This book presents interdisciplinary scholarship on art and visual culture that explores disability in terms of lived experience. It will expand critical disability studies scholarship on representation and embodiment, which is theoretically rich, but lacking in attention to art.

It is organized in five thematic parts: methodologies of access, agency, and ethics in cultural institutions; the politics and ethics of collaboration; embodied representations of artists with disabilities in the visual and performing arts; negotiating the outsider art label; and first-person reflections on disability and artmaking.

This volume will be of interest to scholars who study disability studies, art history, art education, gender studies, museum studies, and visual culture.

Alice Wexler is Professor Emerita of Art Education at SUNY New Paltz. She is the author of *Autism in a Decentered World* and the co-editor with Vida Sabbaghi of *Bridging Communities Through Socially Engaged Art*.

John Derby was an independent scholar as well as a secondary art and postsecondary art educator for over 20 years.
I dedicate this book to John Derby who unexpectedly passed away in 2019. He was a dear friend and colleague whose knowledge and thoughtfulness made a distinctive impact on disability and the arts.
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Contributors

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John Derby was an independent scholar as well as a secondary art and postsecondary art educator for over 20 years; he was also a former professional metalsmith. He earned his PhD in Art Education from The Ohio State University, MA from Brigham Young University, and BS and BFA from Bowling Green State University. Derby’s research program intersects Art Education and the interdisciplinary field of critical Disability Studies, with specific interests in mental disability, contemporary art and visual culture, and critical race studies. He has published in books and leading academic journals including Art Education, Disability Studies Quarterly, Review of Disability Studies, Studies in Art Education, Visual Arts Research, and Visual Culture & Gender and has served on the editorial review boards of several leading journals.

Taraneh Fazeli’s home and chosen family is in New York. Since working as an art curator, educator, and editor at the arts organizations e-flux, Triple Canopy, and the New Museum of Contemporary Art, she has operated primarily as a freelance curator. Her traveling exhibition Sick Time, Sleepy Time, Crip Time: Against Capitalism’s Temporal Bullying addresses the politics of health by bringing together artists and community
groups to examine the temporalities of illness and disability, the effect of life/work balances on well-being, and alternative structures of support via radical kinship and forms of care. It has taken place at arts organizations including Bemis Center (Omaha, Nebraska), EFA Project Space (New York), Lawndale Art Center and Project Row Houses (Houston, Texas), The Luminary (St. Louis, Missouri), as well as numerous social service organizations. The impetus to explore illness as a by-product of societal structures while also using cultural production as a potential place to re-imagine care was her own chronic illnesses and work in institutional critique.

**Anne James** joined Liverpool Hope University in 2008 as Lecturer in Music Education. She holds the qualifications GRSM, ARCM, PGCE, and MA in education leadership and management and in 2015 completed an educational doctorate. Her research focused on subject knowledge for primary school teachers and how the university can train non-specialist teachers to teach music. She is Subject Lead for Music in the School of Performing and Creative Arts. However, she remains committed to teacher education and continues to lead the PGCE secondary music teacher training course.

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**Michelle Kraft** served as a visual art reviewer on the John F. Kennedy Center’s Office of VSA/Accessibility’s Special Education Committee for the National Coalition for Core Arts Standards (NCCAS). She has published numerous book chapters and peer-reviewed journal articles and presented papers at regional, national, and international conferences on the subjects of difference, disability in visual culture, and preparing pre-service art educators to work with diverse student populations. Kraft co-authored, with Karen Keifer-Boyd, the book *Including Difference: A Communitarian Approach to Art Education in the Least Restrictive Environment* (2013, National Art Education Association). She serves as Program Coordinator for Art at Lubbock Christian University in Texas.

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**Ann Millett-Gallant** is Senior Lecturer for the University of North Carolina at Greensboro, where she teaches art history, visual culture, and liberal studies courses. Her research, like her teaching, crosses the disciplines of art history and disability studies.

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**Carmen Papalia** has lectured on his work at the University of Sunderland (UK), the California College of the Arts, Portland State University, the Pacific Northwest College of Art, the University of Michigan, York University, and Emily Carr University. His recent writings can be found in *Stay Solid: A Radical Handbook for Youth* (AK Press 2013); *Reference Points: Temporary Services* (Publication Studio 2013); and in the “Museum Experience and Blindness” issue of *Disability Studies Quarterly*. His work has been featured as part of exhibitions and programming at The Whitney Museum of American Art, the L.A. Craft and Folk Art Museum, the Grand Central Art Center, the Canter Fitzgerald Gallery at Haverford College, the Portland Art Museum, the Columbus Museum of Art, and the Vancouver Art Gallery.

**Claire Penketh** is Associate Professor in Disability and Education at Liverpool Hope University, where she is a core member of the Centre for Culture and Disability Studies (CCDS). Her research interests include the relationship between art education and disability and particularly the role of observation and drawing within educational practice. She is joint co-editor of the International Journal of Art and Design Education (iJADE) and a member of the National Society for Education in Art and Design (NSEAD) and International Society of Education Through Art (InSEA).

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Carrie Sandahl is Head of the Program on Disability Art, Culture, and Humanities at the University of Illinois at Chicago, which is devoted to research on and the creation of disability art. This program also serves as the administrative home for Chicago’s Bodies of Work, an organization that supports the development of disability arts and culture. Sandahl is active nationally as a public speaker. She is frequently invited to present her research and creative work on disability art and culture at universities across the United States, including University of California-Berkeley, University of California-Santa Barbara, Stanford University, Bucknell University, University of Florida, Smith College, and Davidson College among others. She has keynoted conferences such as the Articulations Conference at the University of Minnesota–Twin Cities and the Portland Disability Art and Culture Festival in Oregon. Sandahl also regularly presents her research at the Society for Disability Studies and the Association for Theater in Higher Education, both professional organizations in which she has been an active member for more than 15 years.

Katherine Sherwood is Professor Emerita of Painting and former Chair of the UC Berkeley Department of Art Practice. She developed two groundbreaking courses—“Art, Medicine and Disability” and “Art and Meditation”—and played a prominent role in the expansion of the Disability Studies program. Katherine Sherwood’s work has been exhibited in the 2000 Whitney Museum Biennial, at Yerba Buena Center for the Arts in 2003 and 2009, and at the Smithsonian in 2010. Solo exhibitions include Walter Maciel Gallery in Los Angeles; Gallery Paule Anglim in San Francisco; Locks Gallery in Philadelphia; Cole Pratt Gallery in New Orleans; Hemphill Gallery in Washington, DC; and Michael Kohn Gallery in Los Angeles. She had an extensive retrospective exhibition at Worth Ryder Art Gallery at UC Berkeley in 2016. The relevance of her work to medicine and brain science has led to her participation in “Visionary Anatomies” at the National Academy of Science in Washington, DC; “Inside Out Loud: Visualizing Women’s Health in Contemporary Art” at the Kemper Museum in St. Louis; “Human Being” at the Chicago Cultural Center; and a solo exhibition “Golgi’s Door” at the National Academy of Sciences in 2007. Sherwood was a recipient of a 1989 National Endowment for the Arts Grant, 1999 Pollock Krasner Foundation Grant, 2005 Guggenheim Fellowship, 2006 Joan Mitchell Foundation Grant, and 2012 Newhouse Foundation Grant.

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Nina Stuhldreher is a Vienna/Berlin-based visual artist who describes herself as reality researcher with multiple incompatibilities. She is an ex-photography prodigy, ex-wannabe rapper, ex-online magazine editor, ex-new media curator, ex-collaborative-workforms junkie, and currently training to be a future ex-art discourse believer. Her activism in the field of disability studies includes research into neurodiversity and the bodymind, into visual thinking and cognitive disobedience, and the danger of Orwellian surveillance for deviant behavior and non-normativities of all kind. She has taught seminars on Disability Studies and on Net Activism from a feminist and cultural-theoretical perspective at the University of Art and Design in Linz, and, together with the technofeminist research group “#purplenoise”, recently dedicated the opening performance at transmediale festival Berlin (2019) to a Haraway-inspired idea of “tentacular thinking.”

Sam Wade started working for DaDaFest in 2009 as a freelance coordinator; she helped to deliver DaDaFest International 2009 and 2010. In 2011, Sam began running the young people’s program at DaDaFest and has since worked with young people in Merseyside to deliver a number of exciting large-scale projects. Sam previously worked within the creative industries prior to becoming a qualified visual arts teacher teaching art and design in secondary schools for five years. Sam’s passions lie with visual arts, in particular art for social change.

Alice Wexler is Professor Emerita in Art Education at SUNY New Paltz. She was a North America World Councilor for InSEA 2017–2019 and Past President USSEA. In 2007, she was a visiting scholar at the Australian Institute for Aboriginal and Torres Strait Islander Studies (AIATSIS), researching the art of children from the Stolen Generations in the south-west of Western Australia. Data from this research will be published in a forthcoming book. A monograph, *Art and Disability: The Social and Political Struggles Facing Education*, was published by Palgrave Macmillan in 2009 and a compendium, *Art Education Beyond the Classroom: Pondering the Outsider and Other Sites of Learning*, was published in 2012 with Palgrave Macmillan. The most recent monograph, *Autism in a Decentered World*, was published with Routledge in 2016, and a collection of essays, *Bridging Communities Through Socially Engaged Art*, edited with Vida Sabbaghi, was published with Routledge in 2019.

Carol Zou is a Texangeleena by way of the Chinese diaspora. Her work focuses on layered human geographies, craft as non-Western cultural production, and polyvocality through a community organizing model. Her work ranges from facilitated community collaborations to more personally driven, conceptual works. Zou is the director of Trans.lation, an arts and cultural platform initiated by Rick Lowe and commissioned by the Nasher Sculpture Center, located in the immigrant, refugee, African American, and Latinx neighborhood of Vickery Meadow, Dallas, Texas. Prior to Trans.lation, Zou organized the art collective Yarn Bombing Los Angeles, a collective ranging from 20 to 500 crafters that creates public art through crowdsourced, participatory models. She has participated in fellowships and residencies from National Art Strategies, Women’s Center for Creative Work, and Common Field and is currently a 2017 Project Row Houses–University of Houston College of the Arts Inaugural Fellow.
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I would like to acknowledge the caring people who wrote chapters in this book. After losing John as a co-editor, they took time to write reassuring words that helped us continue to put this book together. Each of the authors were compassionate about and patient with this tragic event. Their stories and research are reflections of the sensitivity that pervades the network and community of people in disability studies. I thank Lori Derby for her support in completing John’s chapter, and the editors at Disability Studies Quarterly for allowing me to reprint it.

Finally, I thank my Routledge editor Isabella Vitti for her infinite patience and her assistant Katie Armstrong.
Foreword

*Petra Kuppers*

**Going to the Gallery: Wheelchair Tracks, Skin Intimacies, Crip Families**

*Contemporary Art and Disability Studies* covers important ground. It gives a snapshot of the current state of practice, theoretical approaches, and methodological engagements with different aspects of disability in contemporary arts worlds from makers to critics, from museum and gallery environments to healing practices.

In this prologue, I want to pull out some of the riches of these approaches and use them as lenses to address a disability-themed exhibit at Westbeth Gallery in New York City in the winter of 2016, engaging works by Chanika Svetvilas and Chun-Shan (Sandie) Yi. I focus on the cycle of production, display, reception, and embedment. This prologue witnesses ways in which a disabled critic can approach a disabled artist's work not in isolation, not in meditation on singularity, but through a focus on community and coherence, on the building and maintenance of a network of disabled artists. My particular framework is ecosomatic, that is, I bring together environment, materiality, and physicality with histories of embodiment and enmindment—two terms that hold on the temporality of the processes that make up how we experience ourselves.

In 2016, Thai American artist Chanika Svetvilas showed *Side Effects*, a drawing installation with audio, in the Westbeth Gallery in New York City. The installation was part of *Transforming Community: Disability, Diversity and Access*, a national exhibition, which I had been invited to jury for the Women Caucus for Art, a non-profit organization based in New York City, which supports women artists, art historians, students, educators, and museum professionals. Svetvilas’ installation was 1 of 29 pieces I chose for the gallery, assembled through a national call for art.

*Side Effects* emerges from durational labor, from repetition, ingestion, and seriality. The installation revolves around Abilify, a well-known antipsychotic medication that she uses to control her bipolar experience. She writes about the logistics involved in accessing the guide that is part of every packet of the medication: “The Abilify medication guide is 17.5” × 24” with 6 pt. font and the secondary guide is 9.5” × 14.5” with a 10 pt. font that reinforces the side effects information. Both state that they should be read before taken. The entire medication guide can be read out loud in about three hours” (artist statement).

In the gallery exhibit, Svetvilas pasted together 24 original Abilify medication inserts with rice paste to form a white 6’ × 10’ panel. The original printed material is just about visible, a palimpsest of the medical voice. This panel is the substrate for the charcoal drawing, a blown-up image of the first page of the medication guide. All materials, the original medication guides, charcoal, and rice paste, have strong resonance for the artist, who writes:

Charcoal contains carbon and remaining ash after water is removed. Activated charcoal is used to absorb chemical substances and is used when the stomach is pumped...
after an overdose. The medication guides are pasted onto paper rolls with rice paste, a starch, to contrast with consumed chemical substances. Starch is a disintegrant and binder used to make pills consumable. Rice paste was also used by my mom to seal letters she sent to my grandmother in Thailand.

(artist statement)

As an audience member, I bring my own imagination and fantasies to these materials. I imagine the labor of pasting all these guides together, methodical brushstroke by brushstroke. The physical labor of transferring the image onto the sheets, charcoal dust smudging into skin creases, the artist’s stretching body across the white expanse, contraction, release. In the presence of the large panels, I get to think about the durational aspects of handmade objects and manufacture: humans, material, and production.

Then I think about the interplay between the gallery’s urban location and the city’s transformation of materials and land into commerce. Imagine fresh charcoal still drifting in the air, tracking onto the clothes of gallery visitors, being trodden out of the gallery on the bottom of shoes, on the wheels of my scooter, mixing with the different dark dusts and pollution fallout of the city. On the way to the gallery, I remember wheeling past many Thai restaurants, and I contemplate immigrant experiences as I remember the stickiness of starch on my tongue.

Wheeling in and out of the exhibit space in Westbeth, part of the West Village, through the snow-covered February streets, the sense of inside and outside mixed in complicated ways; I could see the slushy traces of my scooter’s traversal of the gallery space when I looked through the large lit-up gallery windows at the gleaming floors. As soon as the opening reception got underway, my curving paths eroded. Gallery visitors’ feet smudged the curves into new constellations. Other wheelchair users came as artists as well as audiences, and they tracked their own marks onto the floor. That night, I sat just outside the big glass window, face into the ice-cold air, taking a breather from the press of voices and sensory overstimulation. I appreciated the ever-changing faint tracks on the wooden floor as their own artwork of intermingled habitation and visitation.

The gallery provided access and, with that, access intimacy (a word that travelled into academic discourse through the activist practices of Mia Mingus and others who are looking for ways to capture nuanced insights into patterns of privilege and intersectional exclusion). Mingus wrote in a 2011 blog post about the emotional/affective charge of access intimacy:

Access intimacy is that elusive, hard to describe feeling when someone else “gets” your access needs. The kind of eerie comfort that your disabled self feels with someone on a purely access level.

(Mingus 2011)

I had an experience of access intimacy as I sat outside the gallery, knowing that I could easily traverse back inside; mix and mingle with feminist, queer, and disabled artists and many friends; but also be safe and well in this edge zone while my ears rested and my nervous system readjusted. I wouldn’t need help to open the door or a ramp brought out specifically for me, embarrassed gallery workers running around on my behalf, a service elevator in the back, or access through an underground tunnel (all fairly regular examples of how I get to see art in public spaces, given the lack of wheelchair access in so many sites). Here, I could see, hear, or feel fellow disabled people as artists and, as viewers, shifting the (floor) patterns of physical spaces. Creating access intimacy in the context of art is a powerful tool toward enlarging who feels that they can have ownership in art creation.
Many art administrators and curators now have begun to engage with the multiple ways that a gallery can be more than just legally accessible but can offer access intimacy: access baked in, and foregrounded, with announcements of sensory engagement days or regular visits of dementia access groups; “easy language” guides; social practice work that enlarges who feels they can have ownership of art practices; hanging practices that make visual art viewable from many different levels; and active acknowledgment and remediation of the classist, racist, misogynist and ableist pasts of museum and gallery history, both through the art and through the framing statements.

Svetvilas’s installation meditates on medication, hospitalization, and raced and gendered labor. I am attracted to what is burned away and what remains, to the coal dust flaking and mixing with snow and floor patterns. Svetvilas names her attraction to charcoal: “Charcoal for me is a transformative material as a substance that has been burned away, that brought me back to life” (personal communication, 2019). This aliveness and alchemical potential draws me in. Charcoal’s infectious potential grabs me, its infiltration, just as the medication suffuses and permeates the experience of its user, shifts the affect flavor of mania.

Influence intrigues me: how we hold on to the histories of disability art experiences, the often hidden, minor, constricted practices of so many artists who found themselves collected under the label of “outsider artist,” creating their work with mundane and everyday materials, like charcoal and graphite on walls. Most of those practices get scrubbed away; painted over; or, in the popular imagination of prisons and institutions everywhere, stay behind to tell the next inmate about the lives that went before. Some enter into the profitable art market of outsider art galleries, distribution machines and collectors, its own network of art money ever since the first psychiatrists and ethnographers acted upon romantic notions of European modernity’s decadence, and the supposed energy and purity that lay elsewhere.

*Side Effects* has something to say to that history of scribbling on walls, to found materials, and to the inside/outside dynamic of the hospital, drug manufacture, insurance histories, and the infrastructure of the health industrial complex.

But contemporary disability culture artists also draw on other histories, relationships, and effects of their lives on others. Side by side with the Abilify medication leaflet, Svetvilas also remediated other notes of her life during her hospitalization, in particular drawings and notes by her nieces, voicemail messages by friends, and more. She writes about these other ephemera of her stay:

> My nieces’ drawings sent by fax contrast with those of my prescription bottle and hospital admission form. One note states, “I love you! I hope you are having a good time!” To my niece, I am just her aunt who needs to get better.

(artist statement)

Isolation was the guide under which older catalogues of outsider artists were assembled. They were deemed pure from influence, pure from connection. Here, the “mad woman” stereotype is broken by slanting into being an aunt, into loving relationships that span the hospital’s walls, and that undermine the separation of the spheres.

Another artist in this exhibition, Chun-Shan (Sandie) Yi, also creates art out of ephemera, and her work also speaks to connection but in a very different register. She exhibited small pouches of material made of human skin flakes, silk organza, sewing thread, embroidery thread, and lotion. You come across them as you wander the gallery: small shimmering pouches, about the size of the inner circle of a palm. They are mysterious, pink and white and gleaming, with darker patches the color of blood. They don’t easily give away
what they are: remnants, relics of tender engagement between humans, captured in material that holds a charge of abjection.

Once you start to read about their creation, you realize what you are seeing: the ubiquitous element of sloughed off skin cells, visible/invisible detritus of human presence, captured and honored in precious attention and precious material. Yi uses the vocabulary of intimacy and connection to describe her ongoing project: sharing stories, time, and supportive self-care within the disabled community. She uses the term “crip sister” to point to the chosen family status that some disabled people give as an honorific to others in our world. She describes what binds them, united as Asian disabled women:

Rahnee and I are sisters, not by blood, but by our connections to disability. Our contractured fingers and toes, and our Asian blood, made us sisters: Rahnee is half Thai and half white; I am a Taiwanese. Rahnee has psoriasis and I was born with two fingers and toes.

(Yi 2017)

Yi writes about the piece, which emerged from an ongoing collaboration with Rahnee Patrick, herself a well-known activist in the Chicago scene:

My Crip sister Rahnee grows her skin 100 times faster than average people. I help her with personal hygiene, including showering, applying lotions, massaging her skin and dressing. Sometimes I use my finger tips to peel off the excessive skin to relieve Rahnee from her swollen and inflamed skin. I would feel the body fluid rushing out of her skin between my nails and finger-tips, then I would massage her body with a thick layer of lotion. We often talk throughout this process as peer support time: sometimes we laugh, sometimes we cry, and sometimes we are just exhausted together.

(artist statement)

Loss and pain are part of this experience, not just togetherness. As in Svetvilas’ work, care and relation mix in complex ways. My reception quickly turns to thoughts on the health care system, insurance, support helpers, payment conditions, financial access, and, again, access intimacy: who is enabled or positioned to know someone who would do this intimate service for another adult? What is the “tender” of our lives?

Precarity is part of Yi’s reflection on her skin pods. She asks:

If [Rahnee’s] skin flakes were evidence of her existence, what does it say about the gesture of throwing pieces of her away? . . . I decided to turn to sewing and made pods to hold Rahnee’s skin flakes to document the intimate communications and the care relationships between Crip sisters.

(artist statement)

Yi’s work points us to concepts that have currency in disability culture worlds: crip time, care regimes, and interdependency. Her process offers both confrontation and contemplation. She reclaims material that is part of the traditional catalogue of the abject grotesque in art practice, and she does so through an emphasis on ongoinness and the everyday. Yet in turn she wraps these materials into a presentation practice that has its own quite different art heritage, one associated with uplift and the accruement of value.

Material at the edges of the human/non-human, like skin, blood, shit, semen, piss, hair, have all come to be associated with confrontational body artwork in 20th- and 21st-century art practices. In Yi’s disability culture inflection, the medium of skin is reclaimed
in the feminist surreal vocabulary of the (religious) relic or shrine or the (familial or ancestral) preserved baby-shoes. Yi successfully torques experience by opening up a gap between what gallery visitors see, and what they read about.

In the Westbeth Gallery, I could see people physically step back after reading about the small, dainty organza objects in front of them. Skin cells freak people out. Contamination is the threat that hangs over abject liminal art material. Everybody gets twitchy and itchy—and yet, the smallness of the pouches invite close proximity, leaning in, detailed attention. Visitors pull back and forward, caught bodily in these dynamics, tracking an ecosomatic of self and others’ bodily being.

Hidden aspects of the everyday of disability come into view. It’s not easy to make exciting and gorgeous artwork with the liminal materials that foreground the everyday of disability, from colostomy bags to insulin syringes, from pill maintenance regimes to tricked-out crutches. The materialities of disability life, even after all our activism, pride work, all the normalizing, all the queering, all the crippling still remain abject territory for many non-disabled people. In both of the pieces I discuss here, Svetvilas’ and Yi’s work, infiltration becomes a theme: the material of the work tracks and smudges floats about and goes on journeys inside/outside bodies and spaces.

Still hovering outside the gallery, I can see through the window some of the artists, critics, and curators that are assembled in this book. I can see Riva Lehrer near one of her portraits. I can see curators Chris Smit and Lisa VanArragon, who have driven to New York City from Grand Rapids, Michigan. Later, I reenter the gallery to witness Bronwyn Preece’s performance piece, in which she dances about copper poisoning, her body mobile, alive and thriving.

A book of disability arts is a book about a community, about reaching out toward one another and finding ourselves in galleries and conference spaces, visiting with one another to listen to an artist talk, or to engage in a community arts workshop. And a book like this holds on to the complexities that make different notions of “success” possible: not everybody mentioned in these pages will have enough commissions to make a living or the educational access, ability, and stamina to work in an academic or art administrative position. Many artists do not have the funds to travel to New York City or enter arts competitions, which, in the absence of strong federal, state, or regional funding support in the USA, often support themselves through fees.

Racialized and gendered histories run through the two works I charted here: the histories of Asian women as personal support and care workers in colonial frames, the institutionalization histories of both women and people of color, racialized production pipelines and Asian women’s manufacture, and the histories of negating the embodiment and enmindment of both artists and audiences in mainstream white-male dominated accounts of art history. The emphasis on materiality that both artists here bring to the aesthetic crux of their work offers new openings for reclamation and engagement, without leaving pain behind.

In this prologue, I took you on a quick art foray, a flânerie of engagement. I asked questions and offered quick perspectives on the artwork’s physical location in a particular gallery, which itself was located in a particular city and which was part of a particular network. I focused as much on the material used to create the work as on the representations themselves, and I aligned this interest with the artists’ statements, making sure to center the disabled artist’s own voice if and when they spoke about their intent (which not all artists do). I surveyed quickly some audience responses and located my own critic’s self in the physical space and in physical proximity to the work I analyzed. I also sampled or at least named some historical embedment for the practices we looked at: both in terms of art history (“outsider art,” installation practice, social practice, and body art) and in terms
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of wider frameworks, like colonial histories, gendered and racialized working practices, travel, migration, and the health care industrial complex.

Contemporary Art and Disability Studies invites you on this journey. Each essay in this collection foregrounds some aspect of this kind of art historical engagement and places contemporary work practices in wider dialogues. The history of disability art history is still quite recent, and there is much to explore. Together, we excavate, elevate, and chart the always emerging world of international disability culture labor.

References


The evolution of critical disability studies over the past two decades has shown that disability is comparable to ethnicity, gender, sexuality, and other identity markers in its lived and constructed realities and that it demands nuanced, critical attention. Beyond academia, the theories of disability studies now exist alongside profound questions of social and cultural justice, corporeality, social construction, and aesthetic and political representation (Brueggemann 2002). Following the social construction movement,1 with the important addition of embodiment and the feminist inquiry regarding the role the body plays in disability studies, the flourishing of first-person, experiential disability narratives has further disrupted medical and other deficit models of disability and has significantly contributed to cultural studies. As Swan (2002) suggested, disability studies brings an understanding of the body as “writing is not only about the body but of and from the body too” (284). This embodied view of the world, of and from the body, has changed how we think and talk about disability. Self-representations of people with disabilities through literary, visual, and performative narratives have disrupted “the way disabled subjects are often used, then erased,” from the public sphere (Brueggemann 2002, 318). Meanwhile, disability theorists have challenged the field to embrace deeper, more nuanced understandings of disability.

Contemporary Art and Disability Studies explores this nuanced understanding of disability through an interdisciplinary approach to disability, art, and visual culture. The contributing authors expand the growing topics of representation and embodiment in critical disability studies scholarship, engaging in the breadth of social and corporeal conditions of both amateurs and professionals while sliding between the two worlds and challenging the lingering qualifications for these polarizing categories. We argue that while disability studies research on art and creativity has been theoretically rich, it has lacked attention to contemporary visual art and creative, vernacular visual culture compared to other cultural artifacts such as literature, the performing arts, film, museums, mainstream media, and historic photography. This privileging of literary and performative arts has neglected the rich cultural expressions of visual artists, whose aims and methods are diverse, reflecting cultural heritages that differ from those of traditionally educated writers and other professionals. While the editors recognize the importance of literary and performative arts to disability studies, and while several chapters in the book include performance art, we seek to divulge the breadth and depth of disability expressions through contemporary visual art and culture. The authors of this book appreciate the achievements of those who intersect disability and art regardless of sociocultural and professional status while critically examining the exclusionary practices at stake in the art world.

We might have followed Nochlin’s (1971) classic essay on the absence of important women artists by attempting to answer the question, “Why are there no great disabled artists?” It is a valid question. On a superficial but significant level, the list of “Great Artists”
who are disabled is stunningly low, with only a handful of internationally noteworthy disabled artists, many of whom developed impairments late in their careers. Other historic artists have been diagnosed with a disability posthumously, and the miscellaneous works that reference disability have often done so superficially. Nochlin, of course, was not criticizing the lack of women artists in Western art *per se*, nor the representation of women, but rather the sexism that pervaded art history in its definition of the canon and the conditions for being a Great Artist. While simultaneously providing examples of such, Nochlin cautioned against arguing that there have been great women artists or that the womanhood of exceptional women artists was the root of exceptionality and unrecognized superiority. Instead, Nochlin criticized the myth of the Great Artist as a white, male construct. Like Nochlin, we could address the systemic ableism that pervades mainstream art. Akin to sexism, ableism is the belief that being able-bodied and able-minded is normal and desirable and that disability is deviant and undesirable. We could also criticize the field of critical disability studies for neglecting critical attention to the visual arts. Nochlin also discussed the “automatic, institutionally maintained discrimination against women” (25) in art educational contexts, which is obviously pertinent to the discrimination that aspiring disabled artists face, even today. Nochlin’s discussion of low expectations for women is also apropos, as evidenced, for example, in literature on institutionalized outsider artists. As Nochlin concluded by examining Rosa Bonheur as “one of the most successful and accomplished painters of all time” (31)—obviously chosen for her contemporaneously feminist characteristics over conventional notoriety—we might address key artists who embody critical disability studies characteristics, if such is imaginable.

While most of Nochlin’s points are applicable to contemporary art and disability studies, some key differences exist. For one, the status of disability in contemporary art in many societies is arguably lower than that of other minorities, which Nochlin did not believe to be the case for women in 1971. Critical and cultural minority perspectives of gender, race, sexuality, ethnicity, geography, religion, body composition, socio-economic status, and so on are disproportionately represented in contemporary Western art compared to disability. Likewise, considering the percentage of disabled people to other minorities, disability is under-represented among arts professionals, including artists, art historians, and art educators. This is not to suggest that other minorities have achieved artistic or academic equality but that disabled artists and disability art relatively have not benefitted from the civil rights movement and the increased acceptance of diversity within Western culture. While researching this introduction, a prominent artist and scholar who is highly respected within the disability studies community privately suggested to us that the consensus within the art world is that disability will never be accepted in art until it can stand on its own merit. What does such a statement imply? As arts scholars who have a profound appreciation for diverse art expressions, with status ranging from Western masterpieces to street and social medial art to scribblings of children, we wonder what it would take to witness a disability arts movement that parallels the success of the feminist art movement in Western art. We wonder what conceptual and aesthetic qualities of a disability arts genre would captivate non-disabled arts professionals and general audiences to the extent that the art of people of color has. We wonder what rich art forms might emerge if more artists identified as both disabled and belonging to other minority groups. Assuming disability is as worthy of inquiry as other minority characteristics, it would at least necessitate a cultural interest in disability that resembles the serious interest of other minority traits, and that seems far away.

A second difference from Nochlin is our multifaceted motive. Like Nochlin, we are concerned with the pervasiveness of ableism in the art world and art-related disciplines, such as art museum curation, art education, art history, and community art practices. For
this interdisciplinary book, we are concerned with the spectrum of visual artifacts and their makers and the spectrum of art-related disciplines mentioned above that contribute to society’s perceptions of disability art and culture. Furthermore, as Siebers (2010) noted, we live “in the midst of an unprecedented explosion of visuality” for which we are unprepared (121). The impact of visual art and culture is arguably more impactful and more diverse than ever before and therefore more urgent to address. The critical intersection between disability and visual culture was illuminated in a special “Disability–Visuality” themed issue of the Journal of Visual Culture (Davis and Smith 2006), which explored a variety of concerns within the art world, including museum studies and education, disability art, art and blindness, as well as the implications of everyday people who express themselves through visual culture. What this issue and the field of disability studies may have missed is recognition of the importance of visual art as a subset of visual culture in modernity (Nancy 2010). While several texts have explored visuality in disability studies, few studies have addressed aesthetics. As Jean-Luc Nancy (2010) argued, the critical capacity of art has been “to open the world to itself,” and each artist has the potential to open our minds and “our sensibility to a new possibility of forms of which it was unaware until then” (93). Thus, contemporary art remains critically vital through gestures that reflect the witnessing of a difficult, fragile, and unsettling world. The cultural impact of art and related fields is expansive, affecting people of all demographics, disabled and non-disabled, and playing an important role in evolving cultural perceptions and policies on disability. Thus, while we share Nochlin’s desire to infuse criticality into the art world and to criticize the art-related disciplines we represent, we seek to expand disability studies’ interest in contemporary art and culture and to encourage further such interest. Third, representations of disability, particularly self-representation, is vital to this project. With few exceptions, most notably Siebers’ (2010) Disability Aesthetics, Millett-Gallant’s (2010) The Disabled Body in Contemporary Art, Sandell et al.’s (2010) Re-presenting Disability: Activism and Agency in the Museum, Kuppers’ (2014) Studying Disability Arts and Culture, Kelly and Orsini’s (2016) Mobilizing Metaphor, and Millett-Gallant and Howie’s (2017) Disability and Art History, not much attention has been given to representations of disability in art and culture. It isn’t enough that disabled artists proclaim pride and expect equality, as Bonheur did—and in this case, Kahlo may be the lone example. Like women in 1971, disabled people today have few artists to look up to, and of the underwhelming representations of disabled people, few are positive. This book articulates a particular sense of how current disability studies and art intersect, much like Nochlin aspired to intersect feminism and art history. Finally, it is impossible to ignore the colonialist category, outsider art, which has yet to be formally examined within a post-colonial discourse (McCollum 2017). As Christina McCollum points out, the privacy of the poor, disabled, and disenfranchised have been colonized for the benefit of the art market’s obsession with an imaginary art in its purest form. We look toward the post-institutionalized movement that has established several art communities for disabled artists who honor the artists’ autonomy and resist assigning them artificial labels.

Historic Contexts: Disability and Art

While disability has not been a prominent theme in major art traditions, most historic movements included some disability representations, and scholars have suggested that various artists were or may have been disabled and that sometimes this influenced their work. Physical disability was occasionally portrayed in Western Christian art, typically through biblical narratives of Christ healing paralytic, diseased, and blind people. Such depictions have been discovered from as early as the third century, and many accomplished painters...
in the height of Christian art depicted such scenes, for example Poussin’s *Christ Healing the Blind at Jericho* (1651), which exemplified the use of disability as a metaphor in Western art (Mirzoeff 1995). Although a comprehensive analysis of such works far exceeds the limited focus of this book, we suggest that such works rarely address disability from the critical perspectives that disability studies advocates. Mental disability, which has been conceptualized and treated differently from physical disability, was also represented by a variety of acclaimed Western and non-Western artists. Foucault (1988/1965) deeply critiqued representations of mental disability in European art, from the Renaissance through modernity.

Additionally, Foucault (1988/1965) noted that some of the most outstanding visual and literary artists of modernity—Van Gogh, for instance—experienced mental disability. Foucault argued that mental disability engendered their artistic success in terms of conceptual underpinnings, content generation, and novel status of artist-as-madperson, which appealed to modern audiences. Like disability studies scholars, Foucault, who himself experienced mental disability including incarceration and who was trained in psychology (Eribon 1991/1989), recognized disability as a valid force of intellectual and artistic cultural production.

**Outsider Art**

Outsider art is perhaps the most pertinent category of art prior to contemporary art and the disability arts movement. Serious consideration of artwork by so-called, “eccentrics, weirdos, dropouts, recalcitrants, lunatics, convicts, hermits, misfits, and so forth” (Cardinal 2008, para, 5), most of whom were incarcerated in psychiatric institutions, began in 1921 with Swiss doctor Walter Morgenthaler’s (1921/1992) publication *A Mental Patient as an Artist*. Morgenthaler focused on Adolf Wölfli, who began creating epic texts and illustrations about his fictionalized autobiography two years after Morgenthaler arrived at the hospital in 1906. Soon after, German psychiatrist and art historian Hans Prinzhorn (1922/1995) published *Artistry of the Mentally Ill*, the first major initiative to systematically analyze the art of mentally disabled people in institutions. Heidelberg University hired Prinzhorn to expand its collection of over 5,000 artworks by about 500 patients of psychiatric institutions, now known as the Prinzhorn Collection. His collection was the start of an interest in mentally ill and disabled people less as patients and more as producers of a mysterious art form.

Artist and collector Dubuffet was instrumental in promoting *Art Brut*, his neologism for work by artists on the fringes of society who used nontraditional materials and ideas. As a celebrated artist, Dubuffet used these artists to escape from the culture of beauty and indoctrination in the art world. He also rejected the pathologization of “mad art,” which he said was “designed only to restrict the means of addressing it to medical discourse” (Rhodes 2000, 111), and instead positioned the asylum inmate as a radical version of the romantic genius. He assessed the spontaneity and inhibition of these inmates’ artworks to be more authentic than contemporaneous art. The processes of these institutionalized artists appeared to be liberated from the dominant European tradition that Dubuffet and the Surrealists rebelled against. Their romance was dampened, however, when Surrealist writer Antonin Artaud was institutionalized for mental illness. Additionally, Dubuffet’s idealism was not sustainable since no one is impervious to culture. His strictness in protecting the work from cultural contamination and confining his new category fell into the same trap as insider art categories (Wexler 2016).

In 1972, Roger Cardinal coined the term *Outsider Art* for the title of his book (1972). The Anglicized term relaxed the boundaries of Art Brut with an abandoned emphasis on
the social position of the artist. Art historians have begun to dismantle the myth of the outsider, arguing that many classic outsider artists devised innovative strategies that parallel those of the most influential “Great Artists” of the 20th and 21st centuries (Percy 2008). Randall Morris (2001) argues that most of the art labeled outsider is cultural art with few exceptions, while many within the art canon might have been eligible as outsiders if it were not for insider connections. For example, unlike the press that Deaf, non-speaking, and unsocialized outsider artist James Castle received during his lifetime, Percy (2008) describes an intelligent, empathetic, prolific artist who learned from his surroundings, engaged in research-based artistic practices, and expressed aspects of his otherwise enigmatic identity. Using available resources, which did not include new art supplies, Castle developed a strong preference for his invented medium of spitting into jars of soot, which he undeniably meant to be practical rather than vulgar. He also developed several thematic styles that involved invented alphabets, imaginary social situations, and assemblages that appear novel but that sensibly reflect Castle’s social, sociolinguistic, and visual culture interactions. As such, Castle affirms Cardinal’s (2000) theory that the ultimate learning of idiosyncratic self-taught artists is in the consciousness of self, or selfhood, the memorializing of an identity, rather than mastery of material—which Castle, at least, clearly accomplished.

While it could be argued that outsider artists are actually insiders in our sociocultural makeup, their exclusion from the art world should not be downplayed. Philosophically and ethically, outsider art is an imperialist label needing legitimization by the art world canon, while colonizing and pathologizing the Other in Western-speak. In a practical sense, disabled people are vastly underrepresented in schools and professions, and most disabled people are not financially secure. Increasingly high tuition and other logistical factors prevent educational access to economically disadvantaged people, including disabled people, which bolsters the insularity and exclusivity of academe. Additionally, the embodied knowledge that those typically labeled as outsider artists have to offer is undervalued. Foucault (2003) suggested in his Collège de France lectures that such localized knowledges typically are excluded in academia as inferior and unscientific (Wexler 2016). The lack of representation of disabled people and their perspectives in academia in turn prevents privileged learners from directly engaging with peers who possess localized knowledges. The insider, ableist demographics of art students, as well as the ideas discussed within art schools, thus affect the demographics of arts professionals and the content of mainstream professional art.

Disability Arts

Overlapping mainstream art, disability arts refers to visual and performing arts that promote disability identity and culture, with parallel grass roots movements in Great Britain, the United States, Canada, and other nations. Disability arts emerged from the disability rights movement and included what many refer to as the disability arts movement in the UK during the late 20th century. Disability art spans a variety of cultural institutions, including art museums and galleries, community arts programs, disability organizations, and academia. Within and among these related and intersecting areas, Contemporary Art and Disability Studies examines how a confluence of artistic representations in multiple forms and media has disrupted the white, abled dominance of the art world. The authors of this book consider how colonizing and abelist ideologies have shaped and ignited their personal, academic, and community work. These chapters serve as counternarratives that reject such destabilizing theories. We outline five themes that are relevant to disability art and culture, spanning a variety of cultural institutions. We open with Part I, Methodologies of Access, Agency, and Ethics in Cultural Institutions, from the perspective
of experiential access and in terms of rendering built infrastructures more accessible. Disability studies has been the primary motivator in challenging and replacing exclusionary practices. Part II, The Politics and Ethics of Collaboration: Analyzing Social Practices in Communities, continues to investigate who the beneficiaries are when art organizations or artists enter the disabled community purporting to redress marginalization. Part III, Embodied Representations of Artists with Disabilities in the Visual and Performing Arts, examines a variety of media that have the common effect of representing the bodymind as playing a defining role in disability studies as it is felt and as it moves about in the world (Maybee 2017). The authors in Part IV, Emerging from Anonymity: Negotiating the Outsider Label, offer alternatives to a category losing its relevance in the twenty-first century by disrupting the binary positions of insider/outsider. Part V, Life Writing: First-Person Reflections on Disability and Art Making continues to examine in personal prose and autoethnography the important project of disability rights in establishing social justice in the arts.

With the necessary exception of critically addressing outsider art, we resist discussing artists according to their presumed status in the art world (e.g., international, important, niche, self-taught, hobbyist) because such categorizations detract from the rich experiences and expressions of disabled artists at varying levels of professionalism. In reality, such categories are ambiguous inventions, and most people whose careers intersect contemporary art and disability are neither members of the elite art world nor outsiders. They include, among others, arts and disability scholars, teaching artists, art historians, arts educators, activists, art therapists and other allied health professionals, community artists, regional artists, museum and gallery professionals, amateur and semi-professional artists, and allies of disabled artists. The stories and narratives in this book suggest that contemporary life requires that many people occupy spaces of *betweenity* (Brueggemann 2009), as disabled artists are unlikely to achieve equality within the art world as “Great Artists,” and such status is not the aim of most people whose life work intersects disability and the arts and culture. In the remainder of this Introduction, we outline the trajectory of this book according to the five identified themes.

**Part I: Methodologies of Access, Agency, and Ethics in Cultural Institutions**

Tanya Titchkosky (2011) points out that, “Sometimes access comes up as a question, at other times as an answer, and at still other times it doesn’t come up at all” (3). Among several definitions of access presented in *The Question of Access: Disability, Space, Meaning*, Titchkosky calls access an interpretative relation between bodies and a making of meaningful relationships between people and places. We are all engaged in the act of access, yet, in truth, access acts as an invitation for most bodies and a roadblock for others. Access, she writes, is “a space of questions regarding who belongs where, under what auspices or qualifications, and during what times or through what particular thresholds” (3). From this framework Titchkosky suggests that, like race, class, and sexual orientation, we should consider disability as an embodied way in which people orient themselves to the world rather than as an individual and functional limitation. She suggests that disability should be understood as a relationship between people since “one cannot be disabled alone” (5). Similarly, Jay Dolmage (2008) equates accessibility within physical structures with those of ideological structures. Physically, disability might be represented as the ramp alternative to the steep steps of major institutions: libraries, universities, museums, and government buildings. Thus, disability is accommodated, but it does not come through the front door. Per Dolmage’s assertion, the three authors in this section examine how we
might forgo the notion of retrofit and engage in the free flow of all types of bodies on the spatial and cultural main concourses of our institutions. They observe how ideology, “dis-consciousness,” and “life as usual” perpetuates, in Titchkosky’s words, more of the same.

In Chapter 1, “Accessibility in and Beyond the Quagmire of the Present,” Taraneh Fazeli writes how grappling with her own corporeality in curatorial work helped transform institutional structures to support complex emboddiments. Drawing from disability justice and public health policy, Fazeli argues for an ethics grounded in dependency rather than autonomy. Since the curator often acts as a bridge between people, objects, and places, their unique role should be to create structures in and around institutions that offer models of intersectional access that are collectively built. As a case study, Fazeli uses her own experiences working with artists and communities of care in the traveling exhibition Sick Time, Sleepy Time, Crip Time: Against Capitalism’s Temporal Bullying to offer social practices that question normative temporal regimes in institutions.

Artist Carmen Papalia argues in Chapter 2, “For a New Accessibility,” that deep-rooted oppression exists in our cities, schools, hospitals, cultural institutions, policing organizations, and the various arms of government, making one’s effort to claim agency a strategic, high-stakes intervention. He enquires about the implications of an open, collective process of defining disability, which may increase the accessibility of institutional systems as the needs of clientele evolve. Papalia asks what steps would be necessary to unlearn normalcy and to hold a space for a continuum of emboddiments, identities, realities, and learning styles. Following years of experiential, project-based work on topics relating to accessibility, embodiment, and liberated learning, Papalia begins to define the characteristics of openly accessible space and writes about open models for access.

In Chapter 3, “Inclusion Matters: ‘Are You Sure You Belong Here?’” art educators Karen Keifer-Boyd, Michelle Kraft, and Alice Wexler identify and challenge the visual culture, behavior, and language of a dominant social system that produces so-called normal and desirable behavior. The authors then discuss teaching approaches that shift the view of disability away from abnormal and suggest strategies through which students with varying (dis)abilities design their learning environments. While it is not easy to crack the bonds that privilege specific modes of communication, ways of knowing, and physiques, the authors develop feminist, communitarian, and neurocosmopolitan approaches that might transform learning environments.


Community has been central to the concerns of disability studies as a field that emerged from disenfranchised scholars, grassroots activists and artists (e.g., Kelly and Orsini 2016; Sandell et al. 2010), and allies coming together. Disabled artists have typically worked with community programs governed by non-disabled administrators and workers. Carol Zou asks pertinent questions about the personal responsibility and ethics of socially engaged artists who enter and then leave the disabled community: “What are the aftershocks and implications of what the artist has stirred up in the collective consciousness? Is socially engaged art a source of post-traumatic stress disorder?” Zou and other authors in this section examine the claim that artists, particularly non-disabled artists, can help, support, or enrich the disabled community. Many community-based art projects address the concerns of such marginalized community groups, often focusing on social issues in order to develop politically aware community events or programs. Yet while many projects aim toward social justice and build toward a more inherently just future for people with disabilities, there remains a need for critical analysis of these projects. Does the unequal
relationship between the artist and the community prohibit real change in the lives of the community? The authors suggest methodologies and models of communities that might overcome such barriers.

In Chapter 4, “Participatory and Community-Based Contemporary Art Practices With People With Disabilities,” Associate Professor of Art-based Research and Pedagogy Mira Kallio-Tavin discusses how collaboration has become characteristic for much of the contemporary art practices in the 21st century. She suggests that the artist is often a collaborator and producer of situations and events rather than objects. Kallio-Tavin explores and critiques different contemporary and collaborative art practices involving people with disabilities. Questions are raised around who creates the community and by what means, the politics behind defining the participatory and collaborative groups of people with disabilities, and whose interests are being met, as results of collaboration.

In Chapter 5, “DaDaFest Ensemble: Leadership, Voice and Collaboration in the Arts,” Claire Penketh (Liverpool Hope University, UK), Anne James (Liverpool Hope University, UK), Richard Nutter (DaDaFest, UK), and Sam Wade (DaDaFest, UK) offer an exploration of leadership, voice, and collaboration in decision making in recent research examining the development of a music program, Ensemble, with a group of disabled young people. The project was initiated by DaDaFest, an innovative disability arts organization based in Liverpool, England. DaDaFest is a young people's program that encourages and empowers disabled and Deaf young people through creativity. Ensemble promotes collaboration between young people and professional musicians in order to enhance musicianship and performance. This chapter offers insights into the challenges and opportunities of this collaboration, exploring the complexities of leadership and musical apprenticeship.

In Chapter 6, “Post Traumatic Stress Poetics in Socially Engaged Art: Healing as Praxis,” artist Carol Zou posits that an understanding of social practice is incomplete without a corollary understanding of the role trauma and disability plays in individual and community identity. Moreover, social practice is ethically irresponsible without adopting the lens of disability studies alongside critical race analysis and gender studies. The chapter begins by looking at the ways in which trauma shapes individual, group, and community identity and contrasts potential approaches to traumatic communities with approaches found in social practice. Zou interrogates specific social practice forms such as the confessional approach to artmaking, in which community members are invited to share stories of suffering.


In The Disability Studies Reader, Tobin Siebers (2008) argued, “Disability creates theories of embodiment more complex than the ideology of ability allows, and these many embodiments are each crucial to the understanding of humanity and its variations whether physical, mental, social, or historical” (279). While disability representations in literature have exploded in the past two decades, visual representations are still in the embryotic stage, yet visual representations may have more impact in their immediacy and pervasiveness than literary forms. Siebers was one of the first disability scholars to explore the important history of disability stereotypes in visual art and popular media. However, performance art has had a rich, albeit short, history, which has also been richly represented in texts (Eisenhauer 2007; Kuppers 2003; Garland-Thomson 2000; Sandahl and Auslander 2005). Performance art has been appropriated by the Disability Arts Movement as interventions in ablelist practices in public and private places. For example, an author in this section, Jennifer (Eisenhauer) Richardson (Eisenhauer 2007), explored performance artists Carrie Sandahl, Mary Duffy, and Petra Kuppers “as a progressive, emancipatory force at both the
individual and social levels” (Barnes and Mercer, as cited in Eisenhauer 2007, 7). The artists examine the use of performative autobiography through verbal testimony to reverse both the personal gaze and the daily responses from street encounters. Their bodies are also wrested from the medical gaze wherein they become “denigrated to sub-texts in the master narrative” (Eisenhauer 2007, 18).

The authors in this section further disrupt the tropes of disability in art as abject, asexual, and pathological. While the notion of identity itself has fallen from grace, perceived as necessary for those who are dependent and in need of extra help, reclaiming one’s disabled identity from mainstream notions and representations can be understood as an act of defiance. Three of the authors in this section are women who reclaim identity as embodiment, positioning knowledge as in a social location, which is central to both feminism and disability studies.

In Chapter 7, “The (Narrative) Prosthesis Re-Fitted: Finding New Support for Embodied and Imagined Differences in Contemporary Art,” independent curator Amanda Cachia analyzes the contemporary American artists Robert Gober and Cindy Sherman. Cachia argues that these artists use the tropes of the obscene, abject, and traumatic—as discussed by Hal Foster—to make literal and metaphorical reference to David T. Mitchell and Sharon L. Snyder’s narrative prosthesis and its “truth,” while simultaneously leaving out the lived experience of disability. Consideration is given to the works of artists Carmen Papalia and Mike Parr, who use complex embodiment (Siebers 2008) as a new methodology to signify empowerment and agency over what we might previously have considered the obscene, abject, or traumatic. They transform traditional understandings of the “prosthetic” within the specific rhetoric of disability.

In Chapter 8, art historian and artist Ann Millett-Gallant’s “Basilisk and the Representation of Physically Disabled Women in Film” describes the author’s short, narrative film featuring an unconventional, disabled female protagonist and her bevy of lovers. The lead character, Gaza, played by the author, defies stereotypes for physically disabled women and their representations in film, where they are characteristically portrayed as asexual and as victims who burden their caregivers. Independent, sexually active, and sexually confident, Gaza lures and destabilizes the main male lead, Wes (played by John Jimerson), driving him to obsession with her and her body’s likeness in art and in everyday life.

In Chapter 9, “The Phenomenological Turn in Disability Arts: Crip Time and Disability Aesthetics,” professor of Disability, Art, Culture, and Humanities, Carrie Sandahl suggests that disability culture artists are increasingly generating work from their unique ways of experiencing the world through their bodies-as-material, sensation, experience, emotion, and intuition. She proposes that this work might be best understood through disability theorist Alison Kafer’s (2013) formulation of the political/relational model of disability, including her conceptualization of “crip time.” This model can serve as epistemological scaffolding on which to build a useful critical method. Then, as example, she applies these concepts and methods to an analysis of the work of Chicago multimedia artist Matt Bodett.

Art historian Stefanie Snider explores in Chapter 10 the visual representations of disability and cancer in “Intimacy and Illness: Visually Representing Lesbian Sexuality and Disability in Tee Corinne’s Scars, Stoma, Ostomy Bag, Portocath: Picturing Cancer in Our Lives.” Snider contextualizes this project within a lesbian and feminist history of visual and textual cancer narratives, including the artwork of Mania Akbari, Jo Spence, Hannah Wilke, and LaToya Ruby Frazier. Following the imperative set forth by Audre Lorde’s 1979 Cancer Journals, which asserts that making one’s experiences with cancer visible is politically necessary and ethically valuable, Snider considers Corinne’s portraits and self-portraits as aesthetic, social statements about how illness and disability can function in productive, absorbing, and imaginative ways.
In Chapter 11, “Bill Shannon: The Politics of Dancing,” art educators Jack Richardson and Jennifer (Eisenhauer) Richardson examine the performative work of Bill Shannon. Utilizing crutches with rolling wheels, Shannon combines hip-hop, breakdancing, and skateboarding in his disability street performances. Shannon’s audiences become active participants in the performance, having to determine whether to help or just stare. Shannon describes his performances as invitations rather than interventions that explore responses of pity for the disabled body in public space. Richardson and Richardson examine these invitations through the lens of spatial theory and the politics of public space articulated through the work of Jacques Rancière.

**Part IV: Emerging From Anonymity: Negotiating The Outsider Art Label**

The diversity of artists and their biographies underline the postmodern dilemma of divisive and bifurcated terminology such as outsider, self-taught, vernacular, Art Brut, and additional categories that designate the Other. Randall Morris (2001) challenges this tendency to colonize or pathologize the Other in Western-speak:

> We must look into this work for the first time on its own history and its own contexts and learn its languages. . . . The names chosen are not names coming from the nature or demands of the work being named, but rather from the “culture” of the hegemonic namer.

(117–119)

Morris particularly dismisses the notion of an “alternative universe,” a phrase too easily reached for when we are confronted with another’s visual manifestations of interior reality, a way of safely keeping the Other in a defined place in the canon. An alternative universe is in fact the product of all artists, particularly those who are skilled at creating space; but here this terminology is used for the purpose of maintaining outsiderness. Morris uses the term “home-ground” as a common denominator with which to behold the “angst-laden stormscape by Henry Darger or a somnambulistic myth-ride by Francesco Clemente” (118). As mentioned earlier, Morris claims that the art that we have cast under the wide net of outsider culture is in fact *cultural art* with few exceptions. How many “wild children” have existed in history who have been brought up without knowledge of language or other forms of cultural communication? Morris compares the ahistorical curation that emphasizes formal affinities rather than contextualizing the artists within their intentional histories to the colonial approach toward tribal artifacts. He suggests that we restore the control of the narrative—sane or insane—to the artists because, whatever their perspective, the work itself is a narrative rooted in the world:

> Upon the home-ground thus created the artist thrusts the narrative. This further expands the possibilities. The traveler can be in a localized realistic scape, or be an unreal traveler in a real scape or a real traveler in an unreal scape. These reveal various choices and modes of control.

(126)

The authors in this section write about two disabled artists who are radically different and therefore support the earlier statement that they are diverse and perhaps not categorizable. Aurie Ramirez works in Creative Growth Art Center in Oakland, California. In centers such as Creative Growth, artists with a variety of disabilities coexist in spaces that respect
the aesthetic authority and autonomy of the artists. By contrast, Lee Godie chose to live on the streets of Chicago. The lives of these artists therefore follow different trajectories.

Part IV opens with Chapter 12 by art educator Alice Wexler, “Lee Godie: An Accidental Postmodernist Outsider.” Wexler explains that Godie not only disrupts the insider/outside argument but also contributes to the postmodern so-called reflexive, self-conscious awareness of the unstable and fragmented notion of identity. Godie’s representation of identity malleability is seen in her photo-booth self-portraits, or “publick cameras” as she called them, taken in a Trailways bus station, which began in the early 1970s. During her life, she produced several hundred 4.75 × 3.75-inch self-portraits on which she appropriated the styles, clothing, and poses of female film icons based on her favorite celebrities such as Grace Kelly, Princess Margaret, Virginia Woolf, Katherine Hepburn, and Joan Crawford.

Cultural writer Amy Mutza explores the theatrical fantasy worlds of Aurie Ramirez, an artist at Creative Growth Art Center. In Chapter 13, “Dandies, Vamps, and Rockers: Sex and Disability in the Paintings of Aurie Ramirez,” Mutza examines how Ramirez’s watercolor paintings refigure the association of disabled bodies and the “carnival” from sexual fetishization to masquerade. Her artwork is a celebration of indulgence in costume, food, and flesh that is unbounded from the limitations of heteronormative, ableist socio-political orders. Ramirez’s boudoir scenes act as a form of imaginative world-building, where a multiplicity of sexual desires and empowered subjects exists and where sexuality and disability are not viewed as mutually exclusive.

Part V: Life Writing: First-Person Reflections on Disability and Artmaking

The origin of the term autopathography as a distinctive autobiographical narrative was coined by Thomas Couser (1997) in Recovering Bodies to categorize an emerging literary form that engages in the disabled body as a political act. Life writing is an effective way to control disability narratives, which traditionally have been structured by non-disabled authors. As Couser (2013) argues, autopathographical works are not merely spontaneous self-expressions, but responses and resistance to “having one’s life written for one” (458), a riposte to endless misrepresentations and the assumption that disabled people are unable to speak for themselves.

Eli Clare (2019), in an online symposium about his book Brilliant Imperfection: Grappling With Cure, hosted by Syndicate Network, discusses storytelling as resistance with Alice Wong, the first responder in the symposium. Clare explains that resistance and survival take many forms in an ableist world. Storytelling is one such dynamic form in which the ability to reframe formulaic narratives about mind-body difference should not be underestimated. “It is the creation of stories, images, and ideas. It is claiming and reclaiming language, embracing the brilliance of imperfection, impairment, disorders, illness, disability, and all othered others” (n.p.). The four authors who contribute to this section share their distinct voices as artists and educators through candor, humor, and wisdom.

In Chapter 14, “Presence and Absence: The Paradox of Disability in Portraiture,” artist Riva Lehrer explains that “If you are disabled, the world is a mirror that follows you everywhere.” However, in the Western art world, disabled people usually are not reflected in its canon. As a portrait artist, Lehrer speculates that the history of portraiture is a reminder of what people with disabilities are not. She argues that portraiture is historically a collection of reliquaries of the self—flawless, eternal bodies in which the subject is immortalized as a negation of death. She remarks, “If a portrait was to be your eternal body, then you may wish for that body to be flawless, forever.” The obsession with
perfection in portraiture indicates that disability is its default subject. Lehrer regards her portraits as “tools of societal dominance” that criticize discourses of death, impermanence, and bodily imperfection.

In Chapter 15, “Accidents Happen: An Art Autopathography on Mental Disability,” art educator John Derby appropriates autopathography as a creative, autoethnographic methodology for discussing his artwork about major depression and other mental disabilities. Derby explores the circumstances surrounding mental disabilities that arose during his doctoral studies, including competing discourses of cures for mental illness in religion, academia, and medicine. The chapter’s Preface outlines the conceptual framework for research, which critically explores personal, cultural, and institutional contexts of mental disability discourses in response to Foucault’s thesis that the arts dismantle normalizing myths about mental disability. The ensuing four-stage narrative demonstrates how traditional and emerging art practices and creative writing can be hybridized to create complex representations of disability that challenge ableist, normalizing discourses.

In Chapter 16, “Out of the Blue: Art, Disability, and Yelling,” artist Katherine Sherwood writes about the disruption of her life from a cerebral hemorrhage at the age of 44. This chapter explores the manifestations of that change in her art and life. Within her abstract paintings after her stroke, and later her contemporary figurative work that re-appropriated the Western art historical trope of the reclining female nude, there is a preoccupation with expressing the lived-in disabled body. Like Riva Lehrer, Sherwood shows how art history and disability intersect not only within her own work but also how disability has affected various artists, such as Francisco Goya, Claude Monet, Christine Sun Kim, and others. Sherwood examines how these artists exist both inside and outside the so-called canon of art history. The idea of the canon itself is discussed in relation to the institutionalization of disability studies.

In the final chapter, “An Interview with Four Art Professionals With Disabilities About the Traps and Benefits of Opening Up About Them,” artist Nina Stuhldreher summarizes many of the themes of this book: the artificiality of art world labels, the need for artists to camouflage themselves in the self-marketing of ability, and how disability studies has empowered artists. Stuhldreher writes that although the god-like super-human genius has started to crumble in the visual arts, a closer look reveals that the idealized impersonation of an artist has so far only scratched the surface. Therefore, she says, in a field where job security is practically nonexistent “and everybody competes with everybody,” admitting a disability is “an absolute no-go.” Not surprisingly, several visual artists with “secret disabilities” who Stuhldreher asked to interview for this chapter either asked for anonymity or declined. She writes:

Originally intending to simply ask about how their disabilities affect their daily life and their art production, I was intending to gain insights into and help give a voice to experiences in that field that didn’t have a forum yet. Additionally—for my research in neurodiversity—I was hoping to learn about other artists’ experiences with their body as epistemological tool. But I realized that the amount of “camouflage work” delivered on a daily basis by these artists might be a topic rich enough in itself.

Conclusion

In this volume, we aspire to expand the literature on disability art and culture. We intersect disability studies with a variety of arts-related disciplines and practices, including art history, education, professional art, community arts, and the humanities to highlight the range of disability arts and culture perspectives within the field. Disability arts, in a variety
of forms, is of critical importance to the disability studies and disability justice movements because it affords audiences with political, theoretical, and practical insights that can potentially change social structures. Disability arts and culture affirm an alternative system of seeing, valuing, and understanding that disrupts dominant notions about human experience and cultural production.

References

1. The social model in disability studies recognizes disability as a social construction rather than a biomedical deficiency. Michael Oliver (1990) made a clear distinction between impairment as a biological function or description of the physical body and disability as a social impression imposed by environmental conditions (Maybee 2017). However, disability scholars, especially women, have returned to the body as an inevitable part of disability discourse. Thus, while the distinction between impairment and disability was politically necessary in the beginning of the disability rights movement, the return to an embodied presence was crucial in including bodily experiences in the conversation.

2. The social model also evolved in other ways. Critical disability theory argues that the focus on its functionality and built environments does not challenge ableism, which Siebers (2008) defined as the “ideology of ability” (p. 8). Ableist ideology is based on the dominant belief, or common sense, that disability is undesirable, a problem to be eliminated.

3. For Brueggemann, who is Deaf, it is the liminal space between Deaf and disabled but also, more globally, as identity and language (see Brueggemann 2009, Deaf Subjects: Between Identities and Places).

1. Numerous texts have been written while in repose due to illness or other needs for rest. While initially an unconscious reference, this passage is inspired by writer Virginia Woolf’s “On Being Ill” and artist and writer Johanna Hedva’s “Sick Woman Theory.” Both essays take place in bed. Woolf reflects on how her condition separates her from an “army of the upright” (11) to illuminate the poverty of language on illness in literature. Hedva, writing years later, goes one step further to highlight systemic causes of illness and push back against assumptions that protest or political action can only be performed in public not private spaces.

2. The touring process-based exhibition has taken place at art and social service organizations and is tied to an extensive programming series. The artists involved thus far: Navild Acosta and Fannie Sosa, Fia Backström, Berlin Feminist Healthcare Research Group, Canaries, Jesse Cohen, Danilo Correale, Wayne Curtis, Carolynn Lazar, Jen Liu, Park McArthur, Zavé Martohardjono, Jordan Lord, Sondra Perry, Carrie Schneider, Will See Cassie Thornton, and Constantina Zavitsanos. The community groups include: young single mothers in residence at Project Row Houses (Houston, Texas); recently incarcerated women in residence at Angela House (Houston, Texas); recent refugees and asylum seekers through Lutheran Family Services (Omaha, Nebraska); and activists experiencing burn-out through 4A Project (St Louis, Missouri).

3. McArthur and Papalia circulate the artworks discussed in this essay primarily as solo authors, but McArthur frequently cites her multifaceted web of support and Papalia often cites his partner.

4. McArthur has participated in Sick Time, Sleepy Time, Crip Time, and I have taken great inspiration from her writing and artistic work.

5. In Beyond Ramps, writer and activist Marta Russell discusses how transnational capitalist systems require that bodies conform to the central imperative of profit maximization and how this produces death and disability while oppressing people with disabilities by keeping them from the labor market. She challenges conceptions of “empowerment” and “freedom” held under neoliberal systems, particularly in her critical analysis of disability benefit systems and arguments that reformist systems such as the ADA will never lead to economic justice for disabled people.

6. At the time of Ramps, most of Russell’s writing was scattered online. This was the main reason McArthur created the Wikipedia page.

7. The feminist artist protest group Guerilla Girls grew out of a demonstration in response to An International Survey of Painting and Sculpture at MoMA, an exhibition in 1985 at the newly reopened museum that featured 148 men, 13 women, and no artists of color. Years later, shortly after the museum reopened in 2004, art critic Jerry Saltz “tallied the number of women artists included, and then pitched a fit in print.”
8. The segments that comprise Project 195’s audio piece are on MoMA’s website: www.moma.org/audio/playlist/55

9. Shortly after Projects 195 ended, MoMA closed to restructure. It announced more free galleries, partnerships with organizations, and diversification of its staff and collection. Around the same time, MoMA PS1 lost a court case brought by curator Nikki Columbus for gender, pregnancy, and caregiver discrimination. As a result, MoMA promised to change workplace policies regarding caregiving, pregnancy, and disabilities. It has yet to be seen if these promises are merely virtue signaling or to avoid legal ramifications.

10. This is one of several instances where McArthur demonstrates what is left out of the narratives produced and circulated by agents of the museum, including those put forth by current and past curators, exhibiting artists, and architects of the renovation. For example, Projects 195 is part of the museum’s ongoing Projects series which was started in 1971 but only began its current numbering system in 1986. McArthur’s installation would have been numbered Projects 109. Instead, by renaming the exhibition Projects 195: Park McArthur, attention is drawn to the eighty-six shows that happened before the system, thereby pointing to the museum’s partial narrative.

11. Another example of cripping Minimalism is the work of artist Constantina Zavitsanos, a frequent collaborator of McArthur’s who deals with care and dependency. In Specific Objects (stack), Zavitsanos (2016) mounted multiple identical bathroom grab bars in a ladder-like formation up the wall using a pre-determined system resembling the numerous stack pieces artists Félix González-Torres and Donald Judd made throughout their careers. Whereas Judd mounted a series of identical metal boxes on gallery walls and favored industrially fabricated forms because he felt they carried no symbolic meaning and found artistic expression solely in the system he created, Zavitsanos uses pre-fabricated objects that carry heavy symbolic meaning and are designed and standardized for a specific use with specific people.

12. See Alison Kafer, Feminist, Queer, Crip, pp. 25–46. Kafer makes a distinction between “curative time” and “cure.” The former describes the assumption that medical intervention is the only way to address disability (thereby reading disabled people as obstacles to the arc of progress), and the latter designates disabled people’s varying personal relationships to particular medical interventions. Kafer examines how the discourses of queer and crip time are mutually entangled in their imagining of futurity outside of dominant narratives of progress or how they think “straight” time differently, arguing that disability is already present in queer time. However, she argues that while recent theorizations of time by Lee Edelman, Elizabeth Freeman, and others deploy illness or disability in their definitions, they still write disability out of future ways of being.

13. I’d be remiss not to note how experiences of people with developmental, cognitive, and intellectual disabilities are frequently left out of art programs, even those by and for disabled people (mine included).

14. For more background on Open Access, see Papalia’s contribution in Chapter 2 of this volume. To read more about these tours and workshops, see Snyder 2013, pp. 24–28. I have not experienced his workshops or tours firsthand, only through their subsequent presentation in galleries, accounts from participants, and via texts about them.

15. For example, while I was writing this essay, a multi-pronged effort unfolded to oust Warren B. Kanders, the vice chairman of the Whitney Museum, New York. It was shown that his company, Safariland, likely supplied tear gas used against asylum seekers at the US-Mexico border in fall 2018, resulting in a litany of actions pushing for his removal. Through financial support of art, powerful people with dubious ethics can cleanse their public image without changing their actions, thereby enabling more harm to occur. Occurring around the 2019 Whitney Biennial, an exhibition that has historically catalyzed conversations about art and politics, the sustained and escalating pressure from multiple angles included artist boycotts, open letters from staff, open letters from artists, coordinated press coverage, explicitly critical artworks in the biennial, and Decolonize this Place’s weekly protest actions in the museum’s lobby. With Kanders stepping down on July 25, 2019, only time will tell whether this result actually impacts the reach of his products.

16. It is broadly understood that a curator is somebody who cares, with numerous curatorial texts narrating the historical trajectory of the curator from a caretaker of public works during the Roman Era to a spiritual steward of the church in the Middle Ages to a secular custodian of art objects. In the post-1960s period, there’s a shift from art conservation and scholarship to affective labor due to several factors that curator Helena Reckitt outlines in “Support Acts: Curating, Caring and Social Reproduction,” Journal of Curatorial Studies 5:1 (2016), pp. 6–30.
17. Different groups of artists and writers have begun to share samples of documents and tools that they use at the onset of an invitation from an organization to stipulate their access contexts and ideal support. Interdisciplinary artist Ria Hartley shared an “access awareness document” that can be adapted from their Ecologies of Care resource website. Hartley is working with others to make additional Open Source tools, like email responders and signatures. Access Docs for Artists, created by Leah Clements, Alice Hattrick, and Lizzy Rose, also shares samples and a downloadable template.

18. See Whitney Director Adam Weinberg’s response to the staff’s open letter in Jasmine Weber’s article on Hyperallergic.

19. Amidst declining immigration and refugee resettlement alongside increasing xenophobia in the United States, I let them in. takes philosopher Jacques Derrida’s concept of hospitality as a point of departure for thinking about how to deal with one of the most pressing ethical problems of our time: the so-called migrant crisis.

20. Hospitality, meaning the reception of guests or strangers, can be scaled from the micro (the home) to the macro (the nation state), although conventions of welcoming behavior vary among societies. Jacques Derrida (2000) articulated hospitality as a self-contradictory set of ethical rules about how to encounter the Other. On one side is the idealistic law of “unlimited hospitality,” or absolute openness; on the other is the pragmatic “conditional hospitality,” with moral, political, and juridical terms placed on it. Hospitality calls for the constant negotiation between what one sees as their right to a territory and a renunciation of this right for the good of another. In his definition, violence underlies every act of hospitality: the root word hospes (guest/host) comes from the Latin hostis (hostility).

21. See Aruna D’Souza’s Whitewalling for an overview of these two instances, an examination of how it illustrates the values embedded in liberal thought, and an in-depth examination of the Whitney Biennial 2017 controversy over inclusion of white artist Dana Schutz’s painting of Emmett Till’s lynched body in his coffin.

22. In The Right to Maim, Jasbir Puar articulates how, paradoxically, while there is expanded care for disabled rights-bearing subjects under liberalism, the relentless pursuit of profit in racialized capital creates debility for the slow depletion of marginalized populations not afforded these same rights. By not collapsing debility into disability by articulating debility as a supplemental continuum that does not necessarily end with the production of disability, Puar poses a correction to the neat disability/ability binary and the epistemic whiteness of the field.

23. Gay marriage (with associated benefits such as qualifying for a spouse’s health care or citizenship status) would be one example of how some people want to be supported by a system that has excluded them while still working toward making an entirely different one. Conversely, marriage is often avoided in favor of domestic partnerships by people with disabilities due to associated loss of state or federal benefits. Another example is the two-year campaign artist and disability activist Nick Dupree waged known as “Nick’s Crusade” to fight Alabama’s Medicaid cut-off for ventilator-dependent people’s home care after age 21. While he and others fought for institutional support, it was so that they could remain in their homes and communities rather than be fully institutionalized.

24. Arts organizations like Project Row Houses are actively feeding community creativity through communitarian cultural projects. PRH, which merges contemporary art projects with social support structures, is embedded in a culturally rich, historically black neighborhood of Houston that has been under-supported by the government for many years and is now fighting rampant gentrification.

1. The term “neurocosmopolitanism” was coined by both Ralph Savarese and Nick Walker independently of each other.
3. Rosemarie Garland-Thomson first coined the term “normate” in 1997 to refer to “the corporeal incarnation of culture’s collective, unmarked, normative characteristics,” which in dominant U.S. culture is white, able-bodied, heterosexual, and male (2002, 10).
4. Titchkosky (2011) clarifies this perspective as follows: “Understanding disability as a personal need which requires evaluation services, or counseling, rather than collective action or exploration, requires us to engage disability in individualized terms” (12).
5. This often heard phrase, which is spoken with authority based on reasonableness (in the legal language of “reasonable accommodation”), needs unpacking. Titchkosky (2011) writes “‘You can’t accommodate everybody’ is a way of bringing bodies and space to a consciousness where some
bodies are made and regarded as ‘naturally’ a problem for some spaces” (36). It further supports the illusion that “exclusion is an act of nature” (37) rather than a social act.

6. The names of preservice students have been changed to protect confidentiality.

1. The TV documentary program by Eero Wallén is a Finish-Swedish television production, *Autister & Artister*, Finlands Svenska Television (FST), and it is part of the *Seportaasi* series. It was first nationally broadcasted in the spring of 2005, and it has been reshown several times since.

2. The songwriter Kari Aalto has also worked with Pekka Elomaa for many years, and he is portrayed in one of the Mr. Holbein images.

1. For example, the artist collective Los Angeles Poverty Department has been creating socially engaged street theater in collaboration with the homeless residents of Skid Row, Los Angeles, CA, since 1985.

2. Post-traumatic stress disorder manifests physically in long-term changes to brain chemistry and functioning, especially relating to stress responses and memory.

3. The difference between me and Sandra Bland is that I am alive. Other differences include the fact that she was black, and I am not.

4. The Los Angeles Tenants Union and the Bay Area Anti-Eviction Mapping Project are two recent contemporary, socially engaged projects that have arisen to address gentrification.


6. There is not enough institutional support for artists to create continuous works in their own communities over a designated course of time. Some may also understand this impulse to stay and work in one place over an extended period of time as career suicide, especially if that place is not one of the sexy epicenters of art production, such as New York City, Los Angeles, Paris, etc.

7. Another interesting project, Bio-Cartography of Tijuana’s Cultural-Artistic Scene, uses “gynecological” methodologies to write a diagnostic of the Tijuana Cultural-Artistic Scene. Montezomolo once again draws from the language of other fields, in this case medicine, to produce an embodied anthropological commentary on culture.

8. All of my inquiries in life have been related to Gayatri Spivak’s conception of the subaltern.

9. I have chosen to place “neurotypical” in quotation marks to acknowledge the invisible disabilities that were most likely present in the non-hospitalized audience members.

10. For me, it has taken approximately a year—which is the initial timeframe of my residency. The degree to which residents in my community are asked to be the test subjects for finite institutional engagements is, in itself, a form of trauma as processes are begun, abruptly ended, and then taken up again some time later by another organization.

1. The words “abject,” “traumatic,” and “obscene” are inspired by Foster’s essay title.

2. For more information, refer to Kristeva and Roudiez (1982).

1. My use of the phrase “rust and bone” to signify Stephanie’s body with the prosthetic is my own interpretation. The title of the film comes from the book of short stories which inspired it: Davidson, Craig. 2005. *Rust and Bone*. New York, NY: W. W. Norton. The first story in the volume is also titled “Rust and Bone” (1–22) and is about a fighter, Eddie Brown, Jr., who cares for his young nephew while living with his sister and brother-in-law during college. Later, the nephew comes to visit Eddie while he is living at a training facility in Butler, Pennsylvania, and he falls through the ice of a frozen lake. Eddie must punch the ice to release him. His hands never totally recover, and neither does his brain-damaged nephew. In the film version, Ali’s son falls through ice and must be rescued similarly.

The phrase “rust and bone” has multiple significances in the story. While describing a fight, the narrator states “Lips flatten against teeth, mouth filling with the taste of rust and bone” (14–15). “Rust and bone” may also be a metaphor for a fighter’s hands, which are instruments of power, force, and violence yet also vulnerable; each is composed of 28 bones that never heal properly when broken. Breakage of any of these delicate bones causes permanent damage and pain. Next to the title *Rust and Bone* on the cover of the book is an image of hands holding wrapping fabric, assuming the action of a boxer taping his hands.

2. For examples, see Cherney (2001); Fine and Ashe (1998); Guldin (2000); Harris (2002); Moin, Duvedevany, and Mazor (2009, 83–95); Taleporos and McCabe (2001); and Wendall (2010).

3. See, for examples, the essays in Kaplan (2000).


1. For a definition of disability art, see Sandahl (2009).
2. The organization is housed at the University of Illinois at Chicago’s Department of Disability and Human Development, where I am faculty and founder of the Program on Disability Art, Culture, and Humanities. For more information, see https://ahs.uic.edu/disability-human-development/community-partners/bodies-of-work/.

3. The funder, 3Arts, is a non-profit organization that sustains and promotes women artists, artists of color, and artists with disabilities in the Chicagoland area. The National Endowment for the Arts provided further funding for this project. https://3arts.org/residencies/.


5. Throughout this article, I use the term “bodymind” as defined by Price (2011) “to emphasize that although ‘body’ and ‘mind’ usually occupy separate conceptual and linguistic territories, they are deeply intertwined” (9n, 240).

6. For a full discussion of disability studies’ engagement with these models, see Linton (1998).

7. Bodett summarized this part of his performance in a personal email message to me on July 25, 2019.

8. Ibid.

9. Ibid.

1. I use “illness” and “disability” as overlapping terms in this chapter. While the material conditions of being disabled or chronically ill might be experienced differently by people, especially within various branches of the medical industry, I would argue that disabled people and chronically ill people have much to gain from being in solidarity with one another. Further, disability can result from chronic illness and vice versa, not to mention there are many people who live with both disabilities and chronic illnesses at the same time.

2. Like Corinne, I am also a US-based white, lesbian, feminist cisgender woman; in contrast, I am an art historian and live with non-cancer chronic illnesses and physical disabilities.

3. The colleagues Corinne sent this disc to included members of the Queer Caucus for Art (QCA) at CAA (formerly the College Art Association) (Corinne 2005). Corinne was a founding member of the QCA in the late 1980s and early 1990s, when it was called the Gay and Lesbian Caucus for Art.

4. Corinne died on August 27, 2006, in southern Oregon, where she made use of the Oregon Death With Dignity Act (legalized in 1997) to choose when to end her life (Oregon Health Authority). The politics of disability and euthanasia (voluntary and/or involuntary) are complicated and deeply contested within various disability and chronic illness communities, and it is beyond the scope of this paper to make any arguments about these ideas here.

5. Breast cancer, in many ways, has become the most visible—and “visualizable”—form of cancer in the past four decades. It has been embraced by pop culture and its markets, colored pink, and sold as the ultimate women’s disease and disability. Indeed, the “pinkwashing” of breast cancer is very much a prevalent topic in responses to popular culture merchandising of breast cancer awareness as a “feel good” response to the disease without any real impact on those living with breast cancer (Kolata 2015). Furthermore, breast cancer is the most prominently discussed form of the disease in nearly all texts on cancer and the arts. Clearly, the nearly gender-specific breast cancer (women are about 100 times as likely to be diagnosed with and die from breast cancer compared with men, according to the American Cancer Society) coincides easily with a feminist viewpoint that questions the ways in which the medical industry and art world still support a patriarchal structure that takes men as their typical participants and women as the “Other,” secondary and even supplemental to men. Yet the focus on breast cancer above any other form of the disease in visual art as career and/or therapy seems significant. There appears to be no anthologies on feminist narratives of liver cancer or colon cancer, which accounts for the highest number of new cases and deaths of digestive system cancers, and lung cancer, which is cause of the highest number of new cases and deaths by cancer for 2014 (American Cancer Society).

6. Beginning in her early career in the 1970s, when feminist body art came to the fore as a tactic to undermine and complicate masculine viewing practices, Wilke both performed live and directed photographs of herself that deconstructed the “male gaze” and the creation of women as bodies and objects to be looked at: in other words, as subjects of a spectacle. Wilke has been criticized for having used her own white, thin, able-bodied self as the site of the questioning of patriarchal standards of looking and beauty precisely because she appeared to fulfill them so well herself. Yet as art historian Amelia Jones (1998) argues, it is because “Wilke obsessively produce[d] herself as her work through the rhetoric of the pose, reiteratively exaggerating it beyond its veiled patriarchal function of female objectification,” that Wilke’s imagery “unhinge[d] the gendered
oppositions structuring conventional models of art production and interpretation (female/object versus male/acting subject)” (152).

7. Corinne’s essay included photographs from earlier in her career and was composed of five sections, entitled “Making Relationships Visible,” “Crisis,” “My Beautiful Friend,” “Beverly’s Leavetaking,” and “Later” (Corinne 2005).

8. Corinne proudly created multiple series of explicitly sexual—explicitly lesbian—photographs; she was not interested in hiding them or censoring them per se. Instead, she used solarization and kaleidoscopic mirroring of subjects in these photographs to make them less obviously objectifiable by male heterosexual viewers, rewarding those lesbian viewers who spent time to pay close attention to the photographs with scenes that validated their own sexual experiences as queer women (Snider 2013).

9. The images produced in *Scars, Stoma, Ostomy Bag, Portocath: Picturing Cancer in Our Lives* do not have descriptive titles but are rather titled with a combination of letters and numbers, such as H4_0864e, likely representing the image number given to each photograph by the digital camera Corinne used. Corinne might have chosen to keep this jumble of numbers and letters used as titles as a representation of the largely unpronounceable medical/scientific statistics, chemical compositions, or drug names they recall.

10. Corinne’s *Scars, Stoma, Ostomy Bag, Portocath: Picturing Cancer in Our Lives* consists of more than 100 digital photographs of its subjects.

1. In 1972, Roger Cardinal coined the term *Outsider Art* for the title of his book, solving the need for an Anglophone version of *Art Brut* for his British readers. The term has stuck, albeit with changing meanings. But other terminologies are used to categorize this elusive group of artists, such as visionary, vernacular, self-taught, naive, and folk (Wexler and Derby 2015).

2. Jagodzinski (2012) writes that this precariousness of the creative drive might be the source of our fascination with outsider art. “Madness and genius are close allies that are separated by Law that itself is arbitrary. They also reveal the thin line between dream and reality, a border crossing that we make in order to keep our fantasies alive, yet these very fantasies are shaped by ethical and political questions that sustain the symbolic order as it is led” (181).

3. The “Pictures” generation was named after the title of the exhibition at the Artists’ Space in New York City in 1977. They were a group of artists who worked in photography, film, video, and performance art inspired by the ideas of Roland Barthes, Michel Foucault, and Julia Kristeva, who suggested that identity was a fluid state constructed by the social order and the effects of mass media.

4. I use the term “feminist” because I read Sherman’s work as such. Sherman does not identify with this term, however.

5. Sherman, as producer, photographer, and model, is in the unique position of critiquing the male gaze, popularized by John Berger’s (1990) *Ways of Seeing*. In *Practices of Looking*, Sturken and Cartwright (2009) theorize that Sherman poses questions about “spectatorship, identification, the female body image, and the appropriation of the gaze by the woman photographer as her own subject. . . . Sherman inserts herself not only into the image but also into the process of its production, making the viewer aware that the woman in the image is also the woman behind the camera, both the bearer of the look and the object of the gaze. She enmeshes herself in the world being critically interrogated in her work” (323).

1. Rosemarie Garland-Thomson (1997) defines disability as “a representation, a cultural interpretation of physical transformation or configuration, and a comparison of bodies that structures social relations and institutions. Disability, then, is the attribution of corporeal deviance—not so much a property of bodies as a product of cultural rules about what bodies should be or do” (6). Since the 1990s, critical disability theorists have shown how disability is a complex social identity and civil rights concern, similar to race, gender, and sexuality. Garland-Thomson states that disability is culturally constructed as antithetical to accepted standards of “beauty,” “fitness,” “competence,” and “normalcy,” standards that most non-disabled bodies do not meet (6–7).

2. Often those closest to people with autism—family members, friends, caregivers, and doctors—will regard them as asexual and label any expression of sexuality as “abnormal” behavior to be curtailed.

3. Despite Creative Growth’s willingness to be a safe space, they remain limited by laws that are in place to ensure proper conduct between staff and attendees and by their own guidelines as a center for art. Spaces like Creative Growth are few and far between, but they may be the only places where romantic couples with disabilities can be out in the open without fear of judgment or violence.
4. An everyday white paper plate with Ramirez’s dandy face drawn on it hides away deep in her archive. The plate’s scalloped edges mimic the clock face’s dashed markings perfectly, but Creative Growth staff note that it is unclear whether the drawings of the round face dandy or the paper plate came first.

5. Similar to how the Victorian seems an unlikely citation, the Carnival theme in Ramirez’s works seems an ironic connection to ideas of the “carnavalesque” and how they relate to the history of spectacular fetishization of the disabled body. Though I do not speak to this concept in this piece of writing, I address the ways that the carnival is subverted in Ramirez’s work in a previous essay from 2013, titled, “In the Game of Strip Poker, There Are No Losers,” published in the text *Cultures of the Maker: An Anthology of Subjectivities, Dis/abilities, and Desires*.

6. Vietnam era hippie counterculture supported the belief that spectacle, as Guy Debord (1967) saw it, was a tool of the mainstream culture and evil power structures that controlled the means of production of mass media. Psychedelic rock stars wore casual clothing, performed long spontaneous solos, and sometimes even sat with their backs to the audience in order to foster a sense of community with the audience. Authenticity required a stripped-down focus on the music and the music alone, and theatrics and commercialization had no place in rock and roll. Glam rockers capitalized on the capitalism of it all, embracing chart-topping hits and showbiz as symbols of affluence and success.

7. In Jennifer Doyle’s reading of Warhol’s work, she describes the site of sex without referring to a “lack,” something “missing” or “wrong” with the image. This type of troubling ableist language continues to be used in mainstream American narratives, whether specifically describing disability or not, and Doyle’s description demonstrates how unnecessary such ableist language is.

8. So as to not misrepresent Doyle, she states that reading *Where Is Your Rupture?* as a representation of queer performativity is not what she finds interesting about this work. According to Doyle, it is a rather “flat-footed” (102) example of such.

9. This is not to say that people with disabilities do not experience hardships, including physical pain. As Margrit Shildrick (2009) articulated, “I do not mean to suggest naively that anyone going through such bodily disruptions would not experience loss, even despair, in the face of changed circumstances, but that as the new phenomenology of embodiment becomes familiar, different forms of perceptual awareness and interrelationship may become a site of unexpected possibility” (36).

10. Ramirez mix and mingles the dandies’ Victorian-era fashions with traditional Filipino clothing styles, such as the long, straight skirts and wing-like puffed sleeves of a dress called the *terno*. The *terno* is a modernized version in a lineage of formal Filipina dresses that originated with the *Maria Clara*, which was introduced during the Philippines’ Spanish era beginning in 1890. Hollywood-inspired and widely popularized by first lady and fashion icon Imelda Marcos, the *terno* has exaggerated butterfly sleeves that sit high and flat against the shoulder. Like other formal Filipino dress styles, the *terno* exemplifies the mixture of cultures and influences that make up Filipino culture. Though a thorough examination of race in Ramirez’s body of work exceeds the confines of this essay, the white masks and thin washes of watercolor should not necessarily be equated with racial whiteness. References to race and nationality make frequent, albeit subtle, appearances in Ramirez’s body of work. Within her archive, a number of works have a circular version of the Filipino flag painted on the backs, and she incorporates a variety of Filipino foods and dress styles into her paintings.

11. Though it is not explored in this piece of writing, the mask in Aurie Ramirez’s work might be read as a representation of autistic experience. Masks can provide protection as well as act as a filter through which the world is differently processed. Whether the weight and pressure of the mask might feel good or the touch of it to one’s skin is excruciating, the mask might be a template for the person with autism to integrate and negotiate sensory data and emotional response. Conversely, as a form of social camouflaging, masking could be understood as a metaphor for passing as more neurotypical. In this way, the mask represents that which able-bodied normativities demand of the person with autism. Sensory perception and emotions are tied together in a system of input and output, and the person with autism is conditioned to mask oneself in an ongoing negotiation of “acceptable” behaviors and emotional responses in order to conform to neurotypical standards of social interaction.

1. A note on terminology: in places, I make statements that fall within ableist language (e.g., citing physical conditions such as blindness or fatness as denoting corrupt states). I do not agree with or support the use of damaging symbolism but cite the meanings I assume the artist intended.
2. I use religious language in this piece, but I am not speaking from a religious standpoint or position of belief.

3. This can refer to a singular “God” or multiple gods. It is not a statement of my religious beliefs (I am agnostic).

4. These days, we mainly investigate our genome for negative reasons, such as checking for heritable diseases. Power is somewhat less ancestral, so tracing our ancestors is seldom about gaining political influence. Of course, commissioning a DNA study is called having a “profile” done.


6. With exceptions, such as Franz Hals’ work.

7. By contrast, consider contemporary painter Vincent Desiderio’s paintings of his son, Sam (e.g., “Allegory of Painting” 2003) or Tim Lowly’s images of his daughter Temma (“Zoom” 2002). Both children are identifiably disabled, and both artists refer to Christian iconography in their work, particularly the Pieta. Yet every portrait engages the disabled person as an equal subject with the parent. Children are not “proof” of their parents’ devotion or moral superiority. Rather, they are intimate physical presences demanding to be understood and cared for as any beloved child.

8. “Dignity” is a problematic, ableist term that often refers to those who can maintain control of their bodies. Incontinence, spasticity, and intense expressions or gestures are assumed to render someone undignified. For a striking example of disability portraits and dignity, see the Lam Qua painting collection at Yale’s Harvey Cushing/John Hay Whitney Medical Library (c. 1830–40): 80 paintings of Chinese cancer patients who stoically display their enormous tumors.

9. When I learned about these works in art school, no mention was made of either Messerschmidt’s or Gericault’s impairments or the possibility that the strength of the work might have had anything to do with self-knowledge.


11. One that particularly influenced my thoughts for this chapter is Martin Gayford’s Man in a Blue Scarf: On Sitting for a Portrait by Lucien Freud (2013).

12. As my career has grown, I’ve sat for a number of photographs for press usage. I had icicles in my stomach during the sitting and dread as I saw the final image. This lent me such empathy and gratitude for my collaborators every time I sat down in front of the camera.

1. The left-brain interpreter is a neuropsychological concept developed by psychologist Michael S. Gazzaniga and neuroscientist Joseph E. LeDoux. It refers to the way the left-brain hemisphere creates a sense of the world through reconciling new information with what was known before. The neuroscientists who took interest in my stroke hypothesized that the damage to the part of my brain responsible for logical reasoning may have freed up the rest of my mind to think more creatively.

2. When forming Art, Medicine, and Disability, I was reminded of a book I had read decades earlier that discussed the paintings produced after the black plague during the 1340s in Italy. The book showed how populations were mistakenly blamed (the Jews) and how art regressed back to conservative approaches 100 years earlier. I paired this work with art about AIDS that was a crucial part of the New York art world in the 1980s. All the excessive and boundary-breaking behavior of the earlier part of that decade receded as we mourned the lives of many artists who died from that pernicious disease. I concentrated on three such artists: David Wojnarowicz, Felix Gonzalez-Torres, and Jerome Caja.

3. Many of the students continued their internships after the class ended and have become practitioners in the field. Two former students now head two programs—Amanda Eicher is the director of NIAD, and Veronica DeJesus leads the United Cerebral Palsy of Los Angeles in Culver City. Many more are in the ranks of facilitators in the art centers.

4. While “retardation” was the diagnosis at the time, this terminology is no longer used in disability discourse.

1. In the German-speaking part of the art world, the deconstruction of the artistic genius has a long tradition from the early 20th century on (see Zilsel 1918, 1926; Kris and Kurz [1934] 1981). The visual artist Joseph Beuys (1921–86) took the deconstruction of the role of the author and the production process as indicated by the rise of readymades in the opposite direction. With his concept of the “expanded notion of art” and “social sculpture” from the 1960s on, Beuys promoted the idea that anyone can be an artist, and that art academies should subsequently be open to anyone, a philosophy that cost him his job as professor at the Düsseldorf Arts Academy in 1972. From
the late 1990s on, the inspection of the social role of the artistic genius has widely been furthered in context of the debates around the shift of the so-called “cultural exception” to the center of creative economies (for works related to the concept of the “creative imperative” see endnote 2).

2. The term “creative imperative” developed in reaction to the aestheticization of everyday life, marked by political measurements such as the establishment of a “Creative Industries Task Force” by UK Prime Minister Tony Blair in 1997, and became a buzz word for creativity as commodity and artists as new economy pioneers. Numerous artworks, exhibitions, conferences, and books have since dealt with the topic, among them *In the Culture Society: Art, Fashion, and Popular Music* by Angela McRobbie (1999), *Be Creative!* at Museum für Gestaltung Zürich (2002), *The New Spirit of Capitalism* by Luc Boltanski and Eve Chiapello (2005), or the more recent performance *I Blame You, Tony Blair!* by Finnish artist Joonas Lahtinen (2014). As the Italian philosopher Maurizio Lazzarato (1999) points out, this phenomenon has also been investigated by French sociologist and criminologist Gabriel Tarde in 1902.

3. Michael Rothberg made a case arguing against commeasuring and competition of different negative memories that set victims against each other. In a four-part distinction, he maps out “multidirectional memories” and presents their intersection as an axis of comparison that stretches from equation to differentiation and from competition to solidarity.

4. “Behind” is an out of fashion pejorative German word for people with disabilities, abbreviated from “Behinderter” (“handicapped person”).

5. *Domicile* is a movie with a very reduced, Kafkaesque stage design that pictures an earnest young man trapped in his flat with joyless duties and a monstrous, pitch-black, slimy being that is mostly of inapprehensible physical shape but steadily present through a squirm-inducing sound.


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