and into adulthood, but had no way of understanding herself as a “deaf person” (*Listening* 183).

Out All Night and Lost My Shoes remembers childhood as full of sound and story in a complex family context, while adulthood is figured as a site of silence and alienation, which renders adolescence an unusually rich transitional site marked by loss and humiliation. Taking cues from medical and rehabilitation discourses that describe her as abnormal, she “freaks” herself to the audience:

By the time I was twelve I was a freak. I had not yet had the years of speech therapy that allow me to speak this clearly. Naoh. Ayoh taulked kinna lahk des. Or the miracle of contact lens. Or the clever little behind-the-ear hearing aid like this one. No. My first hearing aid was a huge box the size of a Walkman that hung on my chest like a third breast. I had just gotten my breasts. I had just started my period. I had hairy legs and hairy underarms because my mother wouldn’t let me shave. I had a dork kid

³⁸ See Gilmore, p. 69, for a discussion of autobiographical truth.

haircut, and I'd just broken my two front teeth playing a game of war. I was fat as a pig and wore these pink cat-eye glasses, always broken, of course. And I desperately wanted to be normal.

This re-enactment of adolescent misery establishes Galloway's vulnerability by highlighting her physical and social outsider status. She seems to be "queering" her childhood here, focused on the ways her body did not fit. Notions of queer childhood assume this pre-adolescent outsider experience. This passage also serves as a likely site for emotional connection with the audience, since her representation of the bodily trauma of adolescence creates an opportunity for several kinds of audience response. Anyone who remembers their own body-related adolescent awkwardness, those with and without disability, might relate to Terry-the-12-year-old freak through identification with the frustration inherent in this awkward passage to adulthood. Deaf audience members have the option of identifying with her struggles to deal with deafness and adolescence simultaneously, or refusing an identification because Galloway is not authentically deaf, not part of deaf culture, even objecting to her depiction of the "trauma" of deafness. "ABs" (able-bodied audience members) might feel guilt about their able-ness, a guilt that Galloway begins to illuminate, and perhaps evoke in her audience, in the "Lion's Camp" monologue.

Yet, Galloway configures deafness as one of many bodily differences that became adolescent trials, as only part of what was "freaking" her. Galloway acknowledges her vexed dependence on prosthetic technology, which, at that point, was still quite crude:

I would hide my hearing aid box inside my blouse. But it's a microphone so there's feedback – beep, beep. And every time I took a step everything moved along with me – and you'd better believe that nothing was going to come along quietly. I would take a step and it was: Bounce Bounce! Beep Beep! Bleed Bleed! I'm a monster, a monster! BounceBounce! BeepBeep! BleedBleed! Trapped in here forever! Somebody save me! Save me! BOUNCEBOUNCEBEEPBLEEDBLEED! (repeatedly)

Galloway puts her whole body into performing this freakish adolescent version of herself, affecting a “monstrous” labored gait and emphatic arm movements as she steps forward with each “bounce bounce beep beep bleed bleed” repetition, gesturing wildly as her voice reaches the final crescendo of the last line, which she virtually yells.

Galloway's performance is so viscerally relayed that it is not difficult to imagine Terry-as-12-year-old-freak standing before the audience. Galloway's use of her body to achieve dramatic effects sets her performance apart from Roche's *The Church of 80% Sincerity* and *Actual Lives*. Galloway's physicality allows her to convey emotion and add emphasis in ways that the physically disabled performers in *Actual Lives* cannot, partly because they have less command of their bodies, and partly because they have less experience as performers. Roche concentrates on the power of narrative in his performance and has a much more limited repertoire of physical expression.

The vividness of Galloway's performance establishes her freak-ness as a spectacle, one, which often produces uncomfortable laughter and allows a range of other responses as well. Galloway admits that she wants audiences to “gawk” at Terry-as-12-year-old-freak, to catch themselves in the act of staring, and to witness the transition, perhaps the transformation, from adolescent freak to the

Terry-of-here-and -now, as a way to ask the audience to move with her through her various positions in relationship to disability (*Interview*). Temporally locating this monologue of adolescent misery in an unspecified remembered past, devoid of geographic specificity or particularity of context, Galloway suggests that her status as outsider was stable across multiple social contexts. That outsider relationship to mainstream culture was dramatically confirmed when her parents “shipped me off to the Lion’s Camp for Crippled Children.”

Lion’s Camp was Galloway’s introduction to other children with disability, and to the idea of disability as a possible identity category based on physical differences that were viewed as flaws. Experiencing herself in the context of “crippled children” was not reassuring, but terrifying. “I was bewildered by the array of things that could go wrong. And I wasn’t even that familiar with what had gone wrong with me. It was all brand new to me” (*Interview*). When awards night arrived at the end of camp, Galloway remembers recognizing her relatively able position in the hierarchy of disability at the camp, watching “a steady stream of kids going up to the stage to get their awards,” kids “without legs, kids with artificial legs, kids on crutches, kids in braces, kids in wheelchairs.” She sits alone in her isolating quiet, understanding that she is not-quite-disabled-enough to fit in with this group without feeling guilty for her abilities. Rising to accept her swimming award, won in “competition” with a group where she was “the only one who could do much more than float,” in a moment of sheer panic she limps all the way to the stage, and limping back on the

other leg, she pauses to think that “even with all the paraphernalia making my handicaps visible - among those kids I’d just never be handicapped enough.”

The Lion’s Camp monologue situates Terry-as-12-year-old-freak on two cultural margins: she is not “handicapped enough” to easily adopt disability as an identity and not “normal enough” to move undetected through the larger mainstream culture. Like Roche, Galloway never has an easy fit, but unlike Roche, she willingly probes that experience. Galloway’s self-consciousness about her membership in the category “disabled” allows her to foreground the question of authenticity, which seems to lead the audience to question the meaning(s) of disability as well. This kind of identity struggle only rarely surfaces in *Actual Lives*, because most of the performers are not situated on this particular border.

In the Lion’s Camp monologue, Galloway also *freaks the other children*, seeing herself more as “normal” in comparison to them, as not belonging to the category “crippled children.” It establishes her guilt about her relative able bodied-ness, guilt that motivated her to walk down that aisle with a limp. Galloway’s articulation of her own guilt allows audience members to align themselves with her in guilt, which is something she counts on for the fourth performed identification-based narrative, *People Love Their Freaks*.

PEOPLE LOVE THEIR FREAKS

In *People Love Their Freaks*, Galloway effects a temporal shift from a remembered adolescent past to a more recent past in New York City, and invites the audience to look back on Terry-as-12-year-old-freak with her. Reminiscent of

Roche's vision of "disabled chic," Galloway introduces *People Love Their Freaks* as a literary recovery of a lost connection with a young quadriplegic woman she met at Lion's Camp. This "beautiful," "sweet," nameless girl, "paralyzed from the neck down," an "older woman" of thirteen, enticed Galloway into helping with her personal care each morning, and Galloway "fell in love with her." Galloway (grabbing the wheeled mop bucket to demonstrate the movement) tells us that she would push her friend's wheeled bed down "the verboden hills," and "sometimes she fell out." Together, they negotiated their first summer at Lion's Camp, and developed an intimacy based on their shared identities as disabled.

Many years later, in the here-and-now of *Out All Night and Lost My Shoes*, Galloway tells us that it's different now. Living in New York City, experiencing the shift in cultural attitudes toward difference, she has become aware that "everything that had humiliated us as children – the weird glasses, the thick soled shoes – was all suddenly woo! Hot stuff." Eager to tell her long lost friend that times have changed, and that now it's cool to be disabled, "it's fashionable to have something wrong with you," Galloway realizes that this girl is now only a memory, without a name. She expresses her feelings in a letter, the perfect device for one-way communication. "Dear Friend," the letter begins, "I know just how you feel. But remember – nobody's the real thing. I mean, just look at me – no ears, weak eyes, teeth broke, fat butt and these legs." She repeats that litany of complaints about her bodily faults several times in the letter, drawing attention to the fact that even with these bodily limitations, she's

suddenly in demand. “It’s different somehow out here... Here, people *love* their freaks.”

Trying to explain how this change has happened, Galloway notes that “It helps to have a beautiful face, which I do.” But it isn’t all about looks, it’s about attitude. “Ever since I took up the old trombone my status changed; suddenly this – no ears weak eyes teeth broke fat butt and these legs! Suddenly they are in demand!” To “take up the old trombone” is to “toot your own horn,” to occupy your space of difference with an attitude of defiance, perhaps even celebration. Galloway goes on to celebrate an emotional and sexual connection with her nameless phantom love. In one moment of wistful longing, she remembers “... those beautiful afternoons when I pushed your wheeled bed along the banks of the Rio Grande, And moved your head tenderly to the side so you could see across to the Mexico of your dreams.” Declaring the erotic desires they shared, the kisses that were “...the purest love I’ve ever had,” Galloway promises that she will “never forget them or you, my darling, No, I’ll never forget them or you, and I will write, I promise. Real soon.”

People Love Their Freaks allows Galloway to perform an erotic call to a remembered girl, a wistful call that will never materialize into anything more than that memory. From the dreamy distance of memory, Galloway can eroticize their connection by articulating her lesbian desire. The nameless girl becomes the object of Galloway’s sexual and romantic desire, and seems to be the possessor of sexual desires of her own. *People Love Their Freaks*, then, not only solidifies Galloway’s identification as a “freak” in terms of bodily difference, it locates her

in a queer identity, or at least a queer “phase” of sexual identity. That queer identity was important for her to establish early in the show. “I want the audience to know who they’re dealing with early on,” states Galloway, “I don’t want to give them the satisfaction of relegating me to the position of this harmless little deaf girl – that they can go ‘ahh,’ to, spend all their time going ‘ahh,’ I want them to re-think it. And I also want them to think about eroticism and body” (*Interview*).

People Love Their Freaks also demonstrates some of the connections between guilt and love. Galloway’s guilt over her own relative ability (guilt that first surfaced in “Lion’s Camp”) motivates her empty promise of remembrance for a girl who has been forgotten, and yet not forgotten. In an act of remembering, however incomplete, the act of bringing this girl’s image to an audience, Galloway insists, “I am allowing them to love her. I am letting them feel that sorrow for me as well, for the child I was, for the children we all are ... I have returned to her in the abstract, continued to love her, to express that love” (*Answers*). *People Love Their Freaks*, then, is about the delicacies of love, about how much love and remembrance depend on access to the body. Perhaps most importantly, though, *People Love Their Freaks* reminds us that there is no escaping the process of attaching social meanings to the bodies of people with disability. Galloway’s bodily difference may have been in style for a time, but style is fickle. And, unlike Roche, she does not believe in the possibility of willfully transforming the meaning of her body, rather recognizes that her body will be the site of endless meaning-making by others. Galloway wonders “When

that fashion runs out, what replaces it?” and hopes for a cultural evolution that will allow people to “look beyond the body all the time, to see the person” (*Answers*).

These engagements with deafness and identity in *Out All Night and Lost My Shoes* do the work of revealing Galloway’s personal history and evoking emotions that, hopefully, foster an intimacy between Galloway and her audience. By reminding us of our need for and vulnerability to the dangerous technologies of medicine, comically reenacting the pain of growing up, confronting issues of difference and disability by exposing the social constructedness of categories of difference, Galloway establishes her vulnerable subjectivity, and challenges audience members to consider their own.

JAKE RATCHETT: SHORT DETECTIVE

Through the character of “Jake Ratchett, Short Detective,” Galloway critiques one possible response to vulnerability: toughness. Jake Ratchett is a complex disidentification with a stylized hyper-masculine toughness, through which Galloway is allowed to re-imagine the kind of toughness that really matters. In the emotional context of *Out All Night and Lost My Shoes*, Galloway’s motivation for “becoming” Jake hinges on the idea that people misrecognize her, and misperceive her gestures of friendship, a misidentification based on gender bias (not deafness).

Galloway’s transformation into Jake Ratchett occurs completely onstage, accomplished through appropriation of a “tool” usually coded as feminine: an

eyeliner pencil. The first change she makes is to her “beautiful face.” Pulling the eyeliner from her pants pocket, declaring it as the “only defense” against the triple vulnerabilities of being female, disabled and queer, she draws the outline of a beard on her face. As she darkens her chin with the eyeliner, Galloway describes the misfire of much of her communication. “Part of my problem is that I smile a lot. And there are people out there who think that when I smile and say hello I’m really smiling and saying ‘Hello there. Why don’t you beat me black and blue and rape me sixty times.’ So, it’s no wonder that I kinda want to wiseguy things up.”

Wadding up a piece of toilet paper and sticking it up her nose so that her nose will look broken, swaggering across the stage to find a coat (a trench coat, of course) “to hide the voluptuous curves of my body, because whatever else they may be, boobs are *not* tough,” she spits into her hands and rubs her hair down flat, then pulls on a man’s hat. “Now to take on a disgusting habit that will turn some people who are still on (picks up a cigarette butt, straightens it out, lights it) off, and voila! You’ve crossed over a line. And on this side of the line it’s a whole other dark night of the soul.”

On “this side of the line,” Galloway, having affected a virtual sex change, is now Jake Ratchett. The first line she crosses is the gender line, which she reveals to be substantially reliant on artifice, since she can “become” male by simply appropriating objects and surface effects that are coded as masculine (the hat, the coat, the dangling cigarette, the slicked back hair, physical posture, the beard). She also crosses over a “polite society” line (a line that she thoroughly trounces in *The Etiquette of Suicide*). And, most significantly, in making the

change from Galloway to Ratchett, she crosses over into a complex psychic and emotional territory where toughness erases vulnerability.

In the lower lighting that suggests film noir, Ratchett assumes a physical swagger reminiscent of Dashiell Hammett's private eye character, Sam Spade, who made his debut in 1929 in the pages of *Black Mask*, a serialized first portion of *The Maltese Falcon*. His speech is inflected with the understated seriousness of Raymond Chandler's unforgettable private eye, Philip Marlowe, from *The Big Sleep* (played by Humphrey Bogart in the 1946 Warner Brother's movie version, directed by Howard Hawks.) Marlowe is a "tough" guy, a womanizer who has feelings but can never talk about them, tough enough to kill the bad guy and then go out for a beer.

Jake is a parodic kindred spirit to Marlowe, describing himself as "a gumshoe, a private eye, a hardboiled dick!" He performs his toughness in three distinct ways. First, he takes on a tough identity through verbal braggadocio, insisting that in the "cess pool they call a city, I'm the guy they call tough shit. How tough? Tough enough to take it like a man." The second level of toughness that Jake demonstrates is decidedly masochistic. "This tough," he says as he holds a burning cigarette over his palm, barely managing to squeak out – "When you're this tough, (catches himself mid-squeak and starts over, with a firmer voice) "you can look death in the eye and laugh" (puts the cigarette out in his palm). And finally, Jake's third tier of toughness has to do with a studied denial of his own vulnerability. "Nothing scares me," Jake insists, "There ain't a man alive who

can match me. There ain't a woman alive who can resist me. And there ain't no bullet that can kill me."

Jake would be able to get away with these conceits, except that just as he says this, a volley of bullets ring out, Jake keels over, clutching his stomach and declares, "Oh, all right, you've made your fucking point." Jake has been shot down, a cold-blooded murder, in the very act of claiming his invulnerability. Galloway holds Jake's "dead" position for a few beats, then rises, and starts her monologue again. "The thing about tough talk is that it works. You feel six feet tall then Bang! You're six feet under."

When Galloway comes back to life as herself, she rushes to "get this face off," drops the vulgarity, the swagger, the bravado and returns to her pre-Jake embodiment to tell the story of "tough little Kenny Cunningham." Galloway uses this brief reference to Cunningham as a morality tale to complete what she started with Jake Ratchett. Kenny was a cousin, "my mother's favorite," a kind man with a small physique, a "tough" man who managed to play professional football despite his size. Galloway recalls his death, remembering for us, in a hushed voice, an image of Kenny when he was "so thin the needles went right through him. He died on a beautiful afternoon. It's still hard for me to believe that people can die on beautiful afternoons." Recovering her voice somewhat, she muses "I'm older now than he was when he died. The longer one lives, the longer one expects that one shall live." Recovering her sense of humor, she adds, "It just goes to show you, but don't ask me what ..."

“Jake Ratchett, Short Detective” is Galloway’s disidentification with the performance of masculine bravado or “tough guy” attitude that precludes an awareness of vulnerability. This false toughness is specifically gendered as male, and rejected. Interestingly, though, masculinity is not. Masculinity becomes Galloway’s tool. In the character of Jake Ratchett, Galloway performs what Judith Halberstam has termed “female masculinity.”³⁹ Halberstam’s project is to separate concepts of masculinity from their conceptual moorings in the bodies of men and locate performances of masculinity that are not confined by gender. Galloway, too, is interested in wrenching masculinity away from maleness and performing masculinity as a critique of gender bias. Galloway is not a male impersonator here - male impersonators attempt to “produce a plausible performance of maleness” (Halberstam 232). Galloway becomes Jake in full view of the audience, and never attempts to mark herself as male, only to assume a masculine role. Jake comes closer to a “drag king” performance, since Galloway makes “the exposure of the theatricality of masculinity into the mainstay of her act” (232).

Galloway rejects the kind of masculinized toughness Jake represents, but wants to play with his masculinity. The fun is in inhabiting both bodies, holding the possibility of both identities at once. Still, Galloway’s embodiment is the “true” and stable one. Jake has to be short, because he depends on Galloway’s (short) embodiment. Jake is “male,” because Galloway makes him male. She is interested in articulating sexual desire for women from this doubly gendered

³⁹ Judith Halberstam, *Female Masculinity*. Durham: Duke University Press. 1998.

position as Galloway/Jake Ratchett. When she kills Jake off, silencing him in the moment of proclaiming his (false) invulnerability, Galloway is there to pick up the pieces.

Galloway drives home the point that everyone is vulnerable to death, and to the unpredictabilities of life. What she re-imagines as an alternative to the masculinized toughness with which she is disidentifying is a “real” toughness that has something more to do with being who you really want to be (like being a football player, just because you want to, even when you’re not any taller than someone who could be called a “short detective”). Maybe it is still only Granny Doris who is tough enough to take it like a man. “There are people who are afraid to do a tenth of what I’ve done,” Galloway commented in a recent interview, “and they would do it being 6 feet tall and having every sense of theirs available to them, and it takes a lot of guts to go ahead and wade in when you’re not sure, and I’m never sure. I never hear enough, ever, to be sure. So I give myself a pat on the back because I think, frankly, that’s real toughness” (*Interview*).

THE ETIQUETTE OF SUICIDE

Galloway ends the Kenny Cunningham story with this quip: “It just goes to show you But don’t ask me what.” This is her way of indicating that despite the extended didactic lesson on the uselessness of Ratchett’s kind of toughness, and her attempt to imagine for us what “real” toughness looks like, she makes no claim to know all the answers. But if toughness is not an acceptable response to vulnerability, neither is suicide. When Galloway launches her send-

up of etiquette diva Amy Vanderbilt, another carefully performed disidentification, she pulls a small turned-over table upright to expose the knife blade plunged into its center, and suggests to the audience, “Let’s talk about suicide.” Caressing the knife blade as she pulls it from the table top, “suicide ... Man, I’ve been this close, but I just didn’t know the right way to go about it, I was always, you know, ‘what shall I weaaaar?’”

Taking up a lovely strand of pearls, donning a pair of horn-rimmed glasses, and retrieving her bound copy of *The Etiquette of Suicide*, Galloway abandons her status of historical subject of autobiography to revisit the persona of Amy Vanderbilt, etiquette diva extraordinaire. She fashions “The Etiquette of Suicide” after Amy Vanderbilt’s *The Book of Etiquette*, published in 1954. “Our Lady of the Last Word,” as Galloway calls her, devoted her life to educating the public about the nuances of polite society, everything from what to wear to the beach, to how to decline a dinner invitation. Ironically, this icon of the domesticity and manners flung herself out of her apartment window in 1974, falling to her death.⁴⁰

Galloway’s “Etiquette of Suicide” is a how-to guide for anyone who wants to fashionably “end it all when all has ended.” There are wrong ways, like a cheese grater across the wrist, or the prongs of a serving fork in the jugular vein (both of which Galloway enacts with a prop), insisting that even when “one’s life has fallen around one’s ankles, one can relinquish one’s sanity according to the fixed canons of good taste.” And that good taste requires that even in suicide, one

⁴⁰ It has never been completely clarified whether Amy Vanderbilt fell or jumped from her window. Comments of Police officer Alfred Swetokas, NYT, 12/28/74, page 1, column 1.

must be mindful of others. The “shake and bake method of self demise, perfected by Sylvia Plath” calls for arranging your demise between 10 p.m. and 4 a.m. because “you will, after all, be monopolizing a major kitchen appliance.” And, when preparing for “that last leap out of polite society, feet first is the best rule,” being careful to gather your skirt so as “not to afford a too candid glimpse to the vulgar passerby.” Her final caveat for would-be suicides is “Dying well is the last revenge!”

In *The Etiquette of Suicide*, Galloway disidentifies with a system of social formality that she can never fully access as a deaf woman. To Galloway, the structuring of human interactions into the formalities of “polite society” willfully ignores “the primal thing itself” and validates a soulless set of artificial, contrived codes for interaction. Etiquette, after all, is for people who are concerned with appearances and “fitting in,” and Galloway knows that fitting in will not often be an option for her. Yet, *The Etiquette of Suicide* seems almost nostalgic, as though Galloway is expressing a longing for that road map to life that etiquette would like to be. Not a simple disavowal of formality, *Etiquette* recognizes that we do need rules to live by. *The Etiquette of Suicide* comments on the ways that this kind of pretense “kills” us, while acknowledging that codes of conduct are necessary for social life. “I regard Amy Vanderbilt as emblematic of a false formality in culture,” Galloway explains, and “I’ve always felt sorry for the woman, because I felt that what drove her to suicide was the inability to reconcile the wreck of her life with the formality of her language and her work” (*Interview*).

MOMENTS OF NEAR SUSPENSE

How does the “real” Galloway respond to a vulnerability she has so carefully constructed for us to see? Paranoia. Galloway offers a glimpse into her period of “deaf paranoia” (*Interview*) through “Moments of Near Suspense.” This journey into a private paranoia begins with a rumination on the idea of living for the moment. “Implicit in living for the moment is the idea that every minute could be your last.” A lifetime of “last moments,” at least for Galloway, renders each one full of suspense and terror.

“Moments of Near Suspense” is a short skit about the terrors of expecting the worst. Galloway returns to her New York City apartment after work, fearful that a stranger is in her home when she sees a light coming from under the door. As she gathers all her courage and flings the door open, she sees “Daylight! The light switch hasn’t even been touched. I see it now ... Someone stole my key, came in while I was gone, ate the steak I left out to thaw, used up all of the toilet paper, they probably took my winter coat out of the closet – and they didn’t even bother to touch the light switch!” But then, another, more terrible thought. “What if he’s still here?” She slinks over to the coat closet, fantasizing that the intruder lurks there with a razor, her razor, in his hand, but, no. Nobody in the closet. Coat still there. Her paranoid fantasy just keeps on going, and before long she’s afraid to sit down in her dining room chair for fear that dropping her defenses will propel her intruder, or whatever monstrous being he has shape-shifted into, to pounce on her. “Something is bound to happen, if only I sit here and wait!” After a pause, she continues, “For two years I lived like that. And

nobody noticed. Maybe the fact that I was living in New York at the time had a little something to do with it.”

Moments of Near Suspense is a specifically deaf paranoiac’s nightmare response to the out-of-control-ness of urban life. Unable to imagine the heart-stopping sound of a door slowly creaking open unexpectedly, or the terror of listening to a stranger’s foot fall on the stair, the signals that trouble Galloway in this scene, the things that spark her paranoid fantasies, are primarily visual: light at the door, a missing coat, the spectre of a monster morphing from a coat hanger, or a chair. Galloway may be suggesting here that the most reasonable response to the wild unpredictability of life is paranoia, or at least that in the context of the level of violence in the city, it makes sense. Those paranoid experiences were actually useful. “After two years of living like that, I got really tough.”

Yet, still not tough enough to survive the constant onslaught of real life without faltering. Galloway returns to paranoia during a trip to the Museum of Natural History on a Sunday afternoon. Visiting the un-dead of the dioramas, Galloway stares into the eyes of animals who have been killed “just so we could see them,” peering into the quietness of a small contained space where everything, even the dead, looked “so real.” Realizing that, at least on some level, she is “perfectly at home here in this apologia to the dead,” in the artificial “real life” of a silenced natural world, Galloway comes face to face with the hidden violence of the institution of the museum. The capturing, the killing, the falsity of preserving bodies so that they will “look real,” becomes urgently visible beneath the legitimizing veil of science.

The “one that sent me flipping” was a “perfectly innocuous little forest scene,” made up of grass, trees and a stuffed rabbit. As she looks at what seems on the surface to be a tranquil scene, she notices a stuffed fox hidden in the leaves behind a tree. Suddenly she wants to yell out “Run, bunny wunny! Oh run, you idiot, run!” But she doesn’t, because she knows she can’t change fate. “You see it. You know what’s going to happen the minute your back is turned. And there’s not one damn thing you can do about it.” Something snaps inside. The line between “us” and “them,” between animal and human begins to blur, and following the instinct to run, Galloway “escapes” the Museum on foot, full of fear. Fear of an accident, fear of annihilation, fear that she, too, will be “caught” this time, not just culturally, but physically.

But perhaps she wants to be caught. She ends up admitting herself to Gracy Square Psychiatric hospital, caging herself in a “nut house” to get her paranoid, suicidal urges under control.

MR. HANDCHOPS

At Gracy Square, Galloway has the opportunity to experiment with “performance therapy,” getting up on stage on a regular basis to “act out” images, feelings and ideas. Galloway realizes that “being crazy is kind of like being on stage – I mean out there you’re one kind of person, but get up here and you become somebody else altogether.” Galloway seems to suggest here that performance is therapy, at least in terms of being able to formulate your own identity. Or perhaps she means to imply that therapy is performance of the “right”

feelings and emotions. Galloway exits the stage, “leaving the ward,” and offstage she makes cacophonous noises that imply an offstage fight is going on. In that moment she is a deaf woman depending on noises to make meaning, but she knows that *we’ll* make the meaning without her.

As Galloway bursts back onstage dressed in a tattered bathrobe, wearing a ratty string mop on her head like a wig, she re-enacts a performance done for her fellow psychiatric patients at Gracy Square, featuring “Sherrie Loose and Mr. Handchops,” a parody of ventriloquist Shari Lewis and her famous sock puppet sidekick, “Lamb Chop.”⁴¹ Lewis, described as “a cute, bubbly, and very non-threatening lady” (*Lamb Chop*), and Lamb Chop virtually embodied the term “lovable.” Both the 5-foot-tall Lewis and the never-aging Lamb Chop had intensely curly hair that softly framed their faces, and they spoke in high, somewhat delicate voices. Lamb Chop, who was “a shy, soft-spoken fleecy little lamb about 6-years-old with a penchant for mischief and wisecracks” (*Puppets*), made Lewis a mainstay of American children’s entertainment for more than thirty years. In performance, Lewis kept Lamb Chop lovingly close to her body, near her face, so that their intimacy was obvious. To take on Shari Lewis and Lamb Chop is to confront a bastion of niceness and childhood innocence, and Galloway goes after it with a vengeance.

⁴¹ Shari Lewis was an American puppeteer and ventriloquist who invented “Lamb Chop” in 1956 for television’s “The Captain Kangaroo Show.” She continued performing with him until her death in 1998. Lewis learned magic tricks from her father and took lessons in childhood from America’s first and most successful African American ventriloquist, John Cooper. Her entertaining and educational programs geared towards younger children won her a Peabody Award and 12 Emmys.

Stopping for a moment to thank her psychiatrist, who has allowed her to perform a ventriloquist act as part of her therapy, Loose introduces herself and then shows us “Mr. Handchops,” a string mop tied across the knuckles of her right hand, just so that the string forms an unruly fringe around Mr. Handchops’ “face.” When Loose moves her fingers and thumb up and down to make him “talk,” Mr. Handchops uses a “gruff puppet voice” to assert “I can talk!” Loose shows the audience how “We can even talk with me keeping my lips still,” then makes motions with Mr. Handchops, but since she’s keeping her lips still, he can’t be understood. She continues, undaunted. Loose: “Mr. Handchops and I are going to perform a trick for you that we learned from the ventriloquist book,” a trick in which they “eat and talk at the same time.” Grabbing a bag of potato chips, she stuffs them into Mr. Handchops’ “mouth” (her hand). Chips fly, people laugh, and Mr. Handchops, with his “mouth” full, eating and talking at the same time, says “We can eattt and talkkkk at the saameee tiime!” Loose grabs a beer bottle next and yells, “We can even drink and sing at the same time!” and with that she pours the beer down on Mr. Handchops (as well as a few of the people in the front row of the audience), while singing “Singing in the rain” in that “gruff puppet voice.” When the laughter dies down, Loose says “Mr. Handchops and I love each other ever so much,” pausing to kiss him, “but sometimes Mr. Handchops goes a little crazy and he starts throwing himself against the table and screaming!” As Mr. Handchops begins to twitch and “throw himself” against the table, Loose reaches for a hammer. “And the only way we can get him to stop is to hit him with this

hammer,” and she hits Mr. Handchops, hard, with the hammer. “And then we both cry. Because it hurts me more than it hurts him!”

Standing onstage gripping her throbbing hand, sweat streaming down her face, a little breathless amid a pool of broken potato chips, the string mop wig discarded and her hair a wild wet comment on the frenzy she’s just enacted, Galloway seems genuinely crazed. Somehow, she performs Mr. Handchops as a combination of the masochistic performative of Chris Burden⁴² and the comedic energies of The Three Stooges. What could it possibly mean? And why does a deaf woman choose ventriloquism?

There are multiple voices in the performance of “Mr. Handchops” (Galloway’s, Loose’s and Mr. Handchops’) and multiple meanings and motivations for performing it. To a deaf woman recently traumatized by the dead-ness of the “life like” animals in a diorama, ventriloquism could certainly have its appeal, since it allows a breathing of life into a lifeless form through the vehicle of voice. But, unlike traditional ventriloquism, in “Mr. Handchops” there is no “lifeless form,” no “puppet,” there is only Galloway/Loose and an embellished right hand – a living “thing” that is not separate from the living onstage body. Also, Galloway makes absolutely no attempt to appear as though she is actually acting as a ventriloquist, in fact the whole farcical performance highlights the fact that Sherrie Loose and Mr. Handchops are one and the same, that their “separation” is psychical, not physical – a separation that Galloway also refuses in the character of Jake Ratchett.

⁴² Kathy O’Dell includes a discussion of Chris Burden’s 1971 performance “Shoot,” in *Contract With the Skin*. See Chapter One, entitled “He Got Shot,” pages 1-16.

When Loose tells the audience that she and Mr. Handchops are going to do a “trick” that they learned from the ventriloquist book, the “trick” is (usually) that one person speaks for two speaking subjects in a double-speak that is supposed to be undetectable to the audience. The trick of ventriloquism, according to Charles B. Davis in his article “Reading the Ventriloquist’s Lips: The Performance Genre behind the Metaphor,” relies on the “vocal production of sounds or voices that appear to originate somewhere other than their actual source”(Davis 1). When ventriloquism “works,” it appears as if there are two voices, when actually there is only one voice using two registers of pitch and diction. That’s the auditory part of the trick. The psychic or “identity” part of the trick is that one subject “speaks for” another, so that even though it appears that there are two opinions or voices or identities, they both belong to the ventriloquist.

Ventriloquists have traditionally used the voices of the figures they animate to express “subversive humor” and to exercise “a sanctioned voice for social and political satire” (Davis 3). Part of ventriloquism’s success is based on the illusion of “voice throwing,” which relies on “visual misdirection [of the audience’s eye] to an imaginary source of sound, and in virtuoso performance, on the imitation of sounds as they would meet the ear from various distances”(Davis 3). Galloway cannot effect that trick because she cannot localize or even identify sound. She performs “deaf ventriloquism” by subversively appropriating the identity aspects of the act (instead of showing us that Mr. Handchops and Sherrie Loose are different, she shows that they are the same), and using the visual props

of ventriloquism (specifically Shari Lewis's brand, which always included hand puppets). This allows Galloway to fully appropriate a comic performance medium that is otherwise not available to her, a way to re-make the form to fit her own critical and comic designs. Disidentifying with all that is cuteness and childhood innocence, she appropriates ventriloquism by ironically approximating performances by Shari Lewis and Lamb Chops to explore the lie of ventriloquism and slaughter an icon of niceness and lovability – things that cannot possibly co-exist with toughness.

We could also read this moment as masochism, as theorist Kathy O'Dell does in her 1990 review of *Out All Night and Lost My Shoes* for *ArtForum*, by interpreting the hammering of Mr. Handchops as “a metaphor for the shattering of the hand that signs,” which would constitute a re-enactment of Galloway's painful exclusion from the social culture of the deaf community.⁴³ Or maybe Galloway is responding to the “professional ventriloquism” of the institution in which she is contained, trapped by psychiatric discourse and practice that allows people she doesn't even know to re-interpret, mis-translate even, her experience “through professionals' own paradigms of understanding,” leaving her (and others like her) feeling “that their voices were muted or ignored” (Carter 3).

The concept of “professional ventriloquism” would fit into a current theoretical discussion that views the “dummy” in ventriloquism as a “mute puppet” of “an authorial voice” that represents “the master discourse” (Davis 1). In Galloway's performance, it seems that Loose and Mr. Handchops are *both*

⁴³ See O'Dell, Kathy. *Contract with the Skin: Masochism, Performance Art and the 1970's* for a detailed account and analysis of masochism in performance.

“dummies,” and as such, they are required to speak the “master discourse” of psychiatric intervention into mental illness. Sherrie Loose hammers the out-of-control, bodily excess “thing” that makes her feel crazy informed by the (institutionalized, fully offstage) ventriloquized voice of psychiatry’s discourse, only to realize, painfully, that Mr. Handchops is an integral part of her self, and so she does herself harm in the end. For his part, Mr. Handchops is the “dummy” who has to either speak the “master discourse” of Sherrie Loose (i.e. perform “the trick” of “disappearing” or integrating into Sherrie Loose’s persona) or die (just like hallucinations or delusions have to “die” in psychiatric “cure”).

Maybe what comes after “Mr. Handchops” is the best key to understanding how the act of deaf ventriloquism works in *Out All Night and Lost My Shoes*. Galloway charges into the audience, wild eyed, hammer in hand, and yells “Look you guys, I’m not craaaaaazy! I’m just afraid!” And when the doctor asks her what she is afraid of, she says “Everything. Stuffed rabbits. Beautiful afternoons. My own two hands.”

What makes her feel unafraid is Art, specifically her performance art at Gracy Square, because “when I’m up there knocking the shit out of my hand, man, I don’t feel like a freak. I don’t feel crazy. I don’t even feel afraid. I feel tough.” She defines tough as the ability to “take anything life dishes out.” In the end, then, it’s all about trying to get tough enough to survive. A little practiced masochism, an opportunity to reject the vapid niceties and innocence of childhood – grab life by the throat before it grabs you by the ankles, stay on your feet, stare down your demons, get up on stage and hand out your strategies like pills, like

medication, dose by dose, let art get you through. That's what is required to get tough enough to take what life dishes out.

AFRICA

Part of what life “dishes out” is death, and it is with a reverie on death that Galloway ends *Out All Night and Lost My Shoes*, by relating a story about “crocodiles and us being just another tasty morsel on the old food chain.” Galloway shares a story she read that takes place in Africa, a setting she associates with wildness, with nature, and with imperialism. At the time she read the story, she was doing “shit work – bussing tables, washing dishes, scrubbing toilets, swallowing my pride.” This is a moral tale about a group of “prissy rich photographers from England” who travel with their “\$50,000 cameras and their Banana Republic” to “get a true picture of deepest darkest Africa.” Their success depends, of course, on the natives who prepare their path, working “down at the river’s edge washing dishes, washing the underwear ... doing the shit work” while the Englishmen take tea in their tents.

A blood curdling shriek sounds in the distance, and the Englishmen run from their tents to see what has happened. When they arrive at the river’s edge they see “a giant crocodile up on its tail and the croc’s jaws are crashing – yaw yaw yaw!” And all the natives are laughing, so the Brits begin to laugh, too. But when they look more closely, they can just make out a pair of “bare feet, attached to naked legs, and the legs are attached to the poor schmuck who is kicking away from inside the crocodile.” The natives continue to laugh, the Englishmen are

troubled. But Galloway laughs, too, and heartily, “because when you’re doing the shitwork, when you don’t count for nothing, that’s the thing you fear most from this world – that it’s just gonna up and grab you. When it finally does happen, you’ll shout “Behold! As I feared. The Dread Beast exists.” And if you’re around to say that, you better bet you’re gonna laugh – cause it didn’t happen to you.”

Caught, constrained, just like those lifeless animals in the museum, we have to decide how to respond to it. In a closing anecdote, Galloway relates a conversation in which a friend tells her that the best thing about finding out he had cancer was being told that he didn’t have AIDS. “We laughed,” she says wryly, “Sometimes it’s too damn hard to do anything else.” Galloway is making her response to “beasty,” to “the primal thing itself,” in *Out All Night and Lost My Shoes*. She’s gonna laugh, while she can.

STRATEGIES

Several skills and performance strategies place *Out All Night and Lost My Shoes* in a unique position in this inquiry into autobiographical performance by people with disability. First, Galloway performs a complex fence straddling in *Out All Night and Lost My Shoes* in terms of disability as identity. In both her lived daily experience and her performance, deafness as disability is only one of many identity markers for Galloway. In most contexts she is a person who *has* a disability (although her deafness has been mediated to some extent by the prosthetic effects of technology), not a person who *is* disabled (in terms of identity). Galloway came to language through spoken (and heard) word, and

functions primarily in the hearing world, with only a rudimentary American Sign Language vocabulary. Since she was never integrated into Deaf culture, she is not considered “authentically deaf” by the Deaf community.⁴⁴ Her recent video parody of “The Miracle Worker” highlights Galloway’s exclusion from the category of “authentic deaf person” in a short epilogue.⁴⁵ With her hearing aids dangling in front of her ears, Galloway addresses the audience verbally while an American Sign Language interpreter stands behind her and signs what she says, and together they make the visual and verbal point that Galloway is not “deaf enough” to be considered deaf, nor “hearing enough” to be “normal.”

Out All Night and Lost My Shoes seems predicated on what Galloway is not: “not the usual performer, not the usual beauty, not what is usually seen,” producing art that is “deliberately not saying the same old things about art and life that are usually said”(Beach 51). Described by Austin arts critic Michael Barnes as “a scary performer, as fierce as she is talented,” Galloway employs a “piercing voice” and her own brand of intense physicality to drive her message across to the audience. As a hybrid of comedy, drama, critique and autobiographical storytelling, it is difficult to know how and to whom *Out All Night and Lost My Shoes* should be promoted. Is it a disability play? Is it queer theatre? Galloway has no answer for these questions, preferring to see it more specifically as autobiography. “Queerness, like disability, has never been my focal point.” Instead, *Out All Night and Lost My Shoes* is “a complicated vision of the cultural

⁴⁴ The word “Deaf,” with a capital “D,” refers to “culturally deaf people,” as opposed to the word “deaf” with a lower case “d,” which refers to hearing loss. For more on culturally identified “Capital D” Deaf identity, see *Capital D Magazine* online at

<http://www.capitaldmagazine.com/capital.html> or in print: PO Box 104, Germantown, MD 20875.

⁴⁵ citation for the video

fiction I live within” (*Interview*). Unlike *Actual Lives* and *The Church of 80% Sincerity*, which make determined attempts to voice the experience of disability and increase disability awareness, *Out All Night and Lost My Shoes* treats deafness as one of many aspects of Galloway’s experience.

Second, Galloway has the performance skills to embody the “characters” of her autobiographical narrative onstage. Galloway makes full use of her body and the stage, employs her props for maximum effect, displays impeccable timing, plans and implements lighting and sound that complements the images she wants to create, and has full command of her voice and movements. These aspects of *Out All Night and Lost My Shoes* place it more solidly in a tradition of performance art and theatre than Roche’s *The Church of 80% Sincerity* or *Actual Lives*, which depend more heavily on textual narrative. Third, she knows how to work an edge. Combining satirical comedy with bits of performed masochism, introducing queerness as integral to adolescent coming-of-age, farcically engaging with episodes of mental illness, Galloway exposes the raw edges of experience, worrying the seams between “aren’t-we-enlightened-complacency” (*Time Out*) and outright overkill. *Out All Night and Lost My Shoes* exudes what New York City cultural historian and performance art critic C. Carr calls “the energizing quiver of unsettled ground.”⁴⁶ Fourth, Galloway is willing to expose the artifice of theatre in order to establish an intimacy with the audience because she believes in art as epiphany. She simultaneously performs and critiques the

⁴⁶Carr, C. *On Edge*, xiv .

conceits of performance in *Out All Night and Lost My Shoes*, inviting audiences to examine their own participation in the production of performance (in terms of how their responses influence her performance, or even how their purchase of an admission ticket supports her work) as well as in the production of cultural practices that have come to bear on Galloway's identity. Roche does this in *The Church of 80% Sincerity* when he brings the house lights up and asks his audience to interrogate him about his face.

Finally, and perhaps most importantly for my project, Galloway's disability is difficult to locate. In the moments of "identification-based performance" in which she performs herself as Terry Galloway, her deafness is integral. When she is performing disidentifications, as in *Jake Ratchett*, "Etiquette of Suicide," and *Mr. Handchops*, deafness is not clearly evident. She can choose when to perform deafness, at least on stage. This gives her a kind of performative or theatrical range not available to David Roche or to members of *Actual Lives*.

CULTURAL CAPITAL: IT'S NOT ALL ABOUT MONEY

The complexity of Galloway's work, her insistence on infusing her work with issues of queerness, deafness, and gender roles, makes it difficult for Galloway to fit into any recognized theatrical aesthetic. Unlike Roche, she is not afraid to alienate her audience and she resists the kind of sincerity that is evident in much of disabled performance of autobiography. She is brutal in her honesty

to the point of being willing to risk a certain level of unintelligibility, to appear “crazy” in order to get her point across. She performs a certain measured violence toward her body as a way to literalize the social violence of which she is so aware, a violence enacted against her body by others, and that violence registers with the audience because her body is present, in the moment, before them. All of these things make her performances quite compelling, but compromise her ability to reach wider audiences and prevent her from accessing the kind of cultural capital she needs in order to continue to perform.

Despite these material constraints on her work, Galloway continues to make a modest living as a performer, struggling always to find a balance between the activist work she does for free and work that will provide the compensation she deserves. Her commitment to performance, and specifically to disabled performance, is clear. Happily, over the past year she has had many invitations to perform *Out All Night and Lost My Shoes* for groups capable of providing appropriate monetary compensation at venues across the nation. These invitations resulted from connections she made through her performance at the 2002 Queer Disability Conference in San Francisco.

Galloway invests a great deal of her time teaching others how to perform and how to think critically about performance, and the bulk of that time is unpaid. Her biggest unpaid project, *Actual Lives*, would not exist without her. Clearly, money is not the motivator here. Galloway sees her own work and the work of

Actual Lives as two parts of a bigger story, an argument about the personal and cultural worth of people with disability. On a personal level, her solo performance work always “calls into question my sense of self, of worth, of struggle” (*Answers*). In the stories of *Actual Lives* some of those questions find resolution because in them Galloway recognizes “the essence of my own argument – an argument I have to will myself to believe in, will myself to defend, will myself to fight for because it arises from my own less worthy self” (ibid). Just as Galloway’s work motivates much of the hard work done by performers in *Actual Lives*, the work of *Actual Lives* encourages Galloway to continue with her own performance as well as with ensemble work, whatever the cost. “I believe in the worthiness of the people in *Actual Lives*. I believe in it because I am compelled by their stories, compelled by their struggles. Their lives seem so completely worth it to me that I find myself thinking – no question, these lives, these experiences deserve to be heard and heeded” (ibid). Galloway sees performance as a way “to achieve through truth, through art, work, communion, that amazing state of recognition and understanding” that is the highest function of art, an understanding that is absolutely essential to the recognition of viable, visible, vocal, complicated public selves for people with disability.

Epilogue

Accepting the thesis that autobiographical performance by people with disability offers unique opportunities for creating and expressing performative selves, and that these performative selves can exceed confining notions of disability, leads us to consider what continued cultural role might be imagined for these performances. What can future disabled performance offer to “cripdom” and to the general public? And what are the pedagogical applications of my own work of identifying the strategies and stakes of disabled performance?

I want to preface my act of imagining the future of autobiographical performance by people with disability by providing a brief overview of the state of the art as it is today, specifically in terms of who has access to autobiographical performance and what shapes its content. First, autobiographical performance by people with disability is currently an all white affair. *Actual Lives* and *The DisAbility Project* have African-American and Mexican-American⁴⁷ members, but in terms of solo performance, the whiteness of disabled community represented through performance is evident. The lack of racial diversity in the disability activist community and in disabled arts, as well as the whiteness of disabled academia, has been a topic of much concern and

⁴⁷ I use the term “Mexican-American” at the request of members of *Actual Lives* who resist the label of “hispanic” or “latino.”

conversation over the past several years. At the 2002 Queer Disability Conference in San Francisco, the planned final plenary addresses were displaced by a spontaneous and somewhat rowdy town hall meeting in which disabled queers of color and people with psychiatric disorders challenged the mostly white and physically disabled conference participants to a discussion of racism and the hierarchy of disability.⁴⁸ Disabled performance today, like the disability rights movement in general, is the purview of middle-aged white, educated, physically disabled people with activist backgrounds.

In terms of content, it is interesting to note that though there is an insistence on foregrounding issues of sexuality in many of these performances, there is a noticeable lack of graphic description or exploration of sexual practices of people with disability in these works. Nothing in disabled performance comes close to the sexualized content of bisexual performer Annie Sprinkle's *Post Porn Modernist*,⁴⁹ gay performer Tim Miller's bold *My Queer Body* (1992) or *Naked Breath* (1994), or lesbian performance artist Holly Hughes' *Clit Notes*.⁵⁰ Perhaps disabled performers have resisted the disclosure of specifically "crippled" desires and sexual practices, because that disclosure carries with it too much risk of recreating "freakdom" on the stage.

Two exceptions are worth examining here. Queer disabled performer Greg Walloch articulates the specificity of his queer desire as a disabled man in his autobiographical performance *White Disabled Talent* and his film *F**k the*

⁴⁸ See plenary comments by Eli Clare at http://www.disabledwomen.net/queer/paper_clare.html

⁴⁹ Sprinkle's new work, *Metamorphosex*, moves from solo to group performance of sexuality. See <http://www.anniesprinkle.org/html/lectures/metamorphosex.html>

⁵⁰ Written texts of the Miller and Hughes performances are included in *O Solo Homo*.

Disabled, perhaps enabled by his participation in the queer theatre and queer community of New York City.⁵¹ Lesbian disabled performer Julia Trahan, in her largely autobiographical *Queen of the Girls*, offers up a healthy dose of erotic movement and emphatically stated desire which recently stirred up debate about freedom of speech and portrayals of sexuality at Melbourne University's Mudfest and Adelaide's High Beam Festival.⁵²

The fact that “queer crips” seem to be able to authorize explicit expressions of sexuality and desire in their performances, at least in this cultural moment, points us to a discussion of other convergences between queer and disabled performance. In exploring disabled performance work, I have consciously employed queer theoretical frameworks (Sedgwick, Muñoz, Hughes and Román) hoping to make some of these connections clear. As African-American disabled lesbian Vicky D'aoust said in her address to the 2002 Queer Disability Conference in San Francisco, it is useful to see “cripdom and queerness as geographies of culture,” liminal spaces in which “multiplicity of gender and disability and sexuality is made possible” (*Plenary*). “Otherness” or alterity in relation to mainstream culture based on issues of the body is a positionality shared by queer and disabled people in contemporary American culture. It is no coincidence that two of the most visible disability-identified performance ensemble groups in the nation, *Actual Lives* and Joan Lipkin's *The DisAbility*

⁵¹ See <http://www.gregwalloch.com/FTD.htm> for more on *F**k the Disabled*.

⁵² The High Beam Festival is Australia's biennial international arts festival showcasing contemporary works influenced by or emerging from the experience of disability. This ten day multi-arts festival presents the latest in disability arts.
http://www.artsinaction.asn.au/prog_visart.htm

Project, developed through the efforts of out, politically active lesbians. I speak for myself, as well as for Galloway and Lipkin, in asserting that as lesbians, our experience of being cultural outsiders facilitates an appreciation of the ways in which disability creates otherness and social isolation. Activist impulses encouraged through queer identification and queer community have been part of each of our motivations to produce disabled theatre.

There are a number of disabled performers who operate from a queer sensitivity, even though they do not identify as homosexual. Julia Trahan performs “Julia’s Body,” a queered crip work that includes narrative and movement, with six other disabled performers.⁵³ Her co-performers are not queer identified,⁵⁴ but they have no reservations about this collaboration because queerness is not particularly problematic in the disability community. Much of disabled sexual practice and desire is “queer” in the sense of being outside common heterosexual practice, gay or lesbian identities are prevalent, and they are not seen as problematic in disability activist communities.

One of the most important links between queer performance art and autobiographical performance by people with disability is that both forms present multiply situated, historically contextualized selves which reinstate and celebrate issues of difference and the body. Creating a kind of performed postmodern

⁵³ Galloway gave us multiple facets of her autobiographical self in *Out All Night and Lost My Shoes*, but here Trahan even further divorces notions of self and body by incorporating the bodies of others in a work about herself.

⁵⁴ *Julia's Body* consists of Trahan, and disabled performers Rhona Alexander, Afi-Tiombe A Kambon, Neil Marcus, Stephanie Miyashiro, Misha Myers and Lee Williams.

subject position, both traditions advance our awareness of and dialogue about what constitutes subjectivity and how issues of difference inflect identity.⁵⁵

Constructions of postmodern subjectivity have recently been challenged by disability scholar Lennard Davis, who advocates for the employment of a model of “dismodernism” that can produce a dismodernist subject position. In his recent book, *Bending Over Backwards: Disability, Dismodernism and Other Difficult Positions*, Davis urges a move away from disability as an identity toward recognition of a different kind of postmodern subjectivity that “argues for a commonality of bodies within notions of difference” instead of a notion of difference based on a concept of normality (31). “Dismodernism” asks us to recognize that all bodies are different, that difference itself contributes to the stability of culture. In opposition to models of subjectivity that assume a “complete, independent subject, endowed with rights,” Davis posits a dismodernist subject who “is, in fact disabled,” and must rely on “information technology, protective legislation, and globalized forms of securing order and peace” (Davis 30). Davis is not arguing, in the reductive sense, that “everyone is disabled,” but arguing for an awareness that everyone is disabled by injustice and oppression, in all its forms, that in our incompleteness is our unity. Paradoxically, it may well be “the most marginalized group – people with disability – who can provide the broadest way of understanding contemporary systems of oppression” (Davis 29).

⁵⁵ See Betty Bergland’s essay, “Postmodernism and the Autobiographical Subject: Reconstructing the ‘Other,’” in Ashley and Gilmore’s *Autobiography and Postmodernism* for a detailed discussion of postmodern subjectivity as it relates to “otherness.” Bergland is discussing autobiography in terms of ethnicity, but her work is easily applied to disability.

If we recognize the radical implications of Davis' argument that understanding disability exposes mechanisms that oppress people based on physical traits or markings (including gender, sexuality, race, and ability), it is easy to imagine the pedagogical implications of my work. Disability should not be considered as "additive" to general education in the humanities any more than studies of race or gender. Nor should it be quarantined in the social sciences. Instead, I argue specifically for an infusion of disability perspectives into the study of literature, theatre and drama, and throughout the humanities. Michael Bérubé, in his introduction to Simi Linton's *Claiming Disability*, remarks that "If we do not imagine disability as a broad, general subject that shapes the humanities, it is all the less likely that we will manage to imagine disability as a broad, general subject that shapes public life and policy" (vii). Susan Wendell, in her essay "Toward a Feminist Theory of Disability," goes even further to assert that "If disabled people and their knowledge were fully integrated into society, everyone's relation to her/his real body would be liberated" (1989, 104).

More specifically, I argue for the inclusion of disabled autobiography in any study of American autobiography, because the lives of people with disability, expressed through the voices of those who have lived the experience of disability on a daily basis, have the potential to effect profound changes in the way nondisabled people view their disabled peers. Thomas Couser's *Recovering Bodies: Illness, Disability and Life Writing*, taught along with Robert Folkenflik's *The Culture of Autobiography*, would offer students a broader understanding of the material conditions of autobiography and expose the

ways in which specific writing practices depend on the body. And what better entry into an academic discussion of the use of the body in performance than a personalized, specific analysis of the limits (and the abilities) of disabled performers? Why not teach Victoria Ann Lewis's "Dramaturgy of Disability" with Marvin Carlson's *Performance: A Critical Introduction* in order to give students an idea of the ways in which our usual expectations for performance assume and demand able bodies?

FROM HERE, WHERE?

In terms of integrating disability studies into the humanities, the picture is still grim. In my teaching experience at the University of Texas at Austin, each time I proposed a disability-related English course I was flatly denied the opportunity to teach the course. Unconvinced by my argument for the centrality of disability to literary and film studies, the graduate advisor's frequent question to me was "What does that have to do with literature?" Interestingly, during the same semesters that I was refused the opportunity to teach a course that focused on images of disability in literature and film, or *The Rhetoric of Disability*, the department approved equivalent Mexican-American and African-American Literature courses, also taught by graduate students. This picture is repeated every day, all over the country. There are only a handful (seven at last count) of American universities that offer undergraduate concentrations in disability studies in the humanities, and two that offer Master's and Ph.D. Level

programs. The Texas Center for Disability Studies began in 2001, emerging out of the Special Education department. The three on-line courses it offers use a primarily medical model of disability to introduce students to issues of physical difference and disability identity. At the University of Texas, the largest public university in the United States, there is not a single disability studies class offered in the humanities, and there are no plans to offer any in the near future. Those of us in disability studies in the humanities have our work cut out for us.

In terms of disabled performance, I look forward to some much needed change and development. My hope is that an increased awareness of the color line that now characterizes disabled performance will prompt white performers to more actively confront race issues in their work, and urge more conscious recruitment of people of color as disabled performers for both solo and ensemble work. I have made repeated efforts to include people of color with disability as performers for *Actual Lives*, efforts that have now produced a 13 member ensemble group in which three performers are African-American and two are Mexican-American. Two performers are queer identified. This mix reflects the diversity of the Austin community, but it has required a conscious recruitment effort. I agree with Eli Claire when she said in her address to the 2002 Queer Disability Conference that “We haven’t asked enough questions about class, about the experiences of being poor and disabled, of struggling with hunger, homelessness, and a lack of the most basic healthcare. I want to hear from working class folks who learned about disability from bone-breaking work in the factory or mine or sweatshop” (*Address*). Disabled performance, which takes

seriously the ethic of accommodation, offers the potential for this kind of consciously inclusionary practice. We need to strategize as a community what that practice might look like.

If autobiographical performance by people with disability is to continue to be a viable contribution to the cultural conversation about disability, there need to be more disabled performers accessing more venues in more communities. Disabled performers need to develop wider repertoires of performance skills and be better supported financially. Theatre workshops like Joan Lipkin's *The DisAbility Project*, *Actual Lives*, *Interact*, and Victoria Lewis's *Other Voices* project at the Mark Taper Forum must continue to serve as training grounds through which disabled people can become the performers and writers they want to be. Collaborative work between disabled performers and local theatre groups also holds promise as a way to both improve performance skills and influence people who are already in theatre to become involved in disability-related productions. In our experience with *Actual Lives*, these collaborations with local actors, directors and technicians have significantly raised the bar for our performances.

Most importantly, autobiographical performance by people with disability must continue. Disabled people need to keep speaking the voice and experience of disability, putting the disabled body front and center onstage, insisting on sexuality, critiquing cultural practice that impacts their lives, commenting on social relations, and making "selves" that talk back. Without that, as Terry Galloway would warn us, nothing happens, and "beasty wins."

References

Actual Lives Audience Surveys, unpublished, August 2000 and November 2001.

Actual Lives Script, unpublished. November 2000.

“Art and Politics/Politics and Art.” Feb. 08, 2003. Cornell Council for the Arts, Cornell University, Ithaca, New York. 4/20/2003
<<http://www.arts.cornell.edu/cca/artpolitics/about.htm>>.

Auslander, Philip. “Liveness: Performance and the anxiety of simulation.” Ed. Elin Diamond. *Performance and Cultural Politics*. New York: Routledge, 1996. 198-213.

Barnes, Michael. “Two Plays by Terry Galloway elicit diverse responses.” *Austin American Statesman*. Austin, Texas. September 28, 1993.

Beach, Maria and Leslie Pasternack. “Making a Claim on the Empty Space: An Interview with Terry Galloway.” *Theatre InSight* 9.1 (Spring 1998): 50 – 51.

Beauvoir, Simone de. *The Second Sex*. Translated and edited by H.M. Parshley. New York, Knopf, 1953.

Bennett, Susan. *Theatre Audiences: A Theory of Production and Reception*. New York: Routledge, 1990.

Bergland, Betty. “Postmodernism and the Autobiographical Subject: Reconstructing the ‘Other’.” *Autobiography and Postmodernism*. Ed. Kathleen Ashley, Leigh Gilmore and Gerald Peters. Amherst: University of Massachusetts Press, 1994. 130-166.

Bermúdez, José Luis, Anthony Marcel and Naomi Eilan. Eds. *The Body and the Self*. Cambridge: The MIT Press, 1995.

Barnes, Michael. “Two Plays by Galloway elicit diverse responses.” *Austin American Statesman*, September 28, 1993.

- Bruner, Jerome. "The Autobiographical Process." *The Culture of Autobiography*. Ed. Robert Folkenflik. Stanford, Calif.: Stanford University Press, 1993. 38-56.
- Butler, Judith. "Variations on Sex and Gender: Beauvoir, Wittig and Foucault." *Feminism as Critique: On the Politics of Gender*. Ed. Benhabib, Seyla and Drucilla Cornell. Minneapolis: University of Minnesota Press, 1987.
- Carlson, Marvin. *Performance: A Critical Introduction*. New York: Routledge, 1996.
- Carr, C. *On Edge: Performance at the end of the twentieth century*. Hanover: Wesleyan University Press. 1993.
- Carter, B. "Chronic Pain in Childhood and the Medical Encounter: Professional Ventriloquism and Hidden Voices." *Qualitative Health Research*, v12 i1 (Jan 2002): 28 –42.
- Clare, Eli. "Sex, Celebration, and Justice: A Keynote for QD 2002." *Proceedings: Closing Plenary: Eli Clare*. 4/14/2003
<http://www.disabledwomen.net/queer/paper_clare.html>.
- Couser, Thomas. *Recovering Bodies: Illness, Disability and Life Writing*. Madison, Wisconsin: The University of Wisconsin Press, 1997.
- . "The Empire of the 'Normal': A Forum on Disability and Self-Representation." *American Quarterly*, Vol. 52, No. 2 (June 2000): 305-310.
- Crutchfield, Susan and Marcie Epstein. *Points of Contact: Disability, Arts and Culture*. Ann Arbor: University of Michigan Press, 2000.
- Damasio, Antonio. *The Feeling of What Happens*. New York: Harcourt. 1999.
- D'aoust, Vicky. "QD Identity – What is QD?" *Proceedings: Opening Panel*. 2002 Queer Disability Conference. June 2002. 4/21/2003
<http://www.disabledwomen.net/queer/paper_daoust.html>
- Davis, Charles B. "Reading the Ventriloquist's Lips: The Performance Genre behind the Metaphor." *TDR*. v 42 i4 (Winter 1998): 133 -147.
- Davis, Leonard. Ed. *The Disability Studies Reader*. New York: Routledge, 1997.

- . *Bending Over Backwards: Disability, Dismodernism and Other Difficult Positions*. New York: New York University Press, 2002.
- Diamond, Elin. Ed. *Performance and Cultural Politics*. New York: Routledge, 1996.
- Disability Rag*. No longer in publication, citation unavailable.
- Dolan, Jill. "Performance, Utopia, and the 'Utopian Performance.'" *Theatre Journal* 53 (2001): 455-479.
- Eakin, Paul John. *How Our Lives Become Stories: Making Selves*. Ithaca, N.Y.: Cornell University Press, 1999.
- . "Breaking the Rules: Consequences of Self-Narration." *Biography* v 24, i1 (Winter 2001): 113-122.
- Eberly, Rosa. *Citizen Critics: Literary Public Spheres*. Chicago: University of Illinois Press, 2000.
- Folkenflik, Robert. *The Culture of Autobiography: constructions of self-representation*. Stanford, Calif.: Stanford University Press, 1993.
- Frank, Arthur. *The wounded storyteller: body, illness, and ethics*. Chicago: University of Chicago Press, 1995.
- Fries, Kenny. *Staring back: the disability experience from the inside out*. New York: Plume, 1997.
- Garland-Thomson, Rosemarie *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press, 1997.
- . "Staring Back: Self-Representations of Disabled Performance Artists." *American Quarterly* 52.2 (2000): 334-338.
- . *Freakery: Cultural Spectacles of the Extraordinary Body*. New York: NYU Press, 1996.
- . "Redrawing the Boundaries of Feminist Disability Studies," *Feminist Studies* 20 (1994): 583-595.

- Galloway, Terry. *Out All Night and Lost My Shoes*. Tallahassee: Apalachee Press, 1993.
- . "Answers" – Answers to e-mailed questions, received February, 2003.
- . "I'm Listening as Hard as I Can." *Texas monthly*. April 1981. Austin, Tex.: Mediatex Communications, Inc. 183-186.
- . "The Miracle Worker." Videocassette. Dir. Diane Wilkins. Perf. Donna Marie Nudd, Terry Galloway, Jessica Altomera. Faust Films, a subsidiary of Mickee Faust Entertainment, 2002.
- . Unpublished Interview. August 2002.
- Gilmore, Leigh. "Policing Truth: Confession, Gender, and Autobiographical Authority." *Autobiography and Postmodernism*. Ed. Kathleen Ashley, Leigh Gilmore and Gerald Peters. Amherst: University of Massachusetts Press, 1994. Pages 54-77.
- Goffman, Erving. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster, 1963.
- Grealy, Lucy. *Autobiography of a Face*. Boston: Houghton Mifflin. 1994
- Grosz, Elizabeth. *Volatile Bodies: Toward a Corporeal Feminism*. Bloomington: Indiana University Press. 1994
- Halberstam, Judith. *Female Masculinity*. Durham: Duke University Press, 1998.
- Hammett, Dashiell. *The Maltese Falcon*. Middlesex : Penguin Books, 1963.
- Haraway, Donna. "A Manifesto for Cyborgs: Science, Technology, and Socialist Feminism in the 1980's." Ed. Weed, Elizabeth. *Coming To Terms: Feminism, Theory and Politics*. New York: Routledge, 1989. 175-204.
- Hockenberry, John. *Moving violations : war zones, wheelchairs, and declarations of independence*. New York: Hyperion, 1995.
- Hughes, Holly. "Clit Notes." Hughes, Holly and David Román. *O Solo Homo*. New York: Grove Press. 1998. 411-440.
- Hughes, Holly and David Román. *O Solo Homo*. New York: Grove Press. 1998.

“Interact: The Program.” Produced by Interact Center for the Visual and Performing Arts. 3/12/03 <<http://www.interactcenter.com/textthecenter.htm>>.

Jeffreys, Mark. “The Visible Cripple (Scars and Other Disfiguring Displays Included.” *Enabling Humanities: A Disability Studies Sourcebook*. Ed. B. Brueggemann, R. Garland-Thomson, and S. Snyder. New York: Modern Languages Association. 2001.

Jones, Amelia. *Body Art: Performing the Subject*. Minneapolis: University of Minnesota Press, 1998.

Kerby, Anthony Paul. *Narrative and the Self*. Bloomington: Indiana University Press, 1991.

Kuusisto, Stephen. *Planet of the Blind: A Memoir*. New York: Dell Publishing, 1998.

Leroux, Gaston. *The phantom of the Opera*. London : Mills & Boon, 1911. Stage adaptation by Bruce Falstein, Herschfeld Broadway Productions, 1990.

Levine, George. *Constructions of the Self*. New Brunswick: Rutgers University Press, 1992.

Lewis, Victoria Ann. “The Dramaturgy of Disability.” Ed. Crutchfield, Susan and Marcy Epstein. *Points of Contact: Disability, Art and Culture*. Ann Arbor: University of Michigan Press, 2000. 93-108.

Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York: New York University Press, 1998.

Lorde, Audre. *Sister Outsider: essays and speeches*. Trumansburg, NY : Crossing Press, 1984.

Mairs, Nancy. *Carnal Acts*. Boston: Beacon Press. 1996.

Marcus, Neil. *Storm Reading*. Videocassette. Private distribution from the artist.

Miller, Tim. “Naked Breath.” Hughes, Holly and David Román. *O Solo Homo*. New York: Grove Press. 1998. 54-92.

- Mitchell, David. "Body Solitaire: The Singular Subject of Disability Autobiography." *American Quarterly*. Vol. 52, no. 2 (June 2000):311- 315.
- Muñoz, José Esteban. *Disidentifications: Queers of Color and the Performance of Politics*. Minneapolis: University of Minnesota Press. 1999.
- Neisser, Ulric. "Five Kinds of Self-Knowledge." *Philosophical Psychology* 1, 1988 35-59.
- No Apologies*. Penni Hall and Pandoura Carpenter. Videocassette. Produced by Wry Crips, Oakland, California, 1994.
- Norden, Martin. *The Cinema of Isolation: A History of Physical Disability in the Movies*. New Brunswick: Rutgers University Press, 1994.
- . "The Hollywood discourse on disability: some personal reflections." *Screening disability: essays on cinema and disability*. Ed Smit, Christopher R. and Anthony Enns. Lanham, Md.: University Press of America. 2001.
- Nudd, Donna Marie. "An Interview with Terry Galloway." *Out All Night and Lost My Shoes*. Tallahassee: Apalachee Press, 1993, pages 29 –32.
- O'Dell, Kathy. *Contract with the skin : masochism, performance art, and the 1970s*. Minneapolis: University of Minnesota Press, 1998.
- Oliver, Michael. *The Politics of Disablement: A Sociological Approach*. New York: St Martin's Press, 1990.
- "Welcome to PHAMALy." 7/20/2001. *PHAMALy*. Physically Handicapped Amateur Musical Actors League, Inc., Denver, Colorado. 3/12/03. <<http://www.phamaly-colorado.org/indexmain.html>>
- "Puppets and Puppetry." April 25, 2003. *TV Acres*, provided by Distance Education Librarian at Saint Francis University, Loretto, Pennsylvania. 2/22/03 <http://www.tvacres.com/puppets_sharilewis.htm>
- Roche, David. *The Church of 80% Sincerity*. Transcription of videotaped performance. Personal copy of author.
- . Interview 1, unpublished interview, 3/12/2001
- . Interview 2, unpublished interview, 10/12/02

---. "My Face Does Not Belong to Me." 2/21/02
<http://www.davidroche.com/my%20face.htm>

Saxton, Marsh and Florence Howe. *With wings : an anthology of literature by and about women with disabilities*. New York: Feminist Press at the City University of New York, 1987.

Sedgwick, Eve K. *Epistemology of the Closet*. Berkeley : University of California Press, 1990.

Sedikides, Constantine and Marilynn Brewer. *Individual Self, Relational Self, Collective Self*. Philadelphia: Psychology Press, 2001.

---. Sedikides, Constantine and Lowell Gaertner. "A Homecoming to the Individual Self: Emotional and Motivational Primacy." *Individual Self, Relational Self, Collective Self*. Eds. Constantine Sedikides and Marilynn Brewer. Philadelphia: Psychology Press, 2001. 7-23.

Shapiro, Joseph P. *No Pity: People with Disabilities Forging a New Civil Rights Movement*. New York: Times Books, 1993.

Schechner, Richard. *Between Theatre and Anthropology*. Philadelphia: University of Pennsylvania Press, 1985.

"Lamb Chop creator Shari Lewis dead at 65." *Entertainment Television*. 8/03/98. CNN.com. 3/07/03.
<<http://www.cnn.com/SHOWBIZ/TV/9808/03/shari.lewis.obit/>>.

Sprinkle, Annie. "Metamorphosex – The Art of Love." *Annie Sprinkle*. 4/20/2003
<<http://www.anniesprinkle.org/html/lectures/metamorphosex.html>>.

Smith, Sidonie. *Subjectivity, Identity and the Body: women's autobiographical practices in the twentieth century*. Bloomington: Indiana University Press, 1993.

Strickling, Chris Anne. "Actual Lives: Cripples in the House." *Theatre Topics*. Volume 12, Number 2. (September 2002): 143-162.

Tice, Dianne and Roy Baumeister. "The Primacy of the Interpersonal Self." *Individual Self, Relational Self, Collective Self*. Eds. Constantine Sedikides and Marilynn Brewer. Philadelphia: Psychology Press, 2001. 71-88.

Tolan, Kathleen. "We are Not a Metaphor." *American Theatre* Apr 2001: 17-21.

Trahan, Julia. "Where Julia's Body Performed." *Dolphin J.* Trahan Homepage.
<http://members.tripod.com/Dolphin_J/oz.html>.

Turner, Victor. *From Ritual to Theatre: The Human Seriousness of Play*. New York City: Performing Arts Journal Publication, 1982.

Wade, Cheryl Marie. *Sassy Girl: Memoirs of a Poster Child Gone Awry*. Videocassette. Private distribution through the artist.

Vanderbilt, Amy. *Amy Vanderbilt's complete book of etiquette: a guide to gracious living*. Book Club ed., Garden City, N.Y., 1954.

Walloch, Greg. "gregwalloch.com." Walloch homepage. 3/12/03.
<www.gregwalloch.com>.

Wendell, Susan. *The Rejected Body*. New York: Routledge. 1996.

--- "Toward a Feminist Theory of Disability." *Hypatia*. v4 n2 (Summer 1989):104-125.

Vita

Chris Anne Strickling was born in Fort Worth, Texas on March 17, 1952 to Florene Olive Berrier and James A. Strickling. She graduated from Southwest High School in Fort Worth, Texas in 1970, and attended the University of Texas at Austin for two years before going abroad. She returned to her studies in 1974, completing course work that enabled her to apply for admission to the University of Minnesota School of Allied Health. She graduated from the University of Minnesota with a Bachelor of Science Degree in Occupational Therapy in 1979, and has practiced Occupational Therapy continuously since that time. For the past fifteen years, she has lectured widely on motor development in children with visual impairment, and developed a private practice specializing in services to deaf/blind children. She has several clinical publications in Occupational Therapy, including “Motor Focus: Promoting Movement Experiences and Motor Development,” a chapter in *Early Focus: Working with Young Children Who are Blind or Visually Impaired and Their Families* edited by Rona Pogrand, Ph.D., published by The American Foundation for the Blind Press (September 2002) and *Impact of Vision Loss on Motor Development: Information for Occupational and Physical Therapists Working with Students with Visual Impairments*, published by Texas School for the Blind and Visually Impaired, 1998.

Ms. Strickling completed a Master of Arts Degree in English at the University of Texas at Austin in 1997. She taught freshman English through the Department of Rhetoric and Composition from 1998 until the Spring Semester of 2002, developing and teaching an English 309K course entitled “The Rhetoric of America’s Weight Loss Industry” during the 1999-2000 school year. During the 2000-2001 school year, she taught English 314L: *Women’s Popular Genres: Romance and Sentimentality*, which focused on the uses of romance and sentimentality in fiction. In 1999, she formed the *Actual Lives* Performance Ensemble in collaboration with performance artist Terry Galloway and comprised of adults with disability, and this work became the focus of her dissertation. She has guest lectured for three semesters at St. Edward’s University in Austin, Texas on “Disability, Arts, and Culture.” Chapter One of her dissertation was published by Johns Hopkins University Press as an article entitled “*Actual Lives: Cripples in the House*,” in *Theatre Topics* journal, September 2002.

She lives with her daughter, Willa Kramer, and her partner, Kathleen Claps, at her permanent address: 169 Russell Lane, Dripping Springs, Texas 78620.

This dissertation was typed by the author.

