#### Crip Couture as Radical Care: Fashion, Art Therapy, and Disability Art

#### BY

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#### DISSERTATION

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#### **LIST OF ABBREVIATIONS**

AATA American Art Therapy Association

ABR Art-based research

ADA Americans with Disabilities Act

ADAPT American Disabled for Attendant Programs Today

BOW Bodies of Work

DCAL Disability Culture Activism Lab

OSP Open Studio Process

SAIC School of the Art Institute of Chicago

SMADD Sick (chronically ill), Mad, Autistic, Disabled and Deaf

QTBIPOC Queer, Trans, Black, Indigenous, and People of Color

#### **SUMMARY**

Crip Couture is arts-based research and an umbrella term that I created to describe an aspirational theory and set of artistic practices that articulate how disabled people might engage with beauty and fashion without referencing the dominant culture's distortive and oppressive standards of normalcy. As an artist-scholar, I counter medically, socially, politically and culturally oppressive forces by creating wearable art that incorporates disabled people's full intersectional identities, or what Tobin Siebers calls our "complex embodiment." Crip Couture as a practice is also a form of radical care work, which is non-hierarchical mutual support between individual disabled people, and a form of shared culture making. Crip Couture is an example of Aurora Levine Morales' articulation of "homemade theory", which, through what Audre Lorde calls "the power of the erotic", brings together personal and collective disability narratives, activism, community building, and collective artmaking to produce and assemble a disability culture archive toward the end of disability justice. This dissertation is itself a disability culture archive that includes a critical examination of disability representation, a Crip Couture Manifesto, photographs and a discussion of my original Crip Couture body adornments, documentation of disability community art-making projects, and my own life writing that explores my childhood in Taiwan, young adulthood, activism, work as an art therapist, and doctoral research.

#### 1. INTRODUCTION

#### 1.1 **Background**

As a disabled woman of color, I am attracted to narratives that complicate and speak back to oppressive sources of power. The Black feminist writer Audre Lorde explains "[t]here are many kinds of power, used and unused, acknowledged or otherwise" (53). She urges us to consider how the

[...] erotic is a resource within each of us that lies in a deeply female and spiritual plane, firmly rooted in the power of our unexpressed or unrecognized feeling. In order to perpetuate itself, every oppression must corrupt or distort those various sources of power within the culture of the oppressed that can provide energy for change. (53)

I am especially drawn to narratives from my communities that reclaim, redefine and represent our sources of power toward the aim of social justice. These narratives include the alternative representations created by my fellow disabled people that they have reclaimed and reformulated sources of power that they have reclaimed from the history that lives in our bones.

"Crip," short for "cripple," is a derogatory term that has been used to label and torment disabled people. But since the beginning of the disability rights movement in the late 1960s and 70s, many disabled people have reclaimed the power of the term "crip" as identity, unity, culture and artistry to counter shame and stigma. (Sandahl 26-28)<sup>1</sup> I honor the history and use of the word Crip by capitalizing it because I consider it to be

<sup>&</sup>lt;sup>1</sup> For alternative views of using the word "crip", see Leroy F. Moore, "Krip-Hop Nation is Moore than Music." *Wordgathering: A Journal of Disability Poetry and Literature*, vol. 6 no. 12, 2012. doi:https://wordgathering.com/past\_issues/issue22/essays/essays22/html.

an identity. In my art practice since 2001, I have drawn on this tradition in reclaiming and self-naming by creating what would become what I call "Crip Couture" in 2011. Crip Couture is the subject of this dissertation, and it describes a theoretical perspective, art making practice, research method, and collection of wearable art that counters medically, socially, politically and culturally oppressive forces embedded in historical representations of disability. Crip Couture uses "Crip Aesthetics" to describe the artistic and conceptual choices, ideas, styles and production methods created by artists who identify and embed their self-claimed Crip identity as a part of their artistic expression. Crip aesthetics<sup>2</sup> builds on disability studies scholar Tobin Siebers' term "disability aesthetics" (*Disability Aesthetics* ch. 1) to further the conversation about disability representation in the arts and visual culture. I use Crip aesthetics to purposefully discuss the artistic process and products that reflect "Crip" as a distinctive subculture identity and experience within the larger disability culture.

#### 1.1.1 The Power of the Erotic

In this dissertation, I explore strategies that I have used to counter and replace these oppressive forces with disabled women's alternative narratives of skin, scars and flesh. Alone, and in collaboration with other disabled women, I have developed Crip Couture informed by disability studies, disability activism, and my background as an art therapist and studio artist. I explore how disabled women might recognize the power of the erotic to get beyond distortions of ourselves created by dominant culture. I ask: how might we create authentic representations that contribute uniquely to social justice

<sup>&</sup>lt;sup>2</sup> Throughout this dissertation I use "disability aesthetics" as a neutral descriptor for images representing disability in the arts and visual culture. I use Crip aesthetics to further name and articulate the political, social, and cultural connections that Crip artists demonstrate in their artwork.

movements? How might these representations express the human connections that manifest in disability culture communities' interdependent care relationships? And how might disabled artists contribute to the intertwining discourses of disability activism, art therapy and disability studies?

Lorde explains what the erotic means to her:

The very word *erotic* comes from the Greek word *eros*, the personification of love in all its aspects--born of Chaos, and personifying creative power and harmony. When I speak of the erotic, then, I speak of it as an assertion of the lifeforce of women; of what creative energy empowered, the knowledge and use of which we are now reclaiming in our language, our history, our dance, our loving, our work, our lives. (55)

Following and extending how Lorde defines the erotic, I think of the erotic in the context of this dissertation as the authentic, instinctual feelings that disabled women have about their multiple identities and their relationships with others. We live in a society where ableism, racism, and sexism filter the erotic down to sexual acts or feelings. But, like Lorde, I think we can redirect our erotic power through creative engagements in art making about disability experiences that build and sustain disability community.

#### 1.1.2 **Crip Couture**

Crip Couture documents and articulates how disabled people might engage with beauty, fashion, and relationships of collective care without referencing the dominant culture's distortive and oppressive standards of normalcy in any of these realms. In contrast to normalcy and standardization, Crip Couture is a theory and practice that focuses on the specificities of the disability experience, including the impact of

oppressive social and cultural conditions and felt bodily experiences. These disabilityspecific, individual elements are like pieces of a puzzle that are unique but must be assembled to create a larger picture. Crip Couture is that larger picture, our collective narrative, which is held together by the elements of Crip desire (the power of the erotic), Crip identity (affiliation and a sense of belonging to disability community), Crip specificity (centering disabled people's lived experiences), Crip relationality (connections between disabled people), Crip healing (rescripting the meaning of "healing" based on Crip specificity), and Crip collective care (caring for and supporting fellow disabled people). This dissertation explains and explores each of these elements to discuss how, in the big picture, Crip Couture is a form of radical care work, non-hierarchical mutual support between individual disabled people, and a form of shared culture making. Crip Couture is created in contrast to both the fashion industry and the field of art therapy, both of which have represented disability in relation to standards of normalcy, while paradoxically claiming to value disability difference. Both the fashion industry and art therapy represent disability through the following:

Overcoming and inspirational narratives<sup>3</sup>: These disability narratives perpetuate a
monolithic "positive" public face that disabled people are expected to wear in
society. Disabled people are often expected to fit into the roles of "illness heroes"
or "Super Crips" who conquer their illnesses, disabilities, and life challenges. In
fashion, disabled models are mostly portrayed as happy, confident, beautiful, and
sexy "despite" their disabilities. In art therapy, the evidence-based, medical

<sup>3</sup> Young, Stella. "Transcript of 'I'm Not Your Inspiration, Thank You Very Much.'" *TED*, 2014, www.ted.com/talks/stella\_young\_i\_m\_not\_your\_inspiration\_thank\_you\_very\_much/transcript?language=e

industrial complex demands disabled clients/patients show positive progress towards recovery, or that which most approaches normalcy. Both fields inevitably use these inspirational narratives to generate a "feel-good energy" in their consumers as well as their providers, who participate in the market of fashion commodities and health/medical services.

- Centering white, heteronormative, and able-bodied cultures, both the fashion industry and art therapy overlook disabled people's intersectional identities. In 1989, Black feminist theorist Kimberlé Crenshaw defined intersectionality in her article "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics." Crenshaw's concept of intersectionality describes the ways in which different forms of oppression intersect and, therefore, manifest uniquely in various combinations. Instead of recognizing disabled people's complex and intersecting identity formations made up of race, class, gender, and sexuality, they idealize a socially acceptable disabled prototype--individuals who are well-adjusted and assimilated to dominant culture. The majority of disabled models on the catwalk and in commercials are white and meet the expectations of conventional, genderconforming beauty standards. Likewise, successful art therapy case studies focus on how well individual disabled clients/patients adapt to expectations of white, nondisabled, behavioral and emotional norms in the US.
- Normalcy-based, superficial inclusion agenda: When fashion and art therapy do
  attempt to move beyond the prototypes described above to establish an inclusive
  or multicultural agenda, they exclude input by disabled creatives, models, and art

therapists. Both fields have at their base a charity mindset. In the name of diversity, the fashion industry "helps" the disabled and, therefore, gains positive public recognition for featuring disabled models and adaptive clothing lines. When art therapy training curricula and professional organizations finally include disability as a multicultural category, they still ascribe negative connotations to disabled consumers/patients. The field of art therapy has limited capacity to embrace art therapists with disabilities and/or chronic illness. Disabled people's wholeness, autonomy, and potential to connect with one another is overlooked by professionals on the giving end due to the belief that disabled people in general are always fragile and dependent on others. Services, then, are provided as an act of altruism, even when these services are part of fashion creatives' or therapists' paid labor. This charitable, top-down mentality reinforces the marginalization of disabled people.

The stigma of disability preserves a false dichotomy between the supposedly non-disabled, professionally trained fashion creative and the supposedly disabled wearer. It also preserves a false dichotomy between the medically sanctioned and supposedly non-disabled therapist and the supposedly disabled client/patient. This dichotomy precludes the possibility that the fashion creative or therapist themselves might be disabled. It also prevents people on both sides of these relationships from forming equal partnerships and reciprocal care.

The existing ways both fashion and art therapy represent disability are in and of themselves an erasure of disability culture, which is the culture that disabled people intentionally create for themselves. My formulations of Crip Couture, in contrast, centers

disability culture by enacting a Crip identified focus on procedures, working ethics, and aesthetic expressions informed by disability experiences. Crip Couture might manifest in both the fashion industry and art therapy in the following ways:

- Crip Couture refuses to reinforce the binary that creates a hierarchy of ability
  over disability. It rejects individual overcoming narratives and the tokenization of
  disabled people. By producing disability portrayals that show the complexity of
  disabled people's intersecting identities and lived experiences, Crip Couture
  provides language/tools for an alternative, non-assimilationist narrative that
  defines disability as activist-oriented and from which emerge disability aesthetics
  in the arts.
- Crip Couture formulates new ways to relate to and respond to disabled people in society. Crip Couture values Crip relationality, which is a dynamic, interactive, supportive, physical, and emotional connection among disabled people. It refuses to create meanings and images of disability that shore up white, heteronormative, and ableist ideologies. Crip Couture maps out a future where disabled people nurture, relate, and respond to each other in Crip community.
- The materials, tools, products, and delivery of Crip Couture reflect the richness and diversity of Crip communities. From its place in Crip community, Crip Couture intends to set trends and make an impact on the fashion industry's materials, tools, design, construction methods, and exhibition formats as well as art therapy's practice, pedagogy, and professional development.

#### 1.2 **Theoretical Framework**

Crip Couture's Crip-specific aesthetic focus means that my artistic decisions are based on and reflect disabled people's lived experiences. This approach is the root of my art practice, and it also guides my scholarly research in disability studies. Crip Couture is a formulation of what the disabled and chronically ill writer Aurora Levins Morales calls "homemade theory" ("Certified Organic Intellectual"). Morales explains how homemade theory is made:

My thinking grew directly out of listening to my own discomforts, finding out who shared them, who validated them, and in exchanging stories about common experiences, finding patterns, systems, explanations of how and why things happened. This is the central process of consciousness raising, of collective testimonio. This is how homemade theory happens. (Morales 27)

Morales' homemade theory is an apt descriptor for how I have developed Crip Couture as a conceptual framework, methodology, and set of strategies to apply in my practice as an artist-scholar. I use the process of journaling, sewing, sculpture making, exhibition, artist talks, political organizing, and facilitating disability community art workshops to theorize and document disabled people's individual lives and the cultures our communities have created.

My homemade theory is developed through Crip Relationality, which is the heart of what disability justice activist Mia Mingus calls "access intimacy." She first defined access intimacy in a 2017 blog post to describe the deep connections that disabled people experience with others when their access needs are met. Mingus describes it as an "elusive, hard to describe feeling when someone else 'gets' your access needs"

(e.g). I use collaborative, accessible art making with other disabled people to capture the hard to describe feelings of access intimacy visually and haptically. Crip community is formed as we "get" each other's' access needs. Mingus says, "we share a kind of access intimacy that is ground-level, with no need for explanations. Instantly, we can hold the weight, emotion, logistics, isolation, trauma, fear, anxiety and pain of access. I don't have to justify and we are able to start from a place of steel vulnerability" (e.g.). Crip Couture enacts what Mingus lays out for us by holding physical and emotional space for disabled people to be with each other and to take up the space that our bodies need without the expectation to justify why. Crip Couture puts accountability at the center by requiring facilitating artists to commit to the same witnessing process they ask of their collaborators. Through journaling and critical analysis, I document and examine my personal narrative as a disabled woman artist of color as I have experienced access intimacy in the disability community and in the process of writing this dissertation. I wrap this analysis into the chapters of this dissertation.

My personal narrative is also significant to my conceptualization of Crip Couture as homemade theory. The disability studies scholar Tobin Siebers argues that experience is a form of theory making (*Disability Theory* 14). In his book *Disability Theory*, Siebers explains that we are all embedded in forms of complex embodiment. He argues that we must acknowledge the rich, intersectional, lived experiences generated from daily living with disabilities in an ableist society. Such experience is socially constructed and situated. He emphasizes that all our experiences are embodied and therefore informed by impairment, bodily configuration, and sensations such as pain. Complex embodiment takes all these experiences as a source of knowledge,

material that investigates social contexts, and theories from which to direct political action (*Disability Theory* 22-33).

#### 1.3 **Overview**

This dissertation includes theories generated from my embodied experiences of artmaking and community art workshops as well as two chapters already published in article form. I write about some of the artwork and experiences I had prior to and during the doctoral program. My published articles focus on work I did after my preliminary exams, which appeared in two different art therapy anthologies and are presented here as chapter 6, "Res(crip)ting Art Therapy Disability Culture as a Social Justice Intervention" and chapter 7, "Demystifying the Individualistic Approach to Self-care: Sewing as a Metaphorical Process for Documenting Relational and Communal Care in Disability Culture". They were written in APA format originally and are now written in MLA8 format along with other chapters in this dissertation. I also produced a series of disability community art workshops in the Chicago area and in Taiwan. While addressing all of the workshops is beyond the scope of this dissertation, I discuss at some length my artist residency at Access Living in chapter 6. I describe artwork that I created during the dissertation process, Skinny and Hairy Undies, in chapter 5, Crip Couture Manifesto, as the culmination and future of Crip Couture. Parts of Crip Couture Manifesto was published and the content of the manifesto in this dissertation is an extended version. Skinny and Hairy Undies were featured in ten invited or juried exhibitions. Between 2011 and 2020, I also presented numerous artist's talks in places ranging from art galleries to schools to community centers that engaged audiences in dialogue about the foundational concepts of Crip Couture. My dissertation is also

indebted to these conversations, and I draw on lessons learned from them throughout the dissertation.

#### 1.4 **Chapter Breakdown**

#### 1.4.1 Chapter Two, Literature Review

This chapter surveys existing theories, concepts, and modes of disability and contextualizes them as constituent parts of disability narratives. I synthesize this knowledge and relate it to my creative approaches. I also define terms used throughout the dissertation.

#### 1.4.2 Chapter Three, Method: Arts-Based Research

In this method section, I describe the influences of arts-based research (ABR) on Crip Couture. I provide definitions, background, and characteristics of ABR and highlight the contributions of leading scholars and practitioners who have shaped the development of ABR. ABR uses creative arts to understand human beings, produce knowledge about lived experience, and promotes social change. Its phenomenological approach values process-oriented research. ABR centers artist-researchers' sensibility and reflexivity. Crip Couture research retains some elements of social sciences due to my involvement in the field of art therapy, but Crip Couture in this dissertation uses ABR to inform a humanities-based approach to critical theory, arts practice, and community organizing.

#### 1.4.3 Chapter Four, Personal Narrative as Homemade Theory

This chapter is a personal narrative account of how I found my way to Crip

Couture from early childhood experiences in Taiwan in the 80s and 90s through the

period of my doctoral studies at the University of Illinois at Chicago. My personal

narrative is derived from my own complex embodiment, including my experiences, thoughts, and feelings, and how they all have contributed to the homemade theory and practice of Crip Couture. The resulting products that I discuss in this chapter include a series of wearable items (2000-present), fashion-related artwork (2003-present), my brief time as a practicing clinical art therapist in Taiwan (2006-2009), and my artist-in-residency during which I designed and implemented community art-making workshops at Access Living (2013-2016).

#### 1.4.4 Chapter Five, Method: Arts-Based Research

This chapter presents the Crip Couture Manifesto. It lays out the principles and vision for Crip Couture to provide the groundwork for other artists and scholars to take up the work of an arts-based, relational form of community building and Crip-specific artmaking practice. This chapter is an example of arts-based research, a holistic approach to systematic inquiry, which uses creative arts to explore, reflect, understand, and produce new knowledge about people's lived experiences (Leavy, *Methods Meets Art*; McNiff, *Art-Based Research*; McNiff, *Philosophical and Practical Foundations*). My creative research processes include producing wearable art pieces and exhibiting them in several public spaces in this dissertation.

This chapter is an extended version of the following two published works of mine: There is significant material and excerpts from a short essay "Skinny." This essay can be found in *CPSA Quarterly* (The Center for Sustainable Practice in the Arts) in an issue on "dis/sustain/ability" in 2017. This chapter is also an extended version of the "Crip Couture Manifesto," which was first published in *Wordgathering: A Journal of Disability Poetry and Literature* in December 2020. The Crip Couture Manifesto details the visions

and the guiding principles of Crip Couture. It also lists and describes its objectives, practices, and boundaries for others to use as a framework. Crip Couture Manifesto offers ideas and directions for researchers, artists, art therapists, activists, and cultural workers to apply aspects of Crip Couture in their work.

To illustrate the tenets of Crip Couture Manifesto in practice and how they serve to reimagine the disabled bodymind, I present two art projects that I created as creative research for this dissertation, *Skinny* and *Hairy Undies*. In both on-going art projects, I explore the concept of disability as kinship to exemplify Crip specificity and Crip relationality. In *Skinny*, I further reflect on how such Crip kinship provides a haptic essence and design elements for achieving disability aesthetics. In *Hairy Undies*, I experiment with the use of intimate materials to digest and retell traumatic experiences with the help of people from my disability community.

# 1.4.5 Chapter Six, Res(crip)ting Art Therapy Disability Culture as a Social Justice Intervention

This chapter was originally published in *Art Therapy for Social Justice: Radical Intersections* by Routledge in 2019. It describes Crip Couture as an off-shoot of social justice-based art therapy. When I wrote this article, I had not begun to use the term Crip Couture. The article describes work that was not performed in the context of clinical practice but was instead a form of community building that uses techniques I learned in my training and previous clinical practice. Social justice-based art therapy requires therapists to be transparent about their own identities. In the spirit of transparency, I recount my own experiences with seeking help from therapy. I also provide definitions and discuss the function of disability culture through a series of disability community art

workshops (Figure 1-2, Appendix A) from my artist-in-residency experience at Access Living, an independent living center for disabled people in the metropolitan Chicago area. I analyze the tensions that I experience as an artist, a former art therapist, and a disability cultural worker as I theorize ways to create a culturally responsible art therapy practice for those who are still in the profession.

# 1.4.6 Chapter Seven, Demystifying the Individualistic Approach to Self-care: Sewing as a Metaphorical Process for Documenting Relational and Communal Care in Disability Culture

This chapter was originally published in *Craft in Art Therapy: Diverse*Approaches to the Transformative Power of Craft Materials and Methods by Routledge in 2020. Crip Couture addresses and envisions a collective care relationship system in the disability community which is applicable to the field of art therapy. This chapter examines the concepts of the individualized, "pull yourself up by the bootstraps" type of self-care and contrasts it with community care by analyzing relationships and support that take place amongst disabled people (that I more recently have begun to call Crip relationality) through wearable art (Figure 3, Appendix A).

"Self-care" is an important concept and practice for art therapists, whose job is to support other people who experience trauma, disability, mental illness, oppression, etc. The idea of "self-care" in today's world often focuses on an individual's efforts to perform wellness according to the ableist social script: one must prevail and overcome life challenges independently. I argue that the individualistic approach to self-care is not a sustainable practice because it overlooks the pluralistic nature of human desire for

relational and communal care. It also encourages art therapists to share their own disability or illness experiences with each other and their patients/clients.

#### 1.4.7 **Chapter Eight, Conclusion**

In the conclusion to this dissertation, I summarize my findings and theories by connecting the puzzle pieces of Crip desire, Crip identity, Crip specificity, Crip relationality, Crip healing, and Crip collective care that make up Crip Couture. I briefly discuss my latest projects, *Masks for Crips* and *Disability Culture Activism Lab (DCAL)*, which are both the continuation and culmination of Crip Couture as I have come to understand it through the dissertation process. Overall, this dissertation theorizes the erotic power of Crip Couture to see, feel, hear, and touch Crip collective care from a microlevel to a macrolevel. Ultimately, as a disabled artist-scholar, I aim to develop and model new ways to relate to, understand, and interpret disability in the present time and in the future.

#### 2. LITERATURE REVIEW

#### 2.1 **Introduction**

In this chapter, I expand on Crip Couture as a homemade theory by adding more pieces to the puzzle that I began to describe in the Introduction. These pieces are contributions from scholars, artists, and curators. In this chapter, I define key terms and situate Crip Couture within relevant, representative literature to lay a theoretical foundation important to the dissertation. While I do not directly refer to all of this material in the chapters that follow, taken together, they are essential pieces that make up the larger picture of Crip Couture. This material is organized as follows: theoretical foundations; disability representation in visual culture, fashion, and design; disability and art therapy, and disability art and culture.

#### 2.2 Theoretical Foundations: Homemade Theory

In her 2001 essay "Certified Organic Intellectual," the disabled, chronically ill, feminist writer Aurora Levins Morales discusses her connections to the land, ecology, people's wisdom, and Latina ancestral heritage. Morales points to the impact of women of color speaking against a "colonial, patriarchal subordination influence" (25). In the introduction to the book in which Morales' essay appears, the Latina Feminist Group collective explains that Morales' homemade theory grew from her participation in a conscious-raising collective that was inspired by the work of feminists of color since the 1970s, including Toni Morrison, Audre Lorde, Alice Walker, Maxine Hong Kingston, and Leslie Marmon Silko among others (4). I see this collective's work as engaging in what Lorde describes as the "deeply female" power of the erotic to critique dominant culture and envision a new world. The women in this group wrote and shared texts about the political violence that their communities suffer from (Latina Feminist Group 13). Morales

explains that homemade theory is created through narratives. This group created *collective testimonio*, a method of inquiry in which they reflected on their "perceptions, thoughts, and feelings." She writes that they used a "mutually validated body of stories to critique [...] official versions of reality" (29). According to Morales, creating knowledge and theory through lived experiences requires naming pain and using collective support to ensure each member's survival. She considers collective testimonio as "resistance and recovery" and the beginning of a healing process (The Latina Feminist Group 1-24).

I find the Latina Feminist Group's process and Morales' conceptualization of it as a process of creating homemade theory validating because I also center personal narratives in this dissertation and the process and product of all my work. Homemade theory is a model that I find appealing and useful as a disabled woman of color. I find the descriptor of "homemade" an apt one as I make theories in and from Crip communities, which I consider my home, or what the disabled poet Neil Marcus described as a "Disabled Country". In my dissertation, I explore the idea of seeing disability as a culture and a heritage, a home base for disabled people to share knowledge and wisdom with one another. I use sewing as a primary technique to stitch together a testimony of the lived disability experience, which is a reality that dominant culture most often refuses to recognize.

The Latina Feminist Group formed a tight-knit, intimate community where it was safe to explore and develop the *collective testimonio*. Safety and comfort are aspects that are shared in other minority communities. In writing about disability community, feminist disability studies scholar Alison Kafer builds her work on scholars who consider

<sup>&</sup>lt;sup>4</sup> Testimonios with women in Latin America have focused much of the critical attention to the genre in the last two decades." (The Latina Feminist Group 8)

"kin" beyond the biological, reproductive, and legal terms. In Kafer's 2019 article, *Crip Kin, Manifesting*, Kafer argues that "queer possibilities of intimacy with other presences and entities" provides a foundation for crip kin (1). Kafer discusses three disabled woman artists' work as [c]ollaboratively crafting relations in and through their art, and those deeply intimate and lively relations are not easily reducible to family, or reproduction, or identity." (29) How do disabled people form non-biological familial connections with one another?

#### 2.3 <u>Theoretical Foundations: Access Intimacy</u>

Disability activist Mia Mingus writes about "access intimacy" in her blog Leaving Evidence. Mingus coined the term access intimacy to name the deep connections that disabled people experience with others when their access needs are met. Writing from her own lived experience as a queer physically disabled woman of color adoptee, Mingus describes access intimacy as an "elusive, hard to describe feeling when someone else 'gets' your access needs (e.g.). The kind of eerie comfort that your disabled self feels with someone on a purely access level." Nondisabled people often have a charity mindset when providing access and accommodations to disabled people, making us feel pitied in the process. In her class in Disability in American Film at the University of Illinois at Chicago, Carrie Sandahl explains how cinema portrays disabled people as a "moral barometer," against which the nondisabled helpers measure their goodness and generosity. In contrast to this practice and trope, Mingus emphasizes that access intimacy is not charity, nor does it exist to make nondisabled people feel better about themselves. It is the offering and receiving of support operating outside of institutional obligations or legal requirements.

Access intimacy can be shared between disabled people or between disabled and nondisabled people as it does not require a person to have any political literacy in disability, ableism, or access. But it is particularly poignant when Mingus shares access intimacy with her fellow disabled and sick people whose lived experience has been impacted by ableism. The result is a feeling of being with a chosen family. Access intimacy does not mean that everything is perfectly accessible; instead, it considers access a process that is continuously built and cultivated. Access intimacy is a connection, a sense of physical, psychological, and emotional safety. She says, "Instantly, we can hold the weight, emotion, logistics, isolation, trauma, fear, anxiety and pain of access. I don't have to justify and we are able to start from a place of steel vulnerability."

Mingus offers another term that describes the opposite of access intimacy: "forced intimacy." This term refers to the expectation that disabled people should always be ready to reveal personal information about their lives. An example of this would be situations when nondisabled people demand to know "what is wrong" with disabled people or expect them to prove their disability status. Mingus describes forced intimacy as the "cornerstone of how ableism functions in an able-bodied supremacist world." To survive in an ableist world, disabled people experience forced intimacy as the price they pay in exchange for their access needs being met. Forced intimacy also includes situations when non-disabled people touch without permission disabled people's bodies or their assistive technologies such as their wheelchairs, canes, or prosthetics. Forced intimacy requires the disabled person to be vulnerable and to perform unwavering gratitude. Mingus thinks of access intimacy as a tool for liberation that challenges

systems of oppression beyond superficial campaigns for inclusion and equality. She wants to build deep human connections, interdependence, and collective responsibility for providing each other access.

Access intimacy describes the connections that I experience and cultivate in disability communities. Access intimacy is inflected with the power of the erotic, which can sometimes be disorientating for disabled people. For instance, as the artist-in-residence at Access Living, I once had a disabled man share with me his experiences of being the unwanted recipient of embarrassing stares after he became disabled. After a community art workshop that I facilitated, he pulled me aside to tell me something else, but he could not. I did not want to force him to share but sensed that our meeting touched him in a deep way. The following week, he told me, "Oh, you are nice to everyone, not just me." He had misunderstood the connection he had felt with me earlier as a romantic one.

I shared this story with the disability studies scholar Carol Gill. Her reply echoed what Mingus had also said in her blog post about how access intimacy can be mistaken for a romantic or sexual attraction. Gill reminded me that many disabled people do not often experience such deep connections with other human beings, and that he probably did not have another reference point besides a romantic one for what he was feeling. This experience and conversation further confirmed my desire to join my predecessors in the disability culture community and to provide opportunities to cultivate access intimacy in community art workshops. I use art making to capture visually and haptically the "hard to describe feeling" of the erotic's power to bring us together in the spirit of

access intimacy. Lorde's definition of erotic power disentangled from its sexual connotations is what I want for myself and others to experience through Crip Couture.

Many of my art therapy colleagues and art therapy graduate students have only experienced a medicalized relationship to disabled people infused with a charity mindset. Relating to disabled people in these ways fosters forced intimacy, which I find discouraging. Crip Couture, I believe, introduces them to another way of thinking about their own identities, including the possibility that therapists can identify as disabled themselves. Access intimacy is Crip Couture's horizon.

#### 2.4 **Theoretical Foundations: Disability Justice**

Mia Mingus' conceptualization of access intimacy is imbued with disability justice ideals. Disability Justice is a movement developed by disabled people who are Black and Brown queer, trans, activists, thinkers, and artists in 2005 (Sins Invalid, "What Is Disability Justice?"). Mingus was a founding member, along with Patty Berne, Stacey Milbern, Leroy Moore, Eli Clare, and Sebastian Margaret, and others who were original members of the Disability Justice Collective in the San Francisco Bay area. The queer, disabled, non-binary, femme disability activist Leah Lakshmi Piezna-Samarasinha's 2018 book *Care Work: Dreaming Disability Justice* features a collection of essays detailing the background and her involvement in the disability justice movement. Piezna-Samarasinha writes about how the movement's founders recognized that queer, trans, Black, Indigenous, and people of color lives (QTBIPOC) are often excluded from disability rights frameworks, which are single-issue focused and demand state-funded care through services gained by legislation and meagerly supported entitlement programs. They began discussing the potential to revolutionize the disability rights

movement for a second wave that addresses intersectional oppressions. They eventually named this second-wave "disability justice."

Sins Invalid, a performance collective centering on disabled QTBIPOC artists, founded by Patty Berne and Leroy Moore, produces performances and social justice initiatives that explore the intersectional experience of disability. They do this through work that explores sexuality, disability aesthetics, and the beauty of bodily variation. In 2017, Sins Invalid produced and consolidated disabled QTBIPOC activists' wisdom by publishing *Skin, Tooth, and Bone: The Basis of Movement is Our People, a Disability Justice Primer* (now in its second edition), a book that provides history, concepts, and guidelines for others to do similar work.

As a movement-building framework, disability justice emphasizes that all -isms are intertwined: ableism shapes and helps to produce racism, white supremacy, sexism, queer-transphobia. It offers ten principles, including intersectionality, leadership of those most impacted, anti-capitalist politics, commitment to cross-movement organizing, recognizing wholeness sustainability, commitment to cross-disability, solidarity, interdependence, collective access, and collective liberation. Disability justice principles approach multiple systems of oppression and challenge normalcy by forging alliances with other social justice movements to seek collective liberation. Disability justice values sustainability and interdependency; it is a movement that builds relationships outside of productivity defined and demanded by capitalism. Using an anti-capitalist lens, disability justice leads people to recognize that radical actions begin with owning and honoring their non-conforming bodies and minds both of which are considered one and the same.

<sup>&</sup>lt;sup>5</sup> Sins Invalid https://www.sinsinvalid.org/

Piezna-Samarasinha discusses the philosophy and the values of cross-disability access and care as a way to decolonize the medical industrial complex— the institutionalized health care system that privileges medical professional knowledge and operates based on a capitalist marketing system. She points out that people with chronic illness, fatigue, and/or pain are essential members to the success of disability justice and collective access. She reminds the readers that self-care needs sustainability in disability justice work because many inaccessible and ableist organizing cultures have created alienation and burnout. Piezna-Samarasinha's work prompted me to prioritize sustainability in Crip Couture, because Crip healing cannot happen unless we practice both self-care and community care.

#### 2.5. **Disability Representation**

Disability justice brings disabled people of color together to discuss and create art that fills an absent history in disability activism. Disability history is missing from disabled people's lives, and often our community is not even aware that efforts to create it exist. Crip Couture is my way of attempting to fill that gap with what we know of disability representation. Much of this knowledge is a critique of what has been written in the canonical curriculum or recent scholarly contributions coming from disability studies.

#### 2.5.1 **Art History Narratives**

I sought to fill the gap in knowledge about disability history as I was developing my own disability artist identity. I remember that when I was an undergraduate art student during the late 90s and early 2000s, the art history curriculum did not overtly address disability as a category of analysis, much less an identity. When the curriculum

included depictions of disabled people, my professors focused on the paintings' able-bodied figures, compositions, techniques, and historical references. These references did not include disability-specific information or analysis. Even though this material was absent, it did not mean that disability imagery has been lacking in the Western canon. For example, in her book *The Lives of Dwarfs: Their Journey from Public Curiosity toward Social Liberation*, the scholar Betty Adelson has explored how images of dwarfs are "embedded in the history of civilization in general" (3) and can be found in archaeological artifacts across cultures (139).

Disability studies scholars have noted that disability most often appears in canonical representation as a problem, threat, and disruption that representation needs to fix or eliminate. Disability studies scholar David T. Mitchell says, "Nearly every culture views disability as a problem in need of a solution, and this belief establishes one of the major modes of historical address directed toward people with disabilities" (Narrative Prosthesis and the Materiality of Metaphor 15). In their book *Narrative Prosthesis:*Disability and the Dependencies of Discourse, David T. Mitchell and Sharon L. Snyder have called this tendency "narrative prosthesis," which is the reliance on disability as a metaphor for "something out of place" to launch a narrative (ch. 2). Throughout the book, they explore how narrative resolves the problem of disability by killing, curing, rescuing, or revaluing the disabled character.

Their influential literary schema can be applied to visual representation as well.

Cultural beliefs shape the way artists create images of disability unconsciously and without examination. Their artwork becomes visual reinforcement of the same cultural beliefs. For example, many canonical European paintings include disability imagery.

Just a few of these well-known paintings include Netherlandish Renaissance artist
Pieter Bruegel the Elder's *The Beggars* in 1568; the Greek-born artist El Greco's *Christ*Healing the Blind in 1570; and Spanish Golden Age painter Diego Velázquez's Las
Meninas in 1656. All these paintings portray objectified disabled figures that serve as a prosthesis for the actions of their nondisabled subjects.

Scholarship in art history is just beginning to analyze in more depth what these prevalent disability portrayals mean, and many scholars who are contributing to this analysis come from outside the field of art history. In *Disability Aesthetics*, for example, disability cultural studies scholar Tobin Siebers explores how historical and modern art deploys disability imagery pervasively as a metaphor for, on the one hand, brokenness, and degeneracy, and on the other hand, beauty and renewal.

Siebers' analysis of disability as metaphor is echoed in the work of art historians Ann Millett-Gallant and Elizabeth Howie who are among the few who also have a background in disability studies. In their anthology entitled *Disability and Art History*, they explain that "most art historical articles written before the 2000s discuss the presence of individuals with disability in terms of their symbolic function, that is, in a moralizing sense as Christian figures deserving of charity and pity, as in images of Christ among beggars, cripples, and lepers, or as motif (the monstrous or marvelous)" (4). Millet-Gallant and Howie's anthology, though, includes articles after the 2000s that move beyond the identification of stereotypes into a more complex analysis of how these images created meaning about disability in their own historical context.

Millett-Gallant and Howie describe how art history as a discipline emerged in the nineteenth century, a time when the medical model of disability, which situates disability

as an individual pathology, was ascendant. They explain that because of this focus on the medical model, art history analyses of disability have largely "overlooked the social and political status of the disabled subjects" (e, 3). Canonical European artists, such as the Spanish Romantic painter Francisco Goya (1746-1828), the Dutch post-impressionist painter Vincent Van Gogh (1853-1890), the French fauvist Henri Matisse (1869-1954) and the Swiss-born German painter Paul Klee were known to experience illness and disabilities. However, these artists did not foreground their impairments or incorporate them overtly as artistic concept or expression. It has only been over the past 30 years that a group of artists, curators, and scholars have emerged in the United States, Canada, and Europe that claim a disability identity, culture, or aesthetic, which I discuss later in this chapter.

Given the need to expand disability representation and disability studies perspectives in art history, I consider my dissertation an action—the making of history—to preserve and archive self-represented disability art as a genre for the future. The use of disability as narrative prosthesis continues to be prevalent in representation today. This dissertation addresses this prevalence by exploring Crip Couture counternarratives that forefront the agency and self-determination of disabled people.

#### 2.5.2 Cabinets of Curiosity

Before the late-nineteenth century, distinctions between fine arts, popular culture, and science were not yet formulated. Much has been written about how current-day museums evolved from cabinets of curiosity (or "wonder cabinets"), but few art historians have delved deeply into their relationship to disability representation.<sup>6</sup> In

<sup>&</sup>lt;sup>6</sup> For representative studies see books by Gordon Grice (2015), Patrick Mauriès (2019), Oliver Impey and Arthur Macgregor (2018).

general, Western collectors, starting in the 16<sup>th</sup> century, assembled their findings from the natural and human-made worlds into collections called cabinets of curiosity. These cabinets were rooms, or actual furniture, that held a hodgepodge of items--sometimes organized into loose allegories for the fleetingness of human life. These collections often included disability-related items such as preserved pathological body parts, unusual miniatures, or exotic "Oriental" footwear.

In his 2012 article, "The Museum, a Temple or the Forum", the museum director Duncan Cameron explains that how collectors organize their collectibles reflects the power relationship they have with or over them and the people they might represent (48-60). In 2003, The Research Centre for Museums and Galleries (RCMG) at the University of Leicester designed a research project and exhibit called, *Buried in the Footnotes* (Sandell et al). The research team "set out to address a deficit in knowledge and understanding around the hidden history of disability by investigating museum collections and displays in the UK to identify evidence attesting to the lives of disabled people." The researchers explain how this sort of historical material evidence shows that people with physical differences and items associated with them were situated as "exotic, collectable, and displayed." *Buried in the Footnotes* connected the representational strategies of cabinets of curiosities to representations of disability in freakshows, and how these are the antecedents to today's disability representation and in popular culture. (Sandell et al).

#### 2.5.3 **Freakshow Imagery**

During the late 19<sup>th</sup> and early 20<sup>th</sup> centuries, people with actual or alleged cognitive, physical, or psychiatric disabilities were put on display for profit in carnivals,

fairs, and markets. The sociologist Robert Bodgan was the first scholar to apply a sustained disability studies perspective to analyzing the freak show, which had previously gone unexamined. In his groundbreaking study *Freak Show: Presenting Human Oddities for Amusement and Profit*, which was first published in 1988, he emphasized that no one is born a "freak;" instead, they are characters that are entirely socially constructed. Showmen and managers crafted these characters for performance to meet the demands of the market. They advertised and paraded people with various physical or mental "defects" or "deformities" in front of audiences.

Bogdan classifies freaks into three categories: "born freaks" (those with congenital impairments), "made freaks" (those who made themselves different) and "novelty acts" (those who would perform unusual tricks) (24). The showmen made these so-called human oddities a pure commodity by exaggerating and sensationalizing their stories of the freaks to elicit pity and profit. He also categorizes two modes of display: the exotic and the aggrandized. The exotic mode describes displaying people of color and disabled people as if they were "primitives" or "savages" from a faraway land (28-29). The aggrandized mode describes displaying the freaks as nobility or people of high status (29-31). In his book, Bogdan details how these modes not only showed up in the freakshow's performance choreography and design, but in the commodities that accompanied them as well. Audiences could collect photographs, or "cartes de visites," which were photographs captioned with the freaks' stage names. They could also buy short, often fantastical biographies purportedly written by the performers themselves. These displays, narratives, and photographs were exploitative and objectifying; they seduced the audience's curiosity and voyeuristic impulses. They inspired terror in the

viewers and justified the poor treatment and living conditions which the performers were subjected to for being "monstrous" and inferior to all.

We can also see in these examples of the freak show the importance of an intersectional disability analysis. The scholar Curtis Hinsley discusses how freakshows and displays appearing at the World's Columbian Exposition in 1893 and others like it in the United States were racialized (in Karp et al. 344-365). Human exhibits were displayed in the exotic mode that Bodgan describes in Freak Show. Hinsley explains that "primitive others" —non-white people from supposedly distant lands—were displayed to highlight the "civilized" status of the fair-attendees, which reinforced a sense of class and race privilege. The feminist disability studies scholar Rosemarie Garland-Thomson edited a highly regarded anthology about the freak show called Freakery: Cultural Spectacles of the Extraordinary Body in 1996. She explains in its introduction that immigrants to the United States were diverse in terms of race, ethnicity, and language. Staring at exotic and physically different freaks together solidified their identity as "normal" Americans through their having a shared experience. For centuries, people in power, including royalty, showmen, and medical professionals, had dominated and controlled both the physical bodies and the narratives of human oddities. They instructed audiences (who were assumed to be nondisabled) how to look at and speak about them. Audiences were given permission to peek at, stare at, and react emotionally to the display of those society considered inferior.

### 2.5.4 **The Medical Gaze**

The tradition of exhibiting anomalous bodies shows up again in the realm of medicine. Bodies with congenital abnormalities and rare diseases became a central

medical interest in the late 19th century as the 20th century progressed. Garland-Thomson wrote that "the exceptional body began increasingly to be represented in clinical terms as pathology, and the monstrous body moved from the freakshow stage into the medical theater" ("Introduction" 2). The French philosopher Michel Foucault describes in *Birth of the Clinic: An Archaeology of Medical Perception* how a "medical gaze" developed during this time period as a means of discovering "the truth" about the human body. (*Introduction;* ch. 1; ch. 8) The medical gaze focuses on the patients' bodies, dehumanizing them and transforming them into the subjects of medical research. Foucault argues that the medical gaze is part of a larger system generating forms of knowledge-as-power that separates people into labeled categories.

In her article "Visions of Anatomy: Exhibitions and Dense Bodies", disability performance scholar-artist Petra Kuppers writes about how the medical gaze functioned to frame live patients, corpses, skeletons, and preserved pathological body parts as scientific specimens in the surgical theater. Medical photography acts as a technology of the medical gaze. Disability studies scholar Rachel Adams contrasts these clinical photographs with freak portraiture in her 2001 book *Sideshow U.S.A: Freaks and the American Cultural Imagination*. She writes, "Whereas the freak portrait used props and setting to heighten the body's sensational features, the medical photograph stripped the body of clothing and adornment to provide an unencumbered view of its abnormality" (118). Chris Amirault reinforces Adam's assertion with his suggestion that "medical photography claims to reveal the true subject to *be* the patient, constructed only in relation to that illness" in his 1994 article "Posing the Subject of Early Medical Photography" (73).

Crip Couture creates its own truth by both revealing and adorning disabled bodies. It draws on the rich repository of disability imagery that I have surveyed here in fine art, popular culture, cabinets of curiosity, freak shows, and medical photography. Crip Couture refashions this imagery as fashion itself by, for, with, and between disabled people. Instead of displaying disabled people's body parts in a way that furthers their "othering," my archival approach centers on collecting traces of Crip presence as imagery to treasure. Crip Couture's display of disabled models wearing customized body adornments is a means of rebelling against the history of metaphorization, objectification, commodification, medicalization, and dehumanization.

Crip Couture's disabled models perform alternative versions of these disability representations by wearing and posing for the camera with customized body adornments that I made from narratives in the form of intimate, private conversations we have. The resulting photographs document disabled people exercising agency over their own representation and making their own meanings. This strategy is an extension of what Bogdan said about freaks' agency from the past, an agency to self-determine how and when to reveal our own bodies. Bogdan discusses how many disabled people who performed in freak shows had no agency and were horribly abused by their managers. He reminds us, though, that some disabled people in the freakshow did exercise agency by writing, directing, and performing their own narratives, participating in the larger society, benefiting from being part of a disability community, and enjoying the profits of their labor. Crip Couture honors these Crip ancestral practices by doing the same.

Rather than making art and our bodies available to serve the nondisabled audience, my work assumes that my key audience is disabled. Understanding Foucault's explanation of the medical gaze as a form of power has enabled me to control that power myself by producing performative artwork that explores my body. Crip Couture studies how our disabled bodies have been treated as objects, making a distinction between our reclaimed disabled bodies and the normative standard. Katherine Ott, the lead curator in the Division of Science and Medicine at the Smithsonian's National Museum of American History, observes that disability "is grounded in relationships. The relationships are obvious in the material culture" (Collective Bodies 273). Crip Couture creates a visual record of the relationship between disabled people that Ott describes. Taking after Ott, I am creating and assembling crip artifacts that reflect Crip relationality in the present and for the future. Unlike the objects in the cabinets of curiosity, Crip Couture's objects can only be worn by the disabled people for whom they were made, but they can be held and passed from person to person in audience communities. Crip Couture's artifacts break through the distance that history has erected between objects and those they represent by making a haptic connection between them and people. These objects retain the power of the erotic generated in disability community, are enviable, and cannot be separated from our disabled bodies, identities, and communities.

#### 2.5.5 **Fashion and Design**

Crip Couture both draws on and rebels against representations of disability in the fashion industry. It's an understatement to say that the fashion industry has not considered disabled bodies desirable. Crip Couture's body adornments, though,

redefine fashion by coming up with a visual vocabulary and working process through Crip specificity.

The mainstream fashion industry has made strides in including disabled models and adaptive clothing. A well-known example is Aimee Mullins, an athlete and fashion model who is a double below-the-knee amputee. Her prosthetic legs enable her to be flexible with her height (Esculapio; "Changing My Legs"; "My 12 Pairs of Legs"). She modeled garments for world-renowned fashion designers throughout the early 2000s. In recent years, several major fashion catwalks have also featured models with apparent physical disabilities in their diversity campaigns to supposedly challenge body-type prejudice. Ironically, the selected disabled models only reflect conventional beauty standards: symmetrical facial features and athletic, well-toned bodies. On these catwalk stages, the choices of disabled models' fashion wear and accessories are informed by white, nondisabled culture. These disabled models are mostly white or their race is indeterminate due to their faces being painted in silver and white face make-up as seen in the 2015 New York Fashion Week catwalk "Loving You" (Warren). Efforts at inclusion are an attempt to include "everyone," but the interpretation of "everyone" is disingenuous. Inclusive design or fashion's representation of disability inclusion in fashion claims to include all body types and abilities, but it still leaves out a significant group of people with disabilities who have multiple identities. Disability studies, design studies scholar Aimi Hamraie states that gender, race, ability and sexual orientation and other identity signifiers come with their power, and they can shape people's concept of "everyone" in practice ("Designing Collective Access" and Building Access).

The "Loving You" show's clothing might have been attractive and trendy, but from a wheelchair user's point of view from off the catwalk, it would not have been realistic to sandwich a briefcase-sized handbag under her armpits, let alone draping her sleeves over her wheels. These irrational designs are telling of how the fashion industry positions disability representation as narrative prosthesis to signal their virtue. In another 2015 catwalk featuring stylish professional women's wear that had the patronizing title "Role Models Not Runway Models," designer Carrie Hammer included a few disabled celebrities among other career women she employed as models, including American Horror Story's actress Jamie Brewer who has Down syndrome (Whitcraft and Zimmerman) and the wheelchair-using psychologist Dr. Danielle Sheypuk. This show reflects the media's tendencies to portray disabled fashion models as human-interest success stories through the tired inspirational narrative of overcoming odds to beat low expectations. The disability studies scholar Tanya Titchkosky explains in her 2007 book Reading and Writing Disability Differently: The Textured Life of Embodiment that in these narrative impairments are considered a personal tragedy, hardship, and barrier that the disabled person is believed to conquer through sheer individual will and perseverance (177-208).

The disability activist community has dubbed the protagonist of such narratives as the "supercrip<sup>7</sup>." This colloquial, pejorative term originated in the mid-to late 1970s

<sup>&</sup>lt;sup>7</sup> "Supercrip" is a term used by disability rights activists and disability studies scholars. It is defined as the representation of people with disability or illness who conquer their "limitations" by succeeding beyond the societal expectations. This representation is problematic because it focuses on the individual person's willpower to overcome difficulties without examining how the ableist society sets up a negative discourse around disability. Its use of positive language to portray disability, such as "overcoming their disability in spite of being a disabled person," fails to recognize the low societal expectations for disabled people. It also sets up a non-realistic expectation for all disabled people to attain the same level of success without considering each person's access to resources.

and has been discussed by many disability studies scholars. One example is the disabled writer and activist Eli Clare who, in his 1991 book *Exile and Pride: Disability, Queerness, and Liberation*, explains how the supercrip stereotype is deployed as evidence that disabled people can be successful and assimilate into the nondisabled world despite their impairments. This narrative relies on the assumption that the disabled person is "defective," and that their personal achievement is a way to make up for their misfortune (1-13). This dynamic is evident in a critic's reaction to the "Loving You" fashion show in an online review. The article praised the disabled models who "did not let their disabilities get in their way of making a bold political and fashion statement" (Bal). The same sentiment is furthered by the testimony of disabled people themselves. For example, the amputee model and personal trainer Jack Eyers is quoted in the same review as stating, "I just want to show that having a disability doesn't need to hold you back."

The seemingly positive language is meant to motivate nondisabled people to overcome their own struggles as much as it is disabled people (Titchkosky 177-208). In his 1994 book, *No Pity: People with Disabilities Forging a New Civil Rights Movement* the journalist Joseph Shapiro details how the media "glorifies" disabled people for doing mundane activities. Rosemarie Garland-Thomson adds in her 2009 book *How We Look: The Politics of Staring* that nondisabled spectators cannot imagine disabled people doing these kinds of mundane activities and therefore think of them as something extraordinary (60–61). In the inclusive fashion catwalks, disabled models were simply wearing garments on stage like other nondisabled models but they received outsized critical accolades. The fashion industry is actually the party responsible for excluding

disabled models in the first place, not disabled people for lack of skill or confidence. Another dynamic is overly praising organizers of inclusive catwalks. An example is this critic's assessment of how disabled models "stole the spotlight — not because of their wheelchairs or canes — but because of their beauty and elegance [...] Organizers proved that the fashion week is indeed about arts and hearts" (Bal). This repetitive and overused portrayal is called "inspiration porn," a turn of phrase made infamous by the late Australian disability activist and artist Stella Young and widely used by the disability community.

Inspiration porn is informed by the concept of the charity model, which advances that idea that disability is tragic and pitiful and disabled people are in need of other people's generosity and rescue (Clare, "Stolen Bodies" 360). Treating disabled people as a charity case takes away their agency and turns the focus to nondisabled people's benevolence as the critic I discussed earlier did by praising organizers for winning hearts and minds rather than for their designs or creativity. Disabled consumers are treated as medicalized charity recipients in the fashion industry's making and advertising of adaptive clothing, a current trend. While adaptive clothing has existed in the medical and rehabilitation industry, especially those serving the elderly, large corporations such as Tommy Hilfiger, Target, and Zappos have created ready-to-wear adaptive clothing and shoe lines that they feature in their advertising. These products' designs exhibit charity model thinking and inspiration porn. Target's t-shirts adapted for people on the autism spectrum are emblazoned with the saying, "Be Thankful." Target's website promotes their adaptive line by urging consumers to "[t]each your tiny tot to appreciate the good in life by having him wear the Adaptive Short-Sleeve." Here, Target is using disability as a moral barometer with the claim that nondisabled people buying the shirt and wearing it is itself a charitable act toward the disabled. These types of representation reflect how the mainstream fashion industry understands and communicates what the inclusion of disabled people means for their consumers. In addition, the industry relies on overcoming and inspiration narratives to sell these products and draw attention to itself as promoting "corporate responsibility."

The concepts of "Access" and "accessibility" represent opportunities, privileges, and power (Williamson). To describe something/some places are accessible is to say that the static objects/information/sites are available for bodies of power to initiate multidimensional (Brown), dynamic interactions and communications. The interpretation of "access" can reflect how disability is understood and how prejudice and misconceptions of disability are applied (Williamson). Critical access studies, coined by critical disability studies and feminist design scholar Aimi Hamraie in their book, *Building Access: Universal Design and the Politics of Disability*, theorizes the discourses surrounding access on the praxis of feminist, queer, anti-racist and disability studies. It examines how, what, who and to whom access is created, constructed, practiced and performed, etc.

Critical access studies attends to "knowing-making," which is how knowledge of access is produced from the lived experiences (Hamraie, "Building Access" 99).

Hamraie offers the term "crip technoscience" to describe disabled people's everyday-skill and knowledge and expertise from living and surviving from the ableist world (*Building Access*; "Cripping"). It follows the feminist technoscience approach—the relational connection between technology and science—and a resistance against the

ableist desire to erase disability. As a "politicized design activism," Crip Technoscience is a critical design practice with a focus on collective efforts and interdependence, which aligns with the disability justice movement. Example of critical access studies informed practice can be found in Tanya Titchokosky's work exploring the definitions and practice of access and their impact on producing/reproducing social meanings of disability, space and relationship; Boys' work in the discourse of disability as a critical and creative investigation of social attitudes in the field of architectural and design thinking.

Following Hamraie, Crip Couture creates wearable art by drawing on the lived experiences of disability that my Crip siblings and I have as individuals and as a community. All my work--presentations, installations, photographic documentation, artist talks, teaching, arts administration, community art workshops, or even my past art therapy clinical practice--develops out of a long process of examining care relationships that I share with my collaborators, audiences, and students as a way to enact access, which Titchkosky describes as "an interpretive relation between bodies" (3). When bodies enter the same space and time, their dynamics naturally shift as they interact with each other. People engage with the wearable art exhibits and exchange stories. Crip Couture provides multiple conceptual and experiential entry points for participants to identify with others' stories and to add their own narratives to the conversation.

### 2.5.6 **Disability and Art Therapy**

Representation of disability also exists in therapeutic, applied fields. These fields incorporate narratives of disability that are very similar to those found in art history, popular culture, and fashion. Traditionally, art therapists worked primarily in health care settings, such as hospitals and rehabilitation centers, where the concepts of diagnosis,

treatment plans, and interventions are executed. Vick describes hospitals as "incubators" for the field of art therapy (6). Before art therapy became a profession, many artists and art educators had worked as teaching artists in psychiatric wards in hospitals. Those artists' use of art to aid patients' treatment prognosis began to receive positive recognition. Hospitals and psychiatry departments began hiring art therapists on staff.

One of the two major frameworks of art therapy is "art psychotherapy" developed by the "Mother of Art Therapy" (Junge and Asawa 22), Margaret Naumburg in the 1940s. Naumburg's work was informed by Freud's psychoanalytic theory and concepts, and defined art therapy as a distinct mental health profession. Naumburg worked in a psychiatric hospital; her approach of art therapy emphasizes eliciting patients' unconsciousness through spontaneous art making and interpreting the symbolic and pictorial expressions in their art. The second major framework of art therapy is Edith Kramer's concept of "art as therapy," which refers to art as the healing agent and its inherit therapeutic effect (Junge and Asawa). Developed in the 1950s, Kramer's theory draws on Freud's personality theory and focuses on achieving sublimation—changing socially unacceptable desires or behaviors into acceptable ones (Ulman et al. 3-13).

Disability representation in art therapy is also shaped by the charity model which considers disabled people as a population that needs professional assistance from art therapists. Henley argues that art therapists need to adapt different approaches to "compensate" ("Approaching Artistic Sublimation" 67) for the client's disabilities and provide themselves as "normal behaving, productive and creatively functioning role models" ("Approaching Artistic Sublimation" 72). Unlike any other types of art practices,

art therapists believe in creating art within the relationship with a therapist (Rubin 270), in the presence of an art therapist (Malchiodi, *The Art Therapy Source Book* 1) and with therapists' "fervent study of client artwork" (Henley, "Art Assessment" 66). This relationship is similar to the inclusive fashion show organizers. Even though the spotlight is on disabled models, the media representation focuses on the non-disabled fashion industry's efforts to create diversity. The charity model may inadvertently influence art therapists' moral stance when it is their ethical responsibility to protect the "vulnerable" disabled population.

My dissertation builds on my predecessors' work in moving beyond medical and charity models by developing the therapist's activist identity through social justice-based art therapy practice. Increasingly, the field of art therapy is identifying the problem of disability to be a social one in addition to an individual psychological problem. In addition, an emphasis on relationality and the therapist's own art practice is a major influence on Crip Couture. Kramer emphasizes the art making process over the final product in art therapy. Other foundational scholars included Elinor Ulman, whose essay "Art Therapy: Problems of Definition" became the cornerstone of art therapy literature (Ulman et al. 3-13).

Art therapy is primarily situated in a European-American tradition with leaders and educators who have mostly been white, middle-class, and non-disabled (Junge and Asawa); Kaplan, "Editorial"; Talwar, *Decolonization*). Critical theory scholars critique art therapy for the absence of race in its discussions (Talwar et al. 123-143; Talwar and Gipson, *Envisioning;* Gipson, "Challenging Neoliberalism"); its normalization informed knowledge and approaches, which not only individualizes disabled people's lived

experiences, but also de-politicizes and de-contextualizes\_disabled people's cultural expressions (Barnes, "Generating Change"; Kuppers, "Art Therapy") Disability studies scholars and disabled artist-activists have advocated for a distinct separation from art therapy for specific political and cultural reasons. However, there is limited conversation and exchange of scholarship between the two fields.

Art therapy practitioners continue to combine a broad range of theories and methods to expand their practice, including humanistic, holistic and cognitive behavioral approaches, etc. The increasing changes in the social and cultural makeup of the world prompted art therapists to examine their own identities. This includes therapists' power positions as experts (Malchiodi, "Authority or Advocacy"; Spaniol, "Guest Editorial") who observe patients without taking part in art making as equal participants (Allen, "Artist-in-Residence") in the traditional therapy relationships. Therapists' own artist identities and art practices as the field was aligning itself to the world of medical clinicians (Allen, "Coyote Comes in from the Cold"; Lachman-Chapin; Moon, Studio Art Therapy). Art therapists challenged the boundaries and the location of art therapy by expanding individual, personal therapy into collective social issues with a postmodern and relational-context approach (Alter-Muri; Alter-Muri and Klein; Byrne). They did this by applying ethnographic and cross-culture models to address the lack of diversity in the field (Kapitan; Spaniol, "Towards an Ethnographic Approach") and developing a therapist-activist identity and consciousness in social issues beyond the clinical settings (Allen, "Wielding the Shield"; Junge et al., Allen, "Special Issue").

In today's political climate, changes in mental health care policy and the uprising of many social movements prompted art therapists to further engage with theories of

difference. Art therapy practice now includes theories and approaches from outside of traditional psychology and psychoanalysis in individual therapy, such as community empowerment (Ottemiller and Awais), community-based practice, (Moon and Shuman; Hocoy) and social action art therapy (Kaplan, *Art Therapy and Social Action*). Art therapists also examine the ethnocentric monoculturalism in art therapy (Talwar, "Culture"; Talwar et al) and redefine psychodynamic practices through a feminist critical lens (Hogan), research on gender and LGBTQ theories (Addison; Pelton-Sweet and Sherry; Zappa), social justice models (George et al.; Talwar, "Creating Alternative Public Spaces") and finally, disability studies (Yi, *Res(crip)ting Art Therapy*; Yi and Moon; Yi and Talwar).

Starting in the 1990s, a few art therapists engaged advocacy and cross-culture frameworks in both community and hospital settings (McGraw; Spaniol, "Exhibiting Art" and "Towards an Ethnographic Approach"). These approaches raised the visibility of disabled clients and their challenges and redefined the traditional power relationships in therapy. To continue raising disability visibility in art therapy, I am motivated to form critical discussions around the cultural and political identity of disability. In addition, I argue that the lack of disabled art therapists' presence and scholarship has been detrimental to the development of art therapy. I am dedicated to support and mentor disabled art therapists and graduate students in the field of art therapy with the intention of bringing disabled practitioners into the field.

As a response to the critiques described above, my dissertation raises questions about how healing can occur when disabled people lack authorship in creating disability representations in art therapy. I also question the meaning of healing when disabled

people are alienated from relationships and community connections in disability culture. In mentoring art therapy trainees, I was informed that my trainees were told by their supervisors to conceal their own experiences of illness/disabilities when working with clients and patients. If we prevent disabled therapists and clients from finding common ground, we risk limiting the range of possibilities for forming relationships. The consequences might be to further objectify disabled people medically without recognizing the values of Crip presence. In an effort to increase disability representation in art therapy, I co-edited a special issue on *Art Therapy and Disability Studies for the Art Therapy: Journal of American Art Therapy Association* and included articles on disabled, Mad, and Deaf art therapists' perspectives (Beck; Ehlert; King; Roots and Roses), disability culture applications in clinical settings (Wilcox), and a discussion of the potential of disability art based studio practice with artists with intellectual and developmental disabilities (Miller).

I believe that disability-culture informed therapy requires transparency about one's disability experience, including the therapist's experience. We need to think about building relationships with disabled people beyond the existing clinical framework. Crip Couture complicates the concept of "healing" by documenting how access intimacy and community care can emerge when the helper and helpee are both disabled people.

#### 2.5.7 **Disability Culture**

Culture is a symbol of place, a way of life (Barnes and Mercer) and "an overarching set of values and norms associated with a particular group" (Barnes, "Effecting Change" 2). "Disability Culture" developed out of the International disabled people's movement in the 1960s and 1970s (Barnes, "Effecting Change"; Kuppers,

Disability Culture). Disability culture reflects disabled people's shared history, memories, experiences, language, survival skills, cultural meanings, and creative expression etc. As disabled people assemble (Kuppers, Disability Culture 270), they form an underground society, a subculture, where participating members can forge alliances based on their shared disabling experiences. Disability culture begins when disabled people resist the dominant, individualized and medicalized representations of disability and gain political consciousness through radical, socio-political perspectives of disability—social model of disability (Barnes, "Effecting Change"; Barnes and Mercer; Peters; Triano). The collective appearances of disabled people create images of disability culture: the way disabled bodies rearrange themselves to counter the hegemonic order and the discipline of silenced bodies.

Disability culture is described as a "defense mechanism against oppression" (Barnes, "Generating Change"); "emotional unity" (Gill "A Psychological View"); a cultural resistance against the passive disability stereotypes, which sees disabled people as lacking agency and burdens on society (Barnes, "Effecting Change"; Barnes and Mercer). Longmore says, "When devaluation and discrimination happen to one person, it is biography, but when, in all probability, similar experiences happened to millions, it is social history" (39). The development and growth of disability culture demonstrates that disabled people are taking on activist identities for social change. Disabled people often live in isolation (Kuppers, "Performing Determinism" 89); lack of information and access to other disabled people contributes to the dissociation of disability culture. Therefore, the disconnection between people and their disability identity is the result of the erasure of social and cultural history.

### 2.5.8 **Disability Art**

The term "Disability Art" emerged in the 1970s mirroring the rising period of disability rights activism in the U.S. and the International disabled people's movement (Barnes, "Generating Change"; Cameron; Peters; Sandahl, *Disability Arts*, and *Disability Art and Artistic Expression*). Disability culture expression, such as visual art, music, poetry, spoken word, dance, and performance reflect and document disabled artists' lived experience, which is often silenced by multiple structures of ableism, colonialism, and patriarchal society. Early artistic expressions of disability culture began with a close connection to disability rights activists' agendas. For example, disability activistmusicians created songs about inaccessible public transportation and the institutionalization of disabled people<sup>8</sup>.

Prior to the signing of the Americans with Disabilities Act (ADA) in 1990, disabled activists addressed the lack of accessible public spaces for disabled people and artists to gather as they seek places to host disability culture cabarets. After the passing of the ADA, civil rights legislation slowly increased disabled people's access to education and public and private arts and culture venues. Most disabled people's exposure to arts and crafts first took place in hospitals where art is offered as treatment and intervention for recreation, occupational therapy, or art psychotherapy (Sandahl, *Disability Arts*). Disability Art and art therapy both have the component of self-expression. However, they each have distinct definitions and goals. Disability art is based on a social, political, and relational model of disability. It stresses the relationship with disability culture in the

<sup>&</sup>lt;sup>8</sup> An example can be found in the work of disability activist, singer and songwriter, Alan Holdsworth whose album was titled, *Tear Down the Walls*. Johnny Crescendo, *Tear Down the Walls*. Johnny Crescendo, 2001.

final product, and it challenges stereotypes about disabled people. Disability art treats the disability experience as a style with an aesthetic component. This may be used as a tactic to transform audiences' views about disability. Art therapy is traditionally based on the medical model of disability, with recent developments in social action or social justice-oriented approaches. It focuses on therapists' role in providing support through the engagement of art processes. Many disability studies scholars advocate to separate disability art and art therapy due to the stigma attached to disability. Disability studies scholar Colin Barnes describes art therapy as an "individualized and depoliticized creativity" and traditionally, disabled people's access to arts and crafts have had a long history situated in paternalistic charity models (7). Disability art seeks a separation from the mental health service providers' work and avoids trading in our disability identity (Finkelstein 1-3).

Disabled people's access to quality art education and equal participation, as both audience members and artists, faces major challenges. Inaccessible environmental/physical barriers, social attitudes, disability stigma, lack of art educators who are knowledgeable about the nuance of disability art, and disability representations all contribute to disabled people's limited access to professional training opportunities (Barnes, "Effecting Change"; Finkelstein, Gill and Sandahl; Kuppers, *Art Therapy*; Sandahl, *Disability Arts*). In addition, many disabled artists are represented through overcoming narratives and inspiration porn. Therefore, there is a lack of positive cultural and artistic identities for disabled people to model after (Barnes, Generating Change" 9; Finkelstein).

Disability Art can explore multiple meanings of disability at a personal, interpersonal, collective, political, and artistic level. The qualification to be in the category of disability art has been a debatable topic. Unlimited<sup>9</sup>, a UK commissioned program supporting disabled artists' creativity strictly follows the social model of disability and considers any art made by disabled people, regardless of whether the content of the art relates to disability, disability art. Some individual artists' impairments are apparent, but they have no association to the disability culture community and may assume that "disability art" is a label devaluing their work. As a genre, disability art can include non-disabled artists, whose artwork reflects their close connection to disability and addresses the core features of disability politics and disability culture thematically 10. Many self-claimed disabled artists centralize disability as a core feature of their artists' identity, theme, conceptual framework, and artistic expressions with an edge of political confrontation. They examine and critique traditional representations of disabled people and disability with complexity (Kuppers, Disability Culture 274). UK actor Mat Fraser creates stage shows such as Thalidomide!! A Musical, an adult-version of Beauty and the Beast on stage. He has also acted in the American Horror Story: Freak Show on tv (The American Horror Story).

Art history scholar Ann Millett-Gallant says, "Like other forms of identity politics, disability culture, in art as in other areas, seeks to allow its members to identify and define themselves, rather than be defined by others" (Millett-Gallant and Howie 2). To address the absence of disability self-representation in art and art history, American

<sup>&</sup>lt;sup>9</sup> Unlimited <a href="https://weareunlimited.org.uk">https://weareunlimited.org.uk</a>

<sup>&</sup>lt;sup>10</sup> An example of disability art and culture exhibition featuring both disabled and non-disabled artists can be found in the following exhibition: *Chicago Disability Activism, Arts, and Design: 1970s to Today.* 14 Sep– 20 Oct, 2018, Gallery 400, University of Illinois at Chicago, Chicago.

painter Riva Lehrer paints portraits of disabled artists whose narratives and agency are present in the paintings. These artists not only use art to reveal and investigate the socio-economic-cultural experiences of living with a disability in society, they also invest in creating disability focused aesthetics.

Early disability cabarets showcased disabled people's poetry and writing in small, wheelchair accessible venues (Cameron) that were for disabled people—Crips—only (Kuppers, *Disability Culture*). Burch and Kuppers point out that in the 21st century, disability cabaret brings non-disabled audiences to increase disability representation and opportunities for educating the public about disability. Barnes warns that "as disability culture and art are assimilated into mainstream, the political significance may be effectively neutralized" (17). Today, disability art and culture events require the venue to be a place where all participating bodies, including audiences and artists, feel free to address their physical, communicational, psychological, sensorial, and emotional access needs (Sandahl, *Disability Art*). Disability art and culture events claim visibility for disability, and also challenge what access means through artistic expression.

Disability Art requires curators to design accessibility as a part of the aesthetics (Cooley and Fox)—an artistic expression, emotional engagement, or sensibility from the perspective of the disabled artist and disability culture.

Crip Couture is a disability art project that focuses on Crip community connections. In Tod Browning's 1932 film, *Freaks*, a group of disabled carnival sideshow performers accept a nondisabled woman to their community by chanting, "We accept her... we accept her... One of us, one of us. Gooba-gobble, gooba-gobble..." The phrase "one of us" ushers her into a well-established disability community. Today, the

iconic phrase "one of us" is a cultural identifier for many politized disabled activists and artists. Crip Couture pays homage to the disabled performers of the freakshow era and uses the phrase "One of us" as a design element (Figure 4, Appendix A). Crip Couture creates space for the disability community to heal from the harmful effects of ableism and attend to our mental health in a way that a disability art event alone cannot. Many audience members open up about their disability experiences during talk-backs after Crip Couture events. "One of us" becomes a rallying cry and an expression of the erotic impulse that compels me to organize more disability art and culture events that invite others to become "one of us."

#### 3. METHOD

## 3.1 Arts-Based Research (ABR) Overview

Crip Couture is influenced by arts-based research (ABR), which is a systematic and disciplined method of inquiry that uses creative arts to understand human beings, produce knowledge about lived experience, and promote social change (Leavy, Methods Meets Art; McNiff, Art-Based Research; McNiff, Philosophical and Practical Foundations). As a holistic approach to research, ABR utilizes creative art-making processes to inspire research questions, process research experiences, produce and analyze data, generate outcomes, and explore different aspects of the human experience (Allen, "Art as Enquiry"; Leavy, Methods Meets Art; Potash). ABR uses creative arts genres, including visual art, music, sound, movement, dance, performance, drama, writing, poetry, installation, any combination of these and more. Applied fields, such as psychology and social work as well as the social sciences use ABR (McNiff, Critical Focus). Crip Couture research retains some elements of the social sciences due to my involvement in the field of art therapy, but in this dissertation Crip Couture uses ABR to inform a humanities-based approach to critical theory, arts practice, and community organizing.

# 3.1.1 **ABR History and Development**

ABR became a method in the late 20th century (Bresler; Sinner et al.). The term "arts-based research" was coined by the late art and education scholar Elliot Eisner, who advocated that pluralistic methods should be used to produce knowledge to "expand human experience and promote understanding" ("Does arts-based research has a future" 16). Traditionally, ABR sits at the intersection of art and science (Leavy,

*Introduction* 3); it facilitates flow of ideas (Bresler 53<sup>11</sup>) and revives partnership between art and science (McNiff, Critical Focus). Most ABR pioneers come from the field of art education and creative/expressive art therapy, including art, music, dance, and movement therapies. The art therapist and educator Shaun McNiff first published Arts Based Research in 1998. He argues that art therapy--the use of art and psychology to connect with mental health--could lay the foundation for ABR's development. Similar to Eisner's ABR philosophy about the use of art to enlarge understanding of human phenomena, McNiff believes that "science tends to reduce experiences to core principles" while "art amplifies and expands" (Art-Based Research 34). In the next 20 years, many other art therapy researchers incorporated and refined approaches to ABR (Allen, "Art as Enquiry"; Leavy, Introduction 6; Potash). Art therapy practitioners and researchers utilize ABR for social and creative arts research (Chilton, Arts-Based Research), pedagogical inquiry through altered book construction and narrative writing (Chilton, "Altered Inquiry"), participatory action research with people with mental illness (Spaniol, "Arts-Based Approach" and "Learned Hopefulness"), and art-based performance in art therapy research and education (Moon and Hoffman). Crip Couture borrows techniques from ABR to foster relationships that promote Crip healing and social justice. It also influences my use of multiple artistic media, the organization of ideas, and the facilitation of group conversations.

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<sup>&</sup>lt;sup>11</sup> Detels and Smith's concept of "soft boundaries" point to the boundaries between transdisciplinary practice. Meaning that art and science are not two separate disciplines, there are commonalities and ideas can be nurtured further when we look beyond the split of art as emotional and science as logical.

## 3.1.2 ABR as a Paradigm

ABR is informed by the philosophical concepts of "the body," embodiment theory, and phenomenology (Barone, Arts-Based Research; Leavy, Introduction 5-6). Some ABR research is qualitative (Barone, "Arts-based educational research" 6) and some could be considered its own stand-alone paradigm (Chilton, Arts-Based Research; Gerber et al.; Rolling). Some ABR research could be considered disruptive to and therefore an extension of the qualitative paradigm (Leavy Introduction 9). In this dissertation Crip Couture is what might be considered one of the stand-alone paradigms that is similar to the work developed by the disability studies scholar, activist, and performance artist Petra Kuppers. Her practice consists of community-based, somatic, and site-specific performance work in the disability culture and other marginalized communities. Kuppers utilizes ABR to combine critical theory with activism. Her work includes, for example, the exploration of narratives about scars through poetry writing and mixed media sculpture making (Kuppers, "Scar Tissue"). Kuppers' Salamander Project (Kuppers, "Swimming") explores companionship and adventure with disabled people and their allies through activities in the water. These activities include swimming together, underwater photography, community art workshops, and creative writing. (Kuppers, Social Somatics). With the exception of Kuppers' work, disability studies has not yet developed much arts-based research in the field.

### 3.1.3 Crip Couture as a Stand-Alone Paradigm

Crip Couture's version of ABR is consistent with practice-based approaches that considers somatic knowledge as one of the multiple intelligences that guide research.

As human beings, our bodies and minds have incredible capacities to receive, process,

digest, respond to, and store experiences and memories. People's lived experiences including their feelings, thoughts and problem-solving strategies—are the sources for developing skills and knowledge about human survival. I believe that through the act of making art, physical and mindful exchanges take place as the artist-researcher and participants work together using tools, manipulating materials, and communicating with each other. For example, a Crip Couture project called "Em-brace," made before I began my doctoral studies, enacts these beliefs. I crafted wearable braces in response to the stories the disabled artist Sunaura (Sunny) Taylor told me about her orthopedic experiences as a child. We shared with each other our feelings about medical professionals' attempts to "fix" our impairments. We also talked about how our disability perspectives had evolved over the years as we became politicized. These conversations led me to make specific artistic choices, such as following the natural close-to 90-degree angle of Tayor's wrist by using malleable plastic material and applying French knot embroidery techniques for aesthetic and tactile quality. These artistic choices transformed the medical model's focus on normalcy and functionality by accentuating difference and pleasure. The design was inspired by Taylor's selfdefinitions of beauty and health. The creation of "Em-brace" is discussed in more detail in chapter 7.

#### 3.1.4 ABR as Social Action

As a transdisciplinary approach, ABR values the process of knowing (Eisner, "Does Arts-Based Research Have a Future?" 16); it aims to build researchers' empathic understanding of others' lived experiences (Bresler 52). ABR's method facilitates interactive human engagement through various physical, sensorial, and emotional

expressions in the arts. ABR does not defer to science as the only form of knowledge. It doesn't rely on science methods to assess or justify its findings. There are fundamental ontological differences between a strictly scientific method and ABR. The positivist research language, such as validity and reliability, are inappropriate for assessing artistic inquiry (Leavy, *Social Research*). Artistic inquiry's ethics revolve around enhancing community participation in an effort to transform society through social action.

## 3.1.5 **Reflexivity Skills**

ABR requires artist-scholars to utilize their own sensations, emotions, and intuitions to formulate understanding of the research topic, and eventually build theories based on what they learned (Allen, "Art as Enguiry"). These strategies are similar to the ones out of which homemade theory is made as Morales describes it. ABR methods can be open-ended, spontaneous and inclusive, as affects and inspirations are constantly changing and shifting. Its infinite possibilities include artist-scholars' own lived experiences and the intuitive nature of somatic knowledge informs the way that they observe, raise questions, and set directions for their research. Chapter 6, "Res(crip)ting Art Therapy" is an example of how my intuitive, somatic feelings led to my thoughts on Crip healing, which would become integral to Crip Couture. I met with a potential therapist who turned me into a supercrip: she said that I was brave and when called out, denied that she was staring at my disabled body overtly during the session. I felt vulnerable both physically and emotionally. I addressed the exhausting emotional labor this session required and the frustrations that it caused by seeking help from my Crip siblings who confessed that they had had similar experiences with mental health care

professionals, and I shared my reactions with them. This experience validated my desire to nurture disabled art therapy graduate students who could provide culturally competent mental health care.

Allen ("Art as Enquiry") confirms that artist-scholars can use their intuition, hunches, curiosity, passion, or epiphany to launch their research. I interpret Allen's approach as ways to harness the power of the erotic described by Lorde. I made use of my anger, frustration, and pain about my interaction with the patronizing therapist as the impetus to change therapists' cultural insensitivity toward disabled people. My supervision of the School of the Art Institute of Chicago interns at Access Living included their participation in a series of community art making projects where they could learn to elicit and listen to disability community stories. In chapter 6, I reflect on one of these projects which consisted of an interactive photobooth that encouraged disabled youth to self-advocate. I use this experience to create the practice of disability culture community care. ABR includes the creation of safe spaces that invite growth through participation (Eisner, Art and Knowledge), caring relationships (Bresler), and empathy. ABR intends to disrupt the privileged route of producing academic knowledge. ABR considers the researchers, participants, and audience members to be equal collaborators in knowledge production. This inclusive collaboration sparks the participants' curiosity by making research processes and results available to them and to the public. Crip Couture does the same.

### 3.2 **Summary**

Crip Couture is inspired by the optimism of ABR, even if its implementation often falls short of its ideals. I recognize that progress towards social justice is incremental

and imperfect. The qualities to which ABR aspires have influenced my conceptualization and practice of Crip Couture. Like ABR, Crip Couture seeks to invite and empower people to speak up about their concerns and world views. It addresses social inequalities and exposes oppressions and discrimination. It is a channel for people from underrepresented or marginalized communities to voice their silenced experiences. The field of art therapy has practiced ABR for some time, and it would benefit from considering the perspectives of disabled artists, activists, and scholars. Likewise, disability studies could benefit from the insights of ABR. This dissertation takes tentative steps toward bringing these two fields together in the service of disability justice.

#### 4. PERSONAL NARRATIVE AS HOMEMADE THEORY

## 4.1 **Introduction**

To remedy the absence of disability self-representation in visual culture, fashion, and art therapy, my homemade theory, Crip Couture, harnesses the power of the erotic, which I described in the Introduction as "the authentic, instinctual feelings that disabled women have about their multiple identities and their relationships with others" by centering first-person disability narratives. It is important to me, then, to include my own personal narrative in this chapter as a means of tracing Crip Couture's development. In this narrative, I highlight different features that make up the puzzle of what Tobin Siebers would call my complex embodiment, one piece at a time. Sieber's concept of complex embodiment seems consistent with Kimberlé Crenshaw's 1989 concept of intersectionality. Both acknowledge that we are made up of unique identity mosaics rather than discrete elements that operate independently from one another. To illustrate how my experiences become homemade theory, though, I am not able to talk about all aspects of my identity at the same time. So, in this chapter, I emphasize different aspects of my identity that are more prominent to me as I recollect them from the following: my childhood in Taiwan, my young adulthood, and my professional and scholarly training experiences in the United States.

Each section in this chapter functions as a piece of an identity puzzle, so to speak, that needs to be assembled and examined before I can put them together into a fuller, more complex picture. I think of theory production as a process of translation. I translate a particular time and space that I experience in the past to the present and develop a vision for the future. I have become an expert at this kind of translation,

because, as a disabled woman, I have always been on the periphery of both Taiwanese and American culture. From the periphery, I make observations about experiences that I need to sort out and then recombine, or translate, so that others from different positions, on the periphery or in the center, can understand them. As uncomfortable as my peripheral position has been, it is the place where my identity's difficult, complexly embodied intersections are located and from which Crip Couture has emerged and continues to develop to this day.

## 4.2 **Learning about Beauty and Disability**

Brows frowned... breath held in the back of my throat...

Shoulders tensed up... hands gripped tight... eyes looked down...

My typical fight or flight response oddly matches my physical reactions whenever I hear, "You're so pretty" in Chinese. "You're so pretty" has always sounded like one of the lines in a terrorizing bed-time story. During my childhood in 1980s in Taiwan, whenever people said, "you have such a pretty face," eight out of ten times such a compliment would end with a heavy sigh, or the phrase "it's a shame that you only have two fingers" rolled out of people's mouths. The only times that people did not say such platitudes was when they were already choking up in tears because they felt sorry for me.

The elders in my family always said that my older sister was the lucky child of my generation; She also had a 50% chance of inheriting the "defective" genes from the Yi's family bloodline, but she was the only one born with all ten fingers and toes. I learned that sibling rivalry was a real thing through my sister's ambivalent relationship with her luck. It is a particular kind of rivalry, which I never wished to partake in. Adults

compensated for my absence of normative fingers and toes by offering the word "pretty" to the rest of my body and facial features; my sister's luck was a symbol of their hopes for normalcy. Such luck serves only as a comparison to the *unfortunate* result of my body, and it never fulfilled my sister's need to receive positive attention as a child without a disability. It was always guaranteed that my sister would get pissed off at me with crossed arms and an eye roll as she heard "you're so pretty" directed at me like an evil witch's curse. The threat of my sister's anger outweighed my desire to be called beautiful.

At a young age, it did not take me long to realize that it was easy for people to see things on the surface. I was determined to work hard and to prove that I had much more substance than what people were able to see with their naked eyes. I first learned the concept of inner beauty from relatives and my parents' adult friends, who worried that I would look down on myself for having only two digits on each limb. They used the topic of "aging" and "death" in their storylines to make their point. Some adults once said to me in Chinese, "everyone's the same, you're no different ... we will ALL end up with sagging skin when we age and die ... pay no attention to the fact that your hands and feet are different. Inner beauty is all that matters!" It always confused me, though; if inner beauty were really all that matters, why would people keep telling me, "at least you have a pretty face"? To this day, people attempt to "normalize" my hands and feet by not using the word disability. Instead, they invoke my inner beauty to justify and avoid my physical being in reality.

Amputees experience phantom pain after their limbs are amputated. Although my body never experienced an amputation, I have been diagnosed with terms such as

"congenital amputee," "missing fingers and toes," and "split hand/feet malformation." If four fingers and four toes are all that I have had since birth, why do people see them as residual fingers and toes? As people imagine the normative fingers and toes as my phantom limbs, the phrase "you're so pretty" became a synonym of people's unspoken, internal sorrow over my "incomplete" body. Each of the long sighs and sympathetic head shakes evokes the phantom pain for me, as does the occasional unsolicited prayers from Buddhists, Evangelical Christians, and Catholics. Such pain is not only induced by the existing cultural understanding of normalcy and the innate human desire for the idealized-but-unrealistic standard of beauty and perfection, but also by the ways in which meaning is attached to disabled people's bodies. "You're so pretty" is a stigmatized buzz phrase that has conditioned me to fear being beautiful.

Adults took my fight-or-flight response to people's staring and my own avoidance of "you're beautiful" as lack of self-confidence, as a sign of "you have not yet come to terms with your disability." It was only years later as an undergraduate student at the School of the Art Institute of Chicago, when I began making art about my hands and feet, that I began the process of revisiting my memories of being stared at, which brought up years of hidden fears and on-going, traumatic objectification. Then, I rediscovered the terror and vulnerability that I had had as a young girl when encountering people's negative, micro-aggressive reactions towards me. I was told to study hard and get an education to make up for my disability, so I would become a woman who was "qualified" to choose a boyfriend or a husband. I had always been taught to be brave and forgive nondisabled people's ignorance and reactions. I had to be willing to

"educate" strangers even if they were rude to me. These experiences preoccupied me and left me no time to search and develop who I was as a person.

The idea that "despite having only two fingers, I am still beautiful" is framed as evidence of my successful psychological adjustment to disability. It resonates as great inspirational material for sappy books like *Chicken Soup for the Soul*. However, as the years went by, the self-hypnosis of "I'm beautiful" never took away the cruel reality of constant objectification. There was no other example of how to be in a body that is different from most peoples in this world. Claiming "my disability is beautiful" became a mask that I saw successful, inspirational, and socially acceptable disabled people wear in public. Better yet, I learned that it was even better to accept disability by denying its existence. Somehow claiming "I am not disabled" at all became the ultimate goal for me and other disabled people.

# 4.3 **Professional Training in the Arts and Art Therapy**

I was scared of my peers in the fashion design department at the School of the Art Institute of Chicago in the early 2000s. They were known for their fashionable (a.k.a. snobbish) vibes back then. A faculty adviser once recommended that I major in fashion design after seeing my portfolio. The intimidation of being fashionable—in the sense of conforming to mainstream, materialistic beauty standards—pushed me away from applying to be a fashion design student. On top of that, my belief in the "inner beauty" mantra must have drilled itself into my head after hearing that inner beauty is all that matters for so many years. It made me think that my outer beauty didn't matter. Instead, I took classes in sculpture, fiber arts, art education, and eventually, art therapy.

Around 2000 in Chicago, I began making small wearable objects for my hands in metalworking and jewelry design classes long before I realized my connection to disability identity or community. Unbeknownst to me, making art in the sculpture department started a long process of self-discovery as it retrieved many of my unconscious memories of being a staree, a term I learned from disability studies scholar Rosemarie Garland-Thomson's book, Staring: How We Look (2009) to call the person on the receiving end of the stare. Garland-Thomson says that disabled people take a clerical approach to a staring encounter. In this encounter, such management skills shift the staring dynamics from aggression to an opportunity for starers and starees to understand each other differently. The way I managed staring often started with an intuitive instigation of the felt experiences of specific social interactions that I had had with others. I then turned those feelings into a design of wearable art. My process often took the following steps: when the memories of those interactions surfaced in my mind a collection of snapshots came to me, not only as visual images, but as emotions and physical sensations as well. I may not always have understood these psychological or biophysical reactions, but they would often lead me to specific materials or construction methods in art. The art making process would then elicit more childhood and young adult memories of being a staree.

For example, in response to a cashier who screamed hysterically at my hands in a store, I made armor in the piece "Blowfish" (2002) (Figure 5-6, Appendix A) for my hand with a felting wool and a sharp fish bone to explore my vulnerability and need for self-protection. As another example, a set of jewelry pieces, "Metamorphosis" (2001) (Figure 7, Appendix A), consisted of two butterflies, one with intricate wings with cracks

(as imperfections) to illustrate my exhaustion with the societal expectation of bravery.

The other wing featured a minimalist design which spoke to my desire to be seen simply as a person. Lastly, as a part of the "Metamorphosis," I made a silver cocoon to create a space to retreat to when too much bravery was expected of me by others. These memories provided the narratives that served as the basis for production of more wearable art about my hands and feet.

The more I made art about the social interactions I had with the public, the more I realized that I had always felt myself battling some strong, invisible, unknown force all alone. And there were no words to name the force. I only learned later in graduate school that this force could be described as disability oppression or ableism. I had not associated any of my experiences with the term disability before the age of 23.

Teachers and other adults sent mixed messages with their compliments and words of encouragement, including not to let my different hands (my disability) hold me back, and that my disability didn't matter anyway because they want me to stay strong. My peers saw me as someone who was brave, hardworking, and great at using my hands to make art. At that time, disability had only meant the inability to function. In my mind, I believed that I was definitely not disabled, because I was able to perform daily tasks independently, including using my two fingers to maneuver scissors and chopsticks as early as age four.

I was taught to see my fingers only as differences instead of as a disability. I knew the importance of having others believe in me, and I approached other disabled people's differences —disability— as something that was also unique and deserving of positive reinforcement. My belief was affirmed in a class during college called

"Exceptional Child, Exceptional Art," which was a special education class in art education class taught by an art therapist. The readings and class discussion emphasized that as therapists we should affirm each child's strengths and abilities by treating them as "special" and each of their artistic expressions as "unique." This course offered me tools to validate disabled children's special qualities and uniqueness as I was becoming a creative art educator.

However, these euphemistic and individualistic approaches to disability had their limitations within the art education curriculum and, later, in my practice as an art therapist. These approaches did not help me see my own or others' disabilities beyond a nondisabled viewer's perspectives, and they further reinforced overcoming narratives. This limited understanding, unfortunately, formed the basis behind an in-class disability simulation exercise meant to evoke empathy in my peers. Disability simulation exercises ask non-disabled participants to pretend to have an impairment by, for example, wearing a blindfold to experience blind people's lives or using a wheelchair while navigating an obstacle course to experience wheelchair users' lives. I was not aware of disability activist and scholarly critiques of such simulations as responsible for reinforcing the medical model. They argue that simulations individualize and depoliticize disability experiences. I had no concept of systematic ableism and its impact on students in special education. My nondisabled teachers and peers applauded me for braving through my own personal challenges as I talked about the importance of giving students with disabilities opportunities to show their capabilities. My position as a special education art teacher- in-training somehow earned me the privilege of being

considered someone who could serve as a role model that could "rescue" other disabled people: "she overcame her disability, and she will now HELP others."

#### 4.4 Making Connections to Disability Identity

In a one-semester long "Creative Process as Art Therapy" class, Dr. Pat Allen facilitated the "open studio process" (OSP). 12 OSP is a ritualized art-making method and process. The process includes beginning with everyone writing intentions for a session, then making art from a variety of supplies and materials provided by the facilitators, writing, reflections of the day's work, optional sharing of these reflections by reading them aloud, and listening to others read without making any comments. Even the session's therapist/facilitator is not allowed to comment. I found the "no comments" structure surprisingly freed up space to discover and connect to my experiences of disability discrimination and oppression. These two concepts were not explained to us in a lecture, nor did they show up in the class reading materials. Rather, they came to me through a series of intensive free-association sessions after I made art. OSP held a space for my teacher and classmates to witness the following experiences: memories of others telling me that my body is a shame, misfortune, mistake, and imperfection; memories of my 6<sup>th</sup> grade teacher gaslighting me by saying that I was paranoid about other kids' staring; and memories of the same teacher saying I should adopt children instead of passing defective genes to my offspring. These are just a few examples of such painful comments.

At the end of the semester, I had a deeply cathartic experience in the OSP studio art class that was both liberating and empowering. I learned art is a powerful medium

<sup>&</sup>lt;sup>12</sup> For more information on the Open Studio Process, see <a href="https://www.patballen.com/pages/process.html">https://www.patballen.com/pages/process.html</a>

for therapeutic self-expression. Making art helped me dialogue with my inner child and fostered strength to exercise self-healing. I wanted to model my teacher, Dr. Allen, by providing art making opportunities for others to deal with their life struggles. I finished my undergraduate degree from the School of the Art Institute in Chicago and stayed for the master's level training in art therapy program in 2003. At this point in my life, I was still estranged from my own disability identity and a disability community. Even though I did internships at mental health care sites that served patients with disabilities and mental illness, I still did not consider myself as one of them or as part of a disability community.

One afternoon, I was out for lunch with a group of clients who had intellectual and/or physical disabilities. I noticed that drivers and pedestrians watched the way we lined up and guided each other as we walked down the street. Upon entering a local restaurant, crowds of customers turned their heads and stared at us with open mouths full of food. I felt safe in a strange way as not "one of them" because my hands were less visible compared to my clients' more obvious impairments. A voice in my head said, "Oh, I hope that they (the driver, pedestrians and restaurant customers) know that I am one of the staff." A part of me was puzzled by this voice, and I questioned my own position as the "staff member," who was there to provide help and knowledge as a therapist—a nondisabled therapist. Another part of me felt ashamed when I realized that I was trying to distinguish myself from my disabled clients. I did not want to be associated as one of *them* in public.

In a class presentation on self-care, I revealed that I was struggling with a personal memory but was not able to make art about it. I ended up sharing a small

Tupperware container full of broken pieces of my disability ID card from Taiwan, which I had cut into pieces the night before. It was an old ID card, a card that had framed my very own existence as a disabled person sanctioned as such by doctors and the social welfare system. They confirmed that I indeed had limited function due to missing several fingers and toes. The ID card that had recorded years of embarrassment over my bodily difference was now in pieces. Following each cut, I was reminded of the many years in which I held it in my hand. This ID card forced me to display my hands in public when I purchased bus fare or made doctor's appointments. This card had outed me as disabled when gatekeepers, such as drivers, receptionists, and clerks questioned my eligibility. The card proved my disability status, and they would apologize profusely after they saw my fingers. "Sorry, sorry! But ... you can still do things, right?" they always asked.

I cried as I talked about the emotion stirred in me by cutting the ID card. I wanted my teachers and peers to see me as "just a person." I had learned about the social model of disability that considers barriers in the environment to be the actual problem of disability, instead of treating the individual as the problem. I had read a few articles and book chapters in disability studies—the academic discipline focusing on how meanings of disability are created within socio-political and cultural contexts. One of the texts I read was Simi Linton's *Claiming Disability: Knowledge and Identity* (1998). But I had yet to claim disability for myself; it was still an abstract, foreign concept to me. At that time, my nondisabled teachers taught me to use person-first language—a person with a disability—I was not yet comfortable describing myself as one. Instead, claiming that "I

am just a person," "I am a person with two fingers," and "I am a person with physical differences" seemed more affirming.

During this process, I was writing a master's thesis in which I examined staring dynamics when I attended an academic talk on eugenics by a University of Illinois at Chicago disability studies scholar, David Mitchell. The history of the eugenic movement devastated me. It felt as if some of the historical events happened to me personally, and I couldn't stop crying as I unleashed emotion in the back of the lecture hall. I was out of breath and my heart pounded as if I had run a marathon. I did not understand why I felt a strong connection to the way Mitchell talked about eugenics and disabled bodies through a humanities lens. I had unconsciously distanced myself from being seen as a disabled person. Now I began to feel a sense of belonging in the world of disability. It made me feel at home.

### 4.4.1 **Armed and Beautiful Series**

Around the same time, I stumbled upon a book that shook my world. It was a collection of creative writing, essays, and poems called, *Staring Back: The Disability Experience from the Inside Out* (1997), edited by a disabled writer, Kenny Fries. In the introduction, Fries describes his emotional and physical response to being stared at and non-disabled people's assumptions about disabled people. I was trembling, breathless, and in tears as I read the work in *Staring Back* because the authors' words described precisely the ways that others stared at me. "Wait a minute, that was me! How did he know?" I felt that someone finally saw and understood me. It also felt like I had discovered a lost family diary, an ancestral history I even didn't know I lost in the first place. Before then, I only learned about disability from the medicalized perspectives of

medicine, rehabilitation, social work, and art therapy. I also never really resonated with disabled authors that I read earlier who wrote about how they overcame life's challenges and succeeded with smiles and bravery.

For my art therapy thesis project in 2005, I designed and modeled body adornments in a series of photographs. This work was my way to revisit the specific social interactions that made me feel hurt, vulnerable, and disempowered about my womanhood, and to re-engage with them on my own terms. This series, titled "Armed and Beautiful," (Figure 8-10, Appendix A) consists of photographs of me modeling a pair of high heeled shoes with sharp horns, another form of protective armor, between my toes, which was exhibited at the Woman Made Gallery in Chicago. As an artist, I synthesize knowledge, experiences, and ideas through the art making process. The process of making "Armed and Beautiful" was my way of synthesizing what I learned, felt, and thought about "staring back" prompted by Kenny Fries' book.

#### 4.4.2 **Reclaiming Me**

Also in 2005, I created a photo documentary series called "Reclaiming Me" (Figure 11-14, Appendix A). For this series, I re-staged a visit I had when I was about 22 years old with a Taiwanese plastic surgeon whom I had seen to simply and safely get my ears pierced. At that visit, the surgeon advised me to have a surgery in which he would excise pieces of my pelvic bone for use in constructing thumbs. The series had four major black-and-white shots (taken by Taiwanese photographer Cheng-Chang Kuo) in which I dramatized that day's interactions with the surgeon. In the first image, the masked surgeon is examining my hands which were covered in a pair of fingerless gloves ("hand scrubs") whose design I created to be reminiscent of surgical scrubs. My

back is to the viewer, exposed in my underwear as the hospital gown gapes open. The second is a close up of the surgeon examining my hands in the hand scrubs. In the third, the surgeon's back is to the counter prepping for a procedure, while I look at myself in a hand-held mirror, as if questioning whether I really needed to change my body (my impairments). And in the fourth, I leave the doctor gazing into the pair of empty hand scrubs with a tweezer, while I cross my arms and stare into the camera, claiming ownership of my body and refusal to become normalized.

#### 4.4.3 **Project ImPerfect Exhibition**

I extended the theme of self-reclamation from these two 2005 works in my first solo exhibition in 2006 at Gallery 901 (Figure 15, Appendix A) in Evanston, Illinois. Titled "Project ImPerfect," it featured several baby onesies (Figure 16, Appendix A) that I altered to have various sleeve lengths and that I had printed with images of multiple, diverse hand and foot shapes. In addition, I made several gloves to fit children with non-normative hands. "Project ImPerfect" played with the wording of "imperfect" and "I'm perfect." Growing up, people described my body as "imperfect." This project made a rebellious statement against these negative labels ascribed to my body. The claim of "I'm perfect" was liberating. I thought I was performing self-care by cutting up my disability identification card and claiming a perfectly imperfect personhood. The art therapy community provided me strong support and empathy in the process of my liberation. Even though I don't see this process as having been liberating now, I am still grateful for having the opportunity to engage in such a cathartic experience. Looking back now, I understand that my internalized oppression and my limited view of disability

remained unchallenged. In other people's eyes, I was praised as a brave young woman who found power in art to heal herself.

As I began to unravel those memories through wearable art tailored to my specific physicality in the context of the interactions, I saw that the puzzle pieces of societal, cultural, and political meanings attributed to my female body marked by a hereditary physical difference were beginning to form a picture. Art therapists believe that metaphor in art connects to the deep unconsciousness, and that the use of these metaphors can enable individuals to explore, express, and potentially find solutions to their personal struggles. Was cutting my disability identification card into pieces a metaphorical gesture of cutting off ties with my disability? Did it work? If I had successfully embraced myself as "just a person" or as "a person with some physical differences," shouldn't I have felt a sense of relief? Why was I, instead, emotionally exhausted? Why did attending an academic talk and reading essays by disabled people make me cry like a hurricane. I couldn't understand why these unsettling questions lingered nor how they originated.

The year 2006 was a profoundly formative one for me as it was also when I attended Chicago's Bodies of Work Festival of Disability Art and Culture, where I finally began to find answers to my questions. This festival showcased visual art, performance, and spoken word centered on the disability experience from an insiders' perspectives. I was one of the artists in the show "Humans Being" at the Chicago Cultural Center, but I hadn't yet had much of an opportunity to get to know the other artists in the Chicago disability culture community whose work was also exhibited. After attending panels and discussions of disabled artists and scholars, I began to realize that my thinking about

disability had been shaped by a culture of ableism. Ableism is a term that describes the discrimination, prejudice, and bias against people who do not fit normative expectations of physicality, mental state, or cognitive ability. I stopped thinking that my disability itself was my problem alone, but that the problem of disability was a systemic and culture one.

#### 4.5 Coming Out as Disabled

At the Bodies of Work festival my perspective on disability drastically changed from being defiant about what I was not to claiming who I was on my own terms. What I had read in Claiming Disability and Staring Back now all sunk in. The festival celebrated disability with pride, authority, and creativity. A few months later, I attended my first disability culture retreat at the Leaven Center in Michigan facilitated by the disability rights activist/artists Mike Ervin and Rahnee Patrick. I roomed, cooked, and dined with other disabled people. I even worked as a personal assistant for fellow disabled attendees. It was a series of intimate awakenings. For the very first time, I named and claimed disability on my own terms. Rahnee asked me to accompany a blind woman, Jackie, on a tour of the retreat center. It was my first time interacting with and lending my elbow to a blind woman. After a few rounds of casual chat, Jackie asked, "So, what brought you here? What's your disability?" What was my disability? Oh, boy, that was THE question. I paused for a few seconds and said simply, "I have two fingers and toes." I surprised myself by how okay I felt naming my two fingers and toes as my disability for the first time.

I came out disabled after meeting other disabled people who were artists, activists, and scholars from the disability culture world. Particularly, disabled people's

artwork and political statements turned my world upside down. I discovered that I was not alone in making art about myself. Attending my first Society of Disability Studies (SDS) conference in 2006, where I met a conference full of activists and scholars who had various impairments, was another wave of awakening. The way they created their own meanings of disability validated my experience. I did not understand all of the academic language, but something about their approach to disability electrified me. It was like a really good shock therapy session! I realized that I always thought I was less intelligent or weaker than others because of my sensitivity towards the ways they had reacted to my disability. I thought my sensitivity was a sign of weakness. I thought, "Wow, those disabled scholars actually wrote about my (or rather, our) experiences in academic books... now, I can finally say that I was not just being sensitive or just imagining the oppression I experienced. My experiences are very real, and they are worthy of scholars' attention and teaching!" I was thrilled and hungry for the disability studies' wealth of knowledge that I hadn't had access to before.

Meeting politicized disabled artists who had reclaimed disability as an identity made me feel home, a home I didn't even know I had always longed for. I realized that I had spent my life constantly proving my abilities to people who had doubted or pitied me; I always had to attend to their feelings about me. Now, I had just met this group of disabled people, and I already felt that they knew me. I did not have to explain myself; they already knew what I had gone through; they'd "gotten" me. It was an emotional rebirth when I found a community of disabled people who were to become my chosen family. I felt joy but also tremendous anger about how I was conditioned to believe in nondisabled values and standards, which had shamed me. I felt that I had lived in

another version of *The Truman Show*, and just woke up from a made-up, ableist world and discovered a real one that contained the truth about disability, disability identity, and disability culture.

## 4.6 Crossing Borders: Multiple Margins and Multiple Identities

Growing up in Taiwan, I was taught to be brave and avoid being "the disabled person". I learned to conform to the norm. My path of "crossing borders" literally took place when I came to the United States in 1997 as a high school exchange student in rural southern Indiana. People did not know anything about my country or my culture. I had to be an ambassador and an advocate not only for who I was but where I was coming from. I was relieved that people rarely asked about my fingers and toes. Instead, they asked questions about my race and ethnicity, and they were confused about where Taiwan was. In Japan? Or they asked me if I was from Thailand. Some even thought that Taiwan and Thailand were the same country. A few people did ask about my disability. They would start by asking, "Do you mind if I ask you a question?" It was empowering that people sought my permission before asking. I had crossed an international boundary and, in the process, learned about personal boundaries as well. I could reply with a "no" to people who were rude to me in English. I then began to cross borders in my artistic practice. My art training since I was young had been focused on skill-based representations, even though making art from my imagination had been more appealing than demonstrating still-life drawing skills. I realized that the discipline of my traditional art training had been another way I learned to conform to normalcy. I was expected to create art that was as good as everyone else's, art that would not reveal my "birth defect." Studying at one of the top art schools in the States, where

conceptual art and personal style are valued, forced me to see that I don't have to be like everyone else. I needed to find my own artistic style. Being an artist meant that people paid attention to my work and world perspective and not just my disability, race, or ethnicity. I found it refreshing that people did not focus on what was "wrong" about my impairment or where I was from. I took pride in being recognized as an artist by name, rather than as the Taiwanese girl who had birth defects. At this stage, it became clear to me that my disability was part of my work, but I was not yet politicized enough to articulate my experience or to connect it to disability.

I took pride in expanding my artist identity to include being an art therapist who could support other people's personal expression and struggles through art. I was sailing smoothly on a career path. I was considered someone who broke through barriers, and now I was even able to help others. As a freshly minted art therapist, I was enthusiastic about spreading the power of art through the gospel of art therapy soon after graduation. My ideal world would quickly shatter, though, after having attended a few disability culture panel discussions in which disabled artist-activists expressed intense anger towards art therapy. They were offended by the assumption that disabled artists' work was not art, but the unfiltered product of art therapy treatments. I had been on the verge of coming out as a disabled person and now I was questioning every aspect of my belief system. I sat in shock as I listened and absorbed disabled activists' charge that art therapy, which I had been taught was a creative, loving, and nurturing helping profession—was oppressive. I was flustered and wondered, "Have I just become a part of the problem when I naïvely thought I was joining the solution?" Things only began to make sense when I came out as a disabled person during the festival and the retreat. I never in a million years would have thought of disability as an art, style, and identity, a home that I was always destined to own. My rebirth as a disabled woman artist finally completed me.

I returned to Taiwan shortly after I came out as disabled. I thought that after years of searching for who I was, I was finally heading back to my motherland with a sense of wholeness. My body was not a defect, and it was not missing anything! I had a solid disability identity. However, I did not anticipate experiencing culture shock when I returned to Taiwan, where disability was still largely seen as a medical problem and my hereditary disability was a curse and bad karma. When I presented my work as an artist and an art therapist in Taiwan, audience questions turned the focus from my work and instead asked personal questions about my impairments. Additionally, they marveled that my politicized disability identity was now something to marvel at. "Wow, you don't look down on yourself. You're so optimistic, like the Americans!" My newly acquired view of disability was seen as naïve or "out of touch" with reality. Many Taiwanese disabled and nondisabled people thought my approach of taking pride as a disabled person was a result of not being disabled enough. "Crossing borders" this time meant that I was considered a foreigner in my own motherland because of the way I now thought about disability.

While working as an art therapist in Taiwan, trying to use art as therapy and personal expression, people within the disability rights community questioned my priorities. They thought I should be focusing on more pressing issues like they were, issues such as accessible housing, public transportation, and employment. Soon I found that the Taiwanese disability community considered art a luxury for the rich or

fodder for talent shows. The artwork and performances of disabled people were supposed to demonstrate their bravery for overcoming all obstacles. As I struggled to fit back into Taiwanese society, I did not have the language for what art as activism could mean. I became discouraged about using art as therapy or personal expression for other disabled people. I realized that my engagement with the disability community needed a different form and purpose. I began organizing disability-related meetings and informal gatherings. I stopped seeing myself as an art therapist; rather, I began to see myself as an organizer in the disability activist community.

I was hungry to learn more about disability studies and the disability culture community. I would often recite passages about disability identity from Simi Linton's Claiming Disability when I felt defeated. I began experiencing panic attacks and symptoms of depression when I was trying to readjust to Taiwanese culture, its language of expression, and customs. My outspokenness about disability as a 25-yearold woman was not well received, especially by men who had seniority at governmental and nonprofit social-welfare organizations. I felt hopeless about the entrenched hierarchical structure, which set up ever changing, unequal power positions based on age, gender, education level, and class. I felt helpless to intervene. I did recognize, though, that my class privilege had granted me educational opportunities in the arts and disability culture in the States, and that privilege had enabled me to re-examine disability and identity. I wondered how best to leverage these privileges to help change the stifling hierarchies of Taiwanese society. How could I make an impact as a young disabled woman? Where were my disability activist comrades and allies? Was I doing anyone any good if my own mental health was falling apart?

After spending three years in Taiwan, I applied to and was accepted by the Master of Fine Arts program at the University of California, Berkeley, I began studying with a highly regarded disabled painter and activist, Katherine Sherwood, in 2009. During the MFA program, I was exposed to grassroots activism in the San Francisco Bay area, which is well-known for its strong disability activist community and leadership. By serendipity, I connected with the national disability rights organization ADAPT. I started attending disability rights rallies, protests, and sit-ins. It was then that I transitioned my art practice from a tool to reclaim my body as beautiful to a tool for making meaning about shared disability experiences. I started making art with, for, and about fellow disabled women artists. I became more and more aware of the disability communities' growing collective consciousness. During that time, I got to know Black disabled activist Leroy Moore and disabled artist Sunaura (Sunny) Taylor, who were using "Krip" and "Crip" respectively to describe their identities and their affiliations with disability culture and their art. I began to identify as a Crip myself. They were my Crip artist role models who helped me to formulate my identity as a Crip artist. I eventually formed bonds of what I came to consider as Crip siblinghood with Leroy, Sunny and the politicized disability community. Crossing borders now meant to me what it means now: an expansion of my identity from being a disabled artist to being a disabled artistactivist. At this point, I let go of my art therapist identity for what I thought were all the right reasons.

In 2010, I reached out to scholars in disability studies and expressed my interest in pursuing a PhD in disability studies. The responses I received included: "disability studies is academic work, not art," or, "You should just make art and leave writing to the

scholars." I wondered whether art practice might be considered a form of scholarship. Could making art about disability be more than self-expression? Could it be a form of disability studies research? I carried my bewilderment until I met professors Carrie Sandahl and Ann Fox, along with a small group of scholars whose practice centered on disability studies in the arts and humanities. Seeing the way they theorized both art and live performances from a disability studies perspective motivated me to consider blending my creative work with disability studies as a form of research. In 2011, I joined the PhD program in disability studies at the University of Illinois at Chicago (UIC) in Carrie Sandahl's Program on Disability Art, Culture, and Humanities.

As an artist and doctoral student, my practice is further enriched by working as an arts administrator for Bodies of Work, which is an arts organization that is devoted to the support and development of disability art and culture at UIC. Working with fellow disabled artists in association with Bodies of Work—the same organization that had brought me to disability identity and activism in 2006—has bolstered my confidence in creating disability visibility in the art world, the disability rights community, and academia. In addition, I have continued to organize forums on disability, activism, arts, and culture in the States and internationally. Crossing borders now takes place in my roles speaking about disabled people's art as a professional arts curator and programmer both in the States and Taiwan. I no longer speak of disability art as an individual, rather, as someone who facilitates dialogue about accessibility, arts policies, and disability representations between artists, community members, and the general public. As I examine and re-examine my multiple identities in this dissertation, I am aware of my own perplexing relationship to my art therapy training and practice. I

thought that I had left art therapy as I moved to my new roles, but instead I eventually transformed what I think art therapy could be, Crip Couture, as I've transformed myself.

This dissertation theorizes and manifests these transformations.

## 4.7 **Crip Healing**

Art therapy is accustomed to approaching disability from a medical model perspective. Therapy is by definition and purpose an intervention to treat, cure, or manage disability and illness. When I was in graduate school back in 2005, social action art therapy—expanding art therapy from the clinical counseling room to community spaces—was emerging. Working with disability activists in Taiwan made me see that making art about an individual's feelings in community settings was not all that social action-based art therapy could be. Art making does bring therapeutic effects to its participants whether intended to be formal therapy or not. Thinking only about art therapy in this limited way, though, runs the risk of simplifying and generalizing disabled people's reality as solely consumed by efforts to overcome the challenges disability presents, which Chapter 4 goes into with more detail. I have been exploring the tensions that I experienced as an art therapist who is herself disabled by crossing art therapy's boundaries—its assumptions, foundations, and approaches—as a means of providing culturally appropriate care to disabled people.

As I continue making and exhibiting art while studying in the PhD program in disability studies, my artist-scholar-activist identity has gradually surfaced. Many people, both disabled and nondisabled, shared with me what resonates with them in my work: issues regarding the body, beauty, staring, illness, identity, care giving and receiving, among others. Sometimes a conversation about a memory or trauma will take place

right in the gallery. Sometimes people reveal their disability or illness to me and realize that they had never spoken about it before. My role as an artist-activist is enriched by using the empathic listening skills I learned in my art therapy training. I also see my roles as just being a fellow disabled person, an equal peer seeking connection and holding space for my Crip siblings.

What propels others to disclose their personal (and sometimes graphic) experiences of disability and illness after seeing my work in a gallery or hearing me speak? Do the displays of body adornments made for the disabled bodies affect both their wearers and viewers by moving them to connect? I think it does. The feminist disability studies scholar Alison Kafer signed a copy of her book for me by writing, "Thank you for making beautiful art that hurts and heals my heart in all the right ways." Performance artist Tekki Lomnicki, who uses theater to talk about her experiences of dwarfism, wrote, "Your art heals me!" in an exhibition guest book. These two Crip sisters both used the word "heal" independent of one another to describe what my art offered them. Why does the healing that Kafer and Lomnicki describe seem different from medicine and art therapy's definition of the same word? If making wearable art about disability is a way to document the wearer's lived experience, can the archival process be a politically therapeutic process for creating meaning and action about disability at a collective level?

To answer these questions, I discovered a parallel between the formation of my Crip identity (from rejection to integration) and the formation of my professional identity as an art therapist: I had to abandon practicing as an art therapist for many years. As I examine my own rejection and embarrassment of art therapy as a profession, I realize

that my own disappointment and frustration came not necessarily from art therapy's focus on healing, but instead from how the medical model's inherent ableism impacted the way in which art therapy positions define and teach about disability. In carrying many of my in-between identities forward, I have come to see my work as "Cripping" art therapy. Cripping, used as a verb, was coined by Carrie Sandahl, as a means of critiquing mainstream representation and practices to expose the ableism of their foundations. As I reflect on my artist residency at Access Living, I have come to realize that Cripping healing can be a means of ridding ourselves of the unrealistic expectation of normalcy. To Crip healing in art therapy can be more than healing disabled people from impairment itself. A Crip healing offers an alternative that grows, validates, and dignifies the collective disability experience. Crip healing is an underlying concept of Crip Couture. The integration of Crip healing in art therapy practice can start with community art workshops on themes of disability culture and self-representation (Chapter 6). While working on this dissertation and crafting the new meanings of selfcare (Chapter 7), I decided to start centralizing Crip healing (though I did not have a term for it yet) in my formulation of Crip Couture as homemade theory and practice. Crip healing provides a sustainable, disability culture-focused practice for mental health care providers and consumers now and in the future. I want to direct my work as an artist-activist-academic toward the disability community's mental health, which is more important than ever as we face great threats from the current pandemic and political environment. Might Crip Couture, as an aspirational theory and concrete practice, hold space and enact techniques for our resistance to and our liberation from ableism? Could Crip Couture be a way of creating a new aesthetic within the disability art

movement? Could it transform art therapy from an individual medicalized experience to collective healing and community building? Could it be a genre that questions the canon of art history?

#### 5. CRIP COUTURE MANIFESTO

This chapter is an extended version of the following two published works:

Yi, Chun-shan (Sandie). "Skinny." CPSA Quarterly (The Center for Sustainable Practice in the Arts), 2017, pp. 48–51. (Please see Appendix B for publisher permission.)

Yi, Chun-shan (Sandie). "The Crip Couture Manifesto." Wordgathering: A Journal of Disability Poetry and Literature, vol. 14, no. 4, Dec. 2020, doi:https://wordgathering.com/vol14/issue4/disability-futures/yi/. (Please see Appendix C for publisher's copyright statement.)

## 5.1 **Introduction**

Artists explore and define boundaries. Artists investigate and search for meaning through materials, space, and time. Artists document the past and present; artists also create, imagine, and envision the future. As a disabled woman artist of color who uses wearable art to articulate new meanings of disability, my creative research is an example of homemade theory (Morale, *Certified Organic Intellectual*) and complex embodiment (Siebers, *Disability Aesthetics*). I name my practice *Crip Couture*, a relational form of community building and a Crip-specific artmaking process. I create my work based on the lived experiences of disability, and I document relationships and interconnectedness between disabled people. My Crip-specific artmaking process shares resonance with Mia Mingus' concept of access intimacy ("Access Intimacy, Interdependence"; "Access Intimacy: The Missing Link"; "Forced Intimacy"). To illustrate how my research process engages with these theories, I present the Crip Couture

creative work and the philosophy behind this dissertation. Crip Couture Manifesto states how my practice is a manifestation of Crip desire (the power of the erotic) and Crip identity (affiliation and a sense of belonging to disability community) and how they cultivate not just my own positionality as a disabled artist-scholar but also provide a platform for building a Crip Culture community for and with other disabled people.

To give a concrete example of how I utilize Crip Couture Manifesto as a creative research process, I will present two artworks, *Skinny* and *Hairy Undies* and show how Crip Couture Manifesto works in action. I argue that Crip specificity (centering disabled people's lived experiences), Crip relationality (connections between disabled people), and Crip healing (rescripting the meaning of "healing" based on Crip specificity) are essential components of Crip collective care (caring for and supporting fellow disabled people). I also argue that the versatile practice of the Crip Couture Manifesto can offer ideas and directions for researchers, artists, art therapists, activists, and cultural workers to apply aspects of Crip Couture in their work.

## 5.2 Crip Desire: the Power of the Erotic in Disability Community Activism

Ableism infiltrates every aspect of our lives in society. It shapes our understanding of human relationships and constructs our everyday life experiences. Ableism also informs the choices we make as artists, whose artistic expressions, tastes, and sources of references are situated and acquired from specific social and cultural contexts. As an artist who was isolated from the larger disability culture community until age 25, my internalized ableism shamed me and kept me away from associating with disability. Right before I came out as a disabled person, while working in a hospital as an art therapist from 2005-2006, I was making a project titled "Project ImPerfect", a

series of baby onesies for children born with limb differences. "Project ImPerfect" was my first solo art exhibition held at Gallery 901 (Figure 12, Appendix A), "a gallery that present exhibits of artists and groups that celebrate the power of the creative process and encourages positive social change," in Evanston, Illinois (Home - Open Studio Project - Non-Profit Arts Organization in Illinois.). My disability consciousness-raising work only began after meeting a group of disabled artists and disability studies scholars at Bodies of Work, a disability art and culture festival in Chicago in 2006. My artwork began expanding from creating narratives of my own impairment experience to narratives of fellow disabled people and our shared disability living history. At the same time, my passion for disability rights activism grew.

## 5.2.1 **Project ImPerfect and Kinship**

I described my practice then as "finding my own kind (of babies)." The desire to collect the hand and feet shapes of other people with limb differences and print them on fabric to produce the one-of-a-kind baby onesies in a gallery exhibition was a way to say, "I exist, you exist, we exist. I see you and I want you to feel welcomed since birth." Alison Kafer's 2019 article, *Crip Kin, Manifesting,* discusses several artworks of mine along with two other disabled artists. Kafer builds her work on scholars who consider "kin" beyond the biological, reproductive, and legal terms. Kafer describes my work as follows:

Through Project ImPerfect, she offers workshops where attendees can trace their hands, fingers, feet, and toes onto fabric, resulting in bright patterns of diverse bodily formations. Although participants are allowed to take some of the fabric home, Yi uses the rest to create clothes for babies as yet unknown, without

regard to the presence of genetic or legal bonds. In sharp contrast to ableist assumptions that disabled babies can only be met with disappointment, Yi's workshops anticipate, prepare for, and welcome their arrival, both real and imagined. If, as Rayna Rapp and Faye Ginsburg (2011) suggest, disability can be the catalyst for new kinship imaginaries, Yi extends such formations, queerly calling new kin into being. (3)

Kafer's use of Crip kinship solidifies what "finding my own kind" has meant for me all these years. For a long time, I had no language to describe this newly found, strong desire to connect to other disabled people and their experiences. The Black feminist writer Audre Lorde's work on the power of the erotic helped me find words to name my desire. Lorde describes the erotic as a creative source and energy of the oppressed which often manifests itself as an unexpressed and unrecognized feeling (53). I would add, such feelings can often remain unnamed because of living in isolation and internalized oppression. In order to create positive change, Lorde believes that we need to use the power of the erotic to deconstruct and corrupt various powers in the culture that produce oppression.

#### 5.2.2 **Cripping Fashion**

Following Lorde's work, I define Crip erotic as disabled people's instinctual feelings and perspectives generated from living in an ableist world. This erotic energy requires conservation and re-generation. The Crip collective erotic power forms when disabled people engage with their crip wisdom alongside other disabled people. The term Crip, short for Cripple, a once derogatory term for naming disabled people, has been reclaimed by many politicized disabled people (Sandahl, Queering the Crip 27).

Crip erotic therefore is activated and recognized when disabled people become politicized. The Crip collective erotic power in the Crip Couture Manifesto addresses ableism by naming its connections to Haute Couture: Crip Couture is the disability culture version of Haute Couture, high fashion. Disability culture's high fashion production is one of a kind and limited editions (much like the baby onesies I made for Project ImPerfect, Figure 16, Appendix A). Haute Couture has a history of being class exclusive and expensive. Crip Couture also has an exclusive nature, its "clientele" is disabled people only, but its wearable art and body adornments have no price tag. Haute Couture originally came from an ableist, sexist, white elite business operation. Crip Couture roots itself in disabled people's desire, healing, community ties, and activism. Haute Couture's creations are luxury designer items. Haute Couture wearers' physicality and body shapes conform to beauty standards for the pleasure of the male gaze. In contrast, Crip Couture creates work for disabled people's pleasure: wearable art as objects made to serve as adornments, assistive aids, protections, armor, archive, and interlocutor of disability experiences.

#### 5.2.3 **Complex Embodiment**

In Crip Couture Manifesto, Crip Couture's creations are based on the agenda and issues identified by people who are Sick (chronically ill), Mad, Autistic, Disabled, and Deaf, (S.M.A.D.D.) who are from a diverse range of race, class, and gender identity expressions. S.M.A.D.D. people may participate in Crip Couture projects as models or collaborators. They are welcome to define their roles and level of involvement, including, but not limited to, the role of a narrative-based content provider, consultant, or receiver of personal care support. The disability studies scholar Tobin Siebers argues

that the rich, intersectional, lived experience of impairment, bodily configuration, and sensation is a form of theory making (*Disability Aesthetics* 14). Siebers argues that such complex embodiment produces knowledge and materials that can further generate direct political action for making changes (22-33). Crip Couture makers are not expected to have professional training in fashion design or dressmaking or any type of formal art education. Makers may or may not have a background in fine arts. What Crip Couture values is how the makers' lived experiences nurture their creative DIY skills in making wearable objects.

"Knowing-making" (Hamraie, "Building Access" 99) which discusses how knowledge is produced from lived experiences is the key for Crip Couture makers. Crip Couture makers' physical impairments bring specific sets of tools and skills into the making, which is absent in Haute Couture and the larger fashion industry. In the world of Crip Couture, the makers' impairments naturally determine the construction methods and the aesthetic choices made for the wearable art. The way that the makers choose to handle tools, materials, and sewing machines are not "adapting" able-bodied makers' procedures or methods. Their use of assistive aids or personal assistants is not meant to "compensate" for their impairment. Rather, the use of assistive aids is a deliberate innovation choice and a way to exercise interdependency. Such "Crip touch" serves as an artist's signature and style. These Crip Couture skills are a form of what feminist disability studies scholar Aimi Hamraie calls "crip technoscience," which refers to disabled people's everyday-skill, knowledge, and expertise from living and surviving in an ableist world (Building Access; "Cripping"). Crip Couture is a resistance against the ableist desire to erase disability.

Crip Couture recognizes that to be able to participate in disability consciousraising work and to be informed by disability studies concepts and disability identity are
forms of access privileges. Such access privileges are not always readily available to all
S.M.A.D.D. Many people cannot afford to claim this identity due to stigma and lack of
resources. While Crip Couture is a practice that seeks S.M.A.D.D. participants, Crip
Couture also creates room for people who may not have access to disability identity or
connect to a disability art and activist community. Crip Couture aims to hold a space for
people who may come out Crip during their involvement with Crip Couture projects and
even those who are exploring their affiliations to the disability community and disability
identity.

During an artist residency I completed at Access Living between 2013-2016, I worked with young students with disabilities in special education settings. These students went to Access Living, an independent living center for people with disabilities, to learn about disability rights history and to participate in a disability art in-house collection tour. They first saw the Project ImPerfect onesies and photographic images of me wearing crochet gloves alongside other disabled artists' artwork. Then they joined me for a series of creative art workshops. This experience offered concrete examples of disability history and culture and concepts of disability identity which are not yet included in the public-school curriculum. Visiting disabled artists' work and interacting with politicized disabled artists can foster a sense of validation and teach this history and culture. It helps students with disabilities open up conversations about their disability from a creative angle. In Chapter 6, I further discuss this disability community art workshop designed for Chicago public school special education students.

## 5.3 <u>Crip Couture Manifesto as a Creative Research Process and a Homemade</u> Theory

As I have argued, Crip Couture echoes what the disabled, chronically ill, feminist writer Aurora Levins Morales calls "homemade theory" (*Certified Organic Intellectual*). Morales explains how homemade theory develops:

My thinking grew directly out of listening to my own discomforts, finding out who shared them, who validated them, and in exchanging stories about common experiences, finding patterns, systems, explanations of how and why things happened. This is the central process of consciousness raising, of collective testimonio. This is how homemade theory happens. (Morales, *Certified Organic Intellectual* 27)

In Crip Couture, my homemade theory grew out of the interconnectedness and relationships between disabled people. I name this connection Crip Relationality, which is a form of "access intimacy" (Mingus, "Access Intimacy, Interdependence"). Mia Mingus describes access intimacy as an "elusive, hard to describe feeling when someone else 'gets' your access needs." In what follows I explore the following questions: How does Crip Couture enact what Mingus lays out for us when it comes to using creative art to build a community? What does an access intimacy-focused, collaborative, accessible art making process with other disabled people look like? How does Crip Couture operate as an instigator for challenging ableist-based practices in the arts and in social relationships through its critical production processes and aesthetic choices? To respond to these questions, I will now provide two project examples.

## 5.3.1 Creative Project Example: Skinny

Making art about and from Crip bodies has always been an urge to not only explore the meaning of our existence—and social relationships with others—but is also a deliberate choice for constructing visual and tactile language to document disability as a cultural phenomenon and familial history. *Skinny* is a project that reflects an interdependent care relationship I share with my collaborator, Rahnee Patrick, a fellow disabled woman activist.

Rahnee and I are sisters, not by blood, but by our connections to disability. Our contractured fingers and toes, and our Asian blood, make us sisters: Rahnee is half Thai and half white; I am Taiwanese. Rahnee has psoriasis and I was born with two fingers and toes. Rahnee's skin grows a hundred times faster than usual. As a personal assistant, I help Rahnee with personal hygiene, including showering, applying lotions, massaging her skin and dressing. Sometimes I use my fingertips to peel off the excessive skin to relieve Rahnee from her swelling and inflammation. I often feel the body fluid rushing out of her skin between my nails and fingertips, then I massage her skin 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. It always feels like I am making sculptural art with Rahnee's body: our conversation—a language through strokes of the hand—becomes a part of the stories woven and shared by each other.

At the end of each "hygiene-care art" session, I sweep the skin flakes off the bed sheet and onto the floor and form mounds of them before tossing them into the trash bin. Most of us are taught to see disability as something negative, debilitating, weak,

incapable, or vulnerable. It is something that people try to get rid of. Peeling and tossing away Rahnee's skin are actions of relieving her from pain and itch, but are they also metaphors of getting rid of her disability? What does it mean to remove traces of her disabled body? If her skin flakes are evidence of her existence, what does it say about the gesture of throwing a piece of her away? While I contemplated the questions above, I decided to turn to sewing and made fabric pods to hold pieces of Rahnee's skin (Figure 17, Appendix A).

In Skinny, I explore the meaning of access intimacy through this on-going carerelationship, conversation, and sewing project that started in 2014 (Figure 18, Appendix A). Crip Couture, as exemplified by Skinny, enacts what Mingus lays out for us by holding a physical and emotional space for disabled people to be with each other and to take up the space that our bodies need without the expectation of having to justify why. Crip community is formed as we "get" each other's access needs. Disability shapes the way we interact with one another; Crip Couture reformulates the way people relate to another human being which is rare in the non-disabled world. As a Crip artist of color, having a disability and providing care to and making art about another disabled sister is about creating intimacy and Crip sisterhood. Most importantly, it is about preserving and sustaining the existence of my own kind. In alignment with Crip Couture's commitment to mutual care, disability community building, and healing, we support each other with the intimate, loving power of the Crip erotic through friendship and private rituals of bodily care as our homemade theory. The production processes of Skinny captures the hard to describe feelings of access intimacy visually and haptically.

Skinny follows the production and aesthetic decision-making process stated in the Crip Couture Manifesto, which says: Crip Couture is a tailor-made process. Like Haute Couture, which takes a large team of people executing intensive labor needle work, Crip Couture is labor intensive, both physical and emotional labor. Crip Couture makers follow Crip time: the design ideas do not arrive based on the production speed required by capitalism. Crip Couture's production processes are creative and relational (intrapersonal and interpersonal) engagements, starting from initiating ideas, to crafting plans, to choosing material, to method, and to the final presentation. The conception for each Crip Couture piece only arrives when the makers bend time to their own and each other's physical, mental, emotional, psychological, and spiritual locations, and states of mind. For example, I planned on making Skinny into a piece of wearable art, but as more fabric pods were made, I re-examined the purpose of sewing them into a piece of body adornment for Rahnee to wear. I decided that the absence of the wearer, Rahnee, would create a dialogue to add to the history of the cabinet of curiosity, which displays disabled people and their impairments as specimens. By reframing the purpose of displaying disability, the preservation of the skin flakes become traces, evidence of disabled people's presence. The ambiguity of the relic-like objects leaves room for imagination and self-projection, and perhaps a space for contemplation.

Skinny has been featured in the following art exhibitions: Transforming

Community: Access, Community Art, Disability, Diversity, Ecology and Spirituality

(Westbeth Gallery, NYC, 2015), MAAT 30th Anniversary Celebration Exhibition (The

LeRoy Neiman Center, The School of the Art Institute of Chicago, Chicago, 2015) and

Process and Presence: Contemporary Disability Sculpture (Frederik Meijer Gardens &

Sculpture Park, Grand Rapids, Michigan, 2018). *Skinny* and *Hairy Undies* were chosen by a jury to receive the Wynn Newhouse Award in 2019 and were exhibited at that year's *Wynn Newhouse Award Exhibition* held in the Palitz Gallery in New York City. *Skinny* and *Hairy Undies* can be seen on the Wynn Newhouse Foundation website. <sup>13</sup> These exhibits were the cumulative work of my creative research and practice as an artist-researcher. I will be editing this chapter into 7000 words and will submit it to the *Journal of Literary & Cultural Disability Studies*, which is a journal published by the Liverpool University Press.

#### 5.3.2 Creative Project Example: Hairy Undies

In the past eight years, I experienced post-traumatic stress disorder and used art and writing to process my experiences. *Hairy Undies* came out of this process. It is a "call for help" art project in which I explore the trauma I experienced at the hands of my former intimate partner. I sent by US mail an artist book (Figure 19-20, Appendix A) detailing my account of domestic violence to a selective group of people whom I consider my chosen Crip family. I asked them to respond by following an instructional letter, which stated responses could be in text and/or donated hair (Figure 21, Appendix A). Without sketching out what the wearable designs would look like, I first sorted through the texts and hair I received in the mail. I glided my fingers on the written texts even though the pen strokes may not be pronounced at all. I carefully took the hairs out of the bags, some with a few strands, some with a full bag. I then used the materials that people offered me to create two sets of undies made with thin stretchy fabric. While my Crip family gave me their stories and their hair, there is no identifying information in

<sup>&</sup>lt;sup>13</sup> Images of *Skinny* and *Hairy Undies* can be found on Wynn New House Foundation website <a href="https://www.wnewhouseawards.com/sandieyi.html">https://www.wnewhouseawards.com/sandieyi.html</a>

the final product, and I frame it as autobiographical. For me, these undies represent safety and are a kind of protective gear (Figure 22-23, Appendix A). The final artwork consists of the undies themselves and a photo portrait of me modelling them. As I finish this dissertation, *Hairy Undies* remains an on-going project.

### 5.4 Crip Specificity, Crip relationality & Crip Healing

The process of making Skinny and Hairy Undies, the art objects themselves, and their display are grounded in Crip relationality, a dynamic, interactive physical and emotional connection about the felt bodily experiences shared among disabled people. The Crip Couture Manifesto states that the artistic choices, such as patterns, colors, shapes, dimensions, textures, temperature of the materials, and construction methods used to create the wearable art, all reflect the density and felt feeling of the wearer's personal narratives and the maker's relational responses to the wearer's needs, experiences, and desires. Crip Couture considers such relational accountability a part of aesthetic expression. Crip Couture maps the meaning of access intimacy and Crip intimacy through this process of building relationships. This is a critical part of the integrity of Crip Couture. In this relationship, consent is built on consistent communications, including confirming what all participants feel comfortable with, checking in with each other periodically, following up with conversations that require time to digest, and building in room for flexibility because people's access needs might change. Providing consent also means supporting people who do not, or cannot, access intimacy with another disabled person by naming the type of access and physical, mental, or emotional space that one needs. Crip Couture puts accountability at the center by requiring facilitating artists to commit to the same witnessing process they ask

of their collaborators. In making these works, my erotic power guided me to experience what Mingus says about access intimacy, "we share a kind of access intimacy that is ground-level, with no need for explanations. Instantly, we can hold the weight, emotion, logistics, isolation, trauma, fear, anxiety and pain of access. I don't have to justify and we are able to start from a place of steel vulnerability."

In Crip Couture, sharing vulnerability amongst disabled people is a part of Crip aesthetics, which purposefully focuses on the artistic process and products that reflect "Crip" as a distinctive subculture identity and experience within the larger disability culture. Vulnerability might also be shared by non-disabled audiences who experience disability via the role of a caregiver. When *Skinny* was on display at the DisArt Festival in Michigan, several gallery visitors shared in-person conversations about their private life with me, including the experiences of taking care of family members with chronic illness, embarrassment about particular skin conditions or body features, and a moment of grief over their own narrow understanding of disability when seeing *Skinny*.

As a homemade theory, Crip Couture's work invites, creates, and documents narratives. It is an inquiry and knowledge production process that requires naming pain and using collective support as "resistance and recovery" to ensure each member's survival (Morales, Latina Feminist Group 14). The Crip erotic power therefore contains survival narratives which utilize vulnerability and fragility as fuel to create meaning about disability and Crip healing. The queer, disabled, non-binary, femme disability activist Leah Lakshmi Piezna-Samarasinha's 2018 book *Care Work: Dreaming Disability Justice* discusses the philosophy and values of cross-disability access and care as a way to decolonize the medical industrial complex— the institutionalized health care

system that privileges medical professional knowledge and operates based on a capitalist market system. Piezna-Samarasinha emphasizes the importance of sustainability and interdependence when practicing disability justice centered care work, including self-care and community care. Guided by disability justice, I name Crip healing, a concept and a practice stemming from my resistance to the definition of "healing" according to the medical and rehabilitation model of disability. Crip healing requires revitalizing Crip collective erotics. Crip Couture's premise builds on redirecting our erotic power through creative engagements in art making about disability experiences that build and sustain disability community. As a versatile practice, the Crip Couture Manifesto offers the following ideas and directions for researchers, artists, art therapists, activists, and cultural workers to apply aspects of Crip Couture in their work.

#### 5.4.1 Crip Couture as a trend setter

Haute Couture buyers are the top 1% people in the world; modernized Haute Couture productions have mostly transformed into showcasing the finest innovation and craft on the fashion runway instead of serving private clients only. Haute Couture designs are often worn by celebrities and socialites who attract media attention and lead popular trends. Crip Couture's aim is not to mass produce adaptive clothing for disabled people. Crip Couture's concepts, philosophy, and methodology are to challenge both disabled and non-disabled designers, artists and fashion companies' approaches to making wearable garments and accessories for disabled people. Crip Couture's production is made as an instigator for broadening the existing fashion production practices beyond their material, commodity values. Crip Couture functions as a trend

setter for generating disability-culture and disability justice-informed art and design productions and community building.

# 5.4.2 Crip Couture as tools for activism and community organizing and care work

Crip Couture welcomes all venues to host its exhibitions, including art galleries, museums, fashion shows, community or academic spaces, artist's talk series, as well as social media. Crip Couture only works with curators and venues where accessibility is integrated into exhibition planning and curatorial practices. It provides tactile samples (Figure 24, Appendix A) of the wearable art objects whenever possible and invites the audience to engage with the piece by exploring the tactile samples with their bodymind. It works with venues with limited budget support who are open to conversations about alternative displays. In addition, Crip Couture collaborate with the venue's marketing team and reporters on crafting Crip-specific aesthetic focused language and approaches for publicity and education.

Crip Couture is a type of care work that revolutionizes the meaning of eugenics, first coined by Charles Darwin's cousin Sir Francis Galton, who defined eugenics as "well-born." (*Origins of Eugenics: From Sir Francis Galton to VIRGINIA'S Racial Integrity act of 1924*). In the world of Crip Couture, S.M.A.D.D. people are considered well-born because this world is all about the survival of the Crippest. Crip Couture's productions serve as a symbol of resistance against the harm created by ableism and other systems of oppression. Crip Couture models a relational design method, which requires the designer/artist/maker to integrate access intimacy and understand the relational/political model of disability in their creative work. The artist/designer's production process

requires time and energy for building relationships and the nature of creating wearable art objects is in and of itself a gesture of holding/nurturing the bodymind. Wearable art objects created under the guideline of Crip Couture are an embodiment of the wearer's history, lived experiences, and narratives; the production process, therefore, is a form of providing care. As an artistic engagement process, Crip Couture's philosophy can make an impact on the ways disabled people are treated in the mental health care system.

#### 5.4.3 **Sustainability**

Crip Couture is a hub for brewing a sustainable Crip siblinghood and family. Its wearable art and artistic social engagements are made to attend to the unknown, joy, confusion, pleasure, sorrow, bliss, anger... a whole spectrum of feelings from living as a disabled person with multiple identities and cultures. Crip Couture prioritizes its practice of supporting Crips finding each other, on our terms; finding history and legacy in fellow Crips. Crip Couture advocates for Crip self-love/self-care to be built based on community love/community-care.

# 5.5 **Conclusion**

Crip Couture models a non-assimilationist approach to creating designs for and with disabled people without reinforcing tokenizing inspirational narratives. *Skinny* illustrates my approach to documenting everyday disability experiences. *Hairy Undies* begins to explore what Crip healing means to generate Crip collective care. As a part of the Disability Art Movement, which focuses on creating self-representations to challenge the stereotypical images of disability, Crip Couture works on unveiling and challenging problematic disability representations. This includes challenging the framing of disability experiences in binary terms, for example, "beautiful vs ugly," "normal vs abnormal," and

"healed vs broken," etc. These binary terms position disabled people in opposition to the able-bodied standards. They overlook the systematic issues that disabled people experience. Crip Couture cautions the use of overcoming narratives and inspiration porn which are often used to please the able-bodied audience by tokenizing disabled people. Crip Couture's relational aesthetic approach rejects able-bodied, gender-conforming, and white privilege-centered definitions of beauty and normalcy. As a trend setter, Crip Couture aims to be a platform for providing concepts, language, tools, and methods for an alternative, non-assimilationist way to create disability representations according to disability justice activist culture. Through its distinct production processes described above, Crip Couture's wearable art presents the complexity of disability instead of simply flipping the binary. By creating in-your-face disability representations that pride themselves on being non-compliant to ableist expectations, Crip Couture intends to reprogram society's limited imagination of disability.

# 6. RES(CRIP)TING ART THERAPY: DISABILITY CULTURE AS A SOCIAL JUSTICE INTERVENTION

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# 6.1 **Background and Personal Narrative**

It takes people time to connect with a good psychotherapist. It can be especially challenging to find a therapist as a disabled woman of color who, as an art therapist, went through training in art therapy and counseling to master the same talk therapy techniques. After a few conversations about the accessibility of the mental health system for disabled people with my Crip sisters—fellow disabled women who identify disability as their socio-cultural and political identity— who reminded me the importance of self-care, I decided to give talk therapy another try.

I sat before Dr. B., a middle-aged, white woman with 23 years of counseling experience. As I returned to my memories of the traumatic break-up that still haunts me days and nights, I couldn't help but catch Dr. B.'s inquisitive eyes land exclusively on my fingers (I was born with two digits on each limb). This was followed by a frown every few seconds during the therapy session. She would then quickly shift to the professional therapist's body language—making eye contact and giving a few gentle head nods with "uh-huh ... mmmm" here and there—but then she would return to staring at my fingers as soon as I looked away. As a Crip since birth, I am an expert at recognizing and deciphering strangers' impulses to stare at my body. I tried to stay focused on the

issues I was discussing and needed help with, but Dr. B.'s behavior was becoming distracting and annoying.

In the midst of retelling my trauma, I had to shove my vulnerability aside. I pulled myself together and asked, "I noticed that you were looking at my hands. Disability is an important part of me; it is my identity, my politics, and activism. Are you comfortable with disability? Have you worked with disabled people?" Dr. B. smiled and began naming various diagnoses and pathologies she had dealt with in therapy. Then she added, "It's very nice that you can put a positive spin on your disability, not every disabled person can reach that point." Didn't she hear my questions? It appeared to me that she was unaware of how her compliments on my individual will to "overcome" disability were a patronizing deflection that amounted to a microaggression. I asked her again, "So, YOU WERE looking at my hands?" Dr. B. first denied it, then responded, "Oh, I may have looked two or three times. I wanted to know what they [my fingers] look like and how uncomfortable they might make others feel!"

Her words brought back the years of embarrassment and heavy guilt that I carried in my body for eliciting jaw-dropping bewilderment, sympathetic sighs, screams, and shivers from people who were shocked at seeing my hands. By then, it was getting close to the end of the session and Dr. B. was ready to send me off. I shook off my internal waves of shame; I imagined the presence of my Crip sisters in the room with me as I gathered my strength and asked Dr. B. for her reasons to stare at my hands once again. This time, Dr. B. further justified herself by saying, "I don't want to look straight ONLY at your face while we sit here and talk." She became animated by thrusting her face and upper body towards my face to make a point. She sharpened the

timbre of her voice, crossed her arms and then concluded, "It [my recognition of her behavior] may have to do with the sensitivities on your part!"

I walked out of the counseling room in shock and exhaustion. I could feel my brain racing as I recounted the dialogue that I just had with Dr. B., but my body felt cold and numb. I tried not to forget how she had just gaslighted me, negating my experience. If I had not had access to other politicized disabled people during my young adulthood, it would have been too easy for me to fall into the old trap and allow my defense mechanisms to kick in and make what she said just a blur. As a child, my sense of reality was repeatedly altered whenever strangers intrusively stared and commented on my hands. Adults expected me to be strong and brave; they would tell me, "Oh, that's not true; it's only in your head ... People mean no harm; they are just concerned!" People's responses have conditioned me to deny, and even shut down, my own feelings at times. It was always about how able-bodied viewers felt about my impairment, never about how I felt as a disabled person.

I wrote about my encounter with Dr. B. on Facebook. Many people responded to my post by sharing their unpleasant, and at times torturous, experiences when their therapists provided counseling based on medical narratives, assumptions, or stereotypes about disability. My friends offered combative self-care strategies that worked for them in dealing with the limited options in the existing mental health counseling/therapy service industry. A few of them offered to connect me with their therapists and told me how they had already "groomed" them with "disability 101," so I would not have to deal with ablesplaining. Conversations like these are why my Crip family matters and why a Disability/Crip Culture community must exist. It comforts me to

know that I can seek peer support and community wisdom. While many of us still live in isolation, and the availability of access to each other requires social capital, having access to my Crip peers in person, and/or via social media, has been essential to my self-care. It angers and saddens me that when disabled people seek help from mental health providers, we first need to manage our therapists' failure to recognize disability as something more than a medical issue, and to confront therapists' misuse of disability as a metaphor that only reinforces able-bodied privilege. How much more therapy do disabled people need in order to undo the damage done by professional and licensed therapists, the medical community, and others whose practices are informed by an ableist history?

As an art therapist with a visible congenital disability, I did not always want to affiliate with my Crip family. For me disability had always been a stigma, a source of shame, and a taboo, and I did not even realize that I was trying to ignore it. I was completely oblivious to "disability culture" and "disability identity" before I became politicized at the age of 25. I still have vivid memories of my transformation, of coming out Crip during Bodies of Work: The Chicago Festival of Disability Arts and Culture in 2006 (Ozler). As a newly minted art therapist, I was enthusiastic about using art as a tool for individual self-expression. My idealistic career vision, however, was shattered soon after attending the festival events, where many self-proclaimed "disabled" or "Crip" artist-activists expressed anger towards art therapy. They were frustrated by the assumption that art made by artists with disabilities is often a subject of psychological assessments or used for rehabilitation purposes, which reinforced the stigmatizing relationship between disabled people and health professionals. I tried to absorb and

understand the rage surrounding art therapy from the disabled activists. I was taught to believe that art therapy is a loving, and nurturing profession. But I learned that the notion of "therapy" can be a form of oppression to disabled people. I was flustered, and wondered: have I just become a part of the problem when I naïvely thought I was joining in the solution to help disabled people?

# 6.2 **Introduction**

This chapter's proposition—res(crip)ting art therapy with disability culture—grew from my concern about therapeutic practices, including art therapy, that overlook social justice for disabled people. As a self-identified disabled artist, woman of color, disability cultural worker, and art therapist, my roles overlap several boundaries when facilitating consciousness-raising work as a part of the emancipatory actions within the disability culture community. The field of art therapy is accustomed to approaching disability with an interventionist impulse. I question the parameters of art therapy, its assumptions and foundations, and even if art therapy is a culturally appropriate and responsible practice.

In this chapter, I critique the deficit model of art therapy, then illustrate a working definition of how disability culture can help broaden the perspective of art therapy. By presenting concepts and theories from disability studies, as well an example from my work at Access Living, an advocacy and disability rights organization in the metropolitan Chicago area, I explore the potential of a community-based art practice informed by the Disability Arts movement and disability culture. I argue that an interventionist analogy of disability in art therapy only works to further the othering of disabled people; by incorporating an intersectional view of disability and Disability Culture in the mental health care industry, art therapists will create long-term systematic change at a

grassroots level and a more encompassing, sustainable social justice-based art therapy practice.

# 6.3 **Disability Discourse**

"Can you do \_\_\_\_\_ (fill in a daily task)?"

"Did the surgery help with your fine motor skills?"

"You should be grateful that your defect is minor ... some people can't even walk, right?"

"Are you waiting for a cure for your 'genetic defect?"

"Have you considered adoption in the future?"

Like many of my Crip brothers and sisters, strangers often question my ability to perform daily tasks and the ramifications of exercising my right to bear children. The questions above reflect the power of the medical model, which sees disability as a defect, a "lack-of," or a dysfunctional and pathological issue situated within the individual (Goodley). The medical model of disability considers individuals as subjects that require corrective and/or rehabilitative procedures to "fix" the condition. It relies on the concept of normality to differentiate, define, and categorize human differences as abnormalities. It often assigns the individual with a disability to the passive role of a suffering patient. The expectation is for the disabled patient to receive help from trained professionals, who are experts at offering a diagnosis, executing treatment and rehabilitation plans, and ultimately eliminating any abnormality (Mackelprang and Salsgiver).

Therapy is an institutionalized engagement and agreement between therapists and clients. The current mental health industry is a part of the neoliberal market, which

prioritizes productivity and profitability (Gipson, "Challenging Neoliberalism"; Kuri). Most art therapists would agree that art therapy is a practice that focuses on clients' artmaking processes rather than on the final products. But the field of art therapy as a whole is not immune to the product-oriented demand of the capitalist world. Therapists monitor and document patients' diagnoses and progress, not only for treatment, but also as evidence in order to receive insurance reimbursements. As a result, disabled people face not only the inherent stigma leveled against disability, but also the structure of a market of care that expects patients to show progress and get better. As long as the mechanism of neoliberalism operates within the mental health care system it is inevitable that the threshold for funneling resources to disabled people will be regulated primarily through medical and rehabilitation models, which reduces disability to individual responsibility. Art therapists must be vigilant about how economic factors determine the institutional infrastructure within art therapy, and how they further control the accessibility and quality of therapeutic services allocated to marginalized communities. Essentially, art therapists must begin seeing disability beyond medical terms by moving into a sociological framing of disability (Longmore).

Disability activists and disability studies scholars<sup>14</sup> use the social model as a framework, and argue that disability is not a lack of normative functioning. Rather, disability is produced when environmental, architectural, physical, attitudinal, and systemic barriers hinder people with impairments from participating as active members of society. The social model breaks the individualized treatment approach to disability. It

<sup>&</sup>lt;sup>14</sup> Scholars such as Garland-Thomson, who has discussed the social model of disability from a feminist perspective (*Integrating Disability, Transforming Feminist Theory*). Kuppers (*Disability Culture*), Sandahl (*Disability art and artistic expression*) and Goodley have also discussed how social model of disability shapes the understanding of disability culture, disability art and disabled people.

acknowledges that a disability is not a singular and isolated human biological attribute. The social model of disability calls attention to how societal, cultural, economic, racial, gender, political, and religious factors both include and exclude disabled people. The late disability studies scholar, Paul Longmore stated, "when devaluation and discrimination happen to one person it is biography, but when in all probability similar experiences happen to millions, it is social history" (39). The term "disabled people" means people who are "disabled" by prejudice, discrimination, and inequality in society. Thus, disability is a systemic and social justice issue.

The social model of disability, however, does not address individuals lived experience of impairments. Removing architectural barriers, rewriting employment policies, and installing lifts on buses will not eliminate the physical and psychological pain, debilitating illness, and chronic fatigue that some people may experience. The political/relational model—a radical social model centered on a feminist framework of disability—acknowledges disability as multifaceted and contextual. It recognizes the need for medical intervention that sustains disabled people's lives (Kafer). In her book Feminist Queer Crip, Kafer reminds us that "... by positioning ourselves only in opposition to the futures imagined through the medical model, and shutting down communication and critique around vital issues, we limit the discourse at our disposal" (8). And, it must be said, advancements in medical technology have improved the physical, psychological, and mental health of disabled people (Mackelprang and Salsgiver). Nevertheless, art therapists need to be equally cautious when defining disability exclusively by either the medical model or the social model.

# 6.4 Critiquing Art Therapy: A Deficit Model

Art therapy has traditionally drawn its theories and practices from a wide range of disciplines, including psychiatry, psychology, psychotherapy, counseling, education and art, among others (Yi and Talwar). As a cross-disciplinary practice, art therapy seeks to reinvent its approach based on its traditional origins, while making an effort to claim that art therapy can be a stand-alone practice. Art therapists also take pains to gain public recognition as professionals whose practice is comparable to that of other prominent mental health services. In doing so, art therapy has inevitably inherited specific paradigms, hierarchies, and power relations from the disciplines it has drawn from (Res(crip)ing Art Therapy).

Hall states that art therapy is a product of its founders' intellectual curiosity. The foundations of art therapy have ignored the marginalization that disabled people have experienced historically. The field of art therapy is founded on the concept of normality versus pathology, thus drawing on a medical interventionist model (Yi, *From imperfect to I am perfect; Res(crip)ting Art Therapy*). Disability studies scholars, such as Petra Kuppers has critiqued art therapy for being an extension of normalization (*Art Therapy*) and Sharon Snyder has described art therapy as product of the "epistemologies of ablebodiedness". This means that the knowledge and working methods behind art therapy inevitably validate and privilege able-bodied people by theorizing "what's wrong" with bodies and their impairments. Along with Kuppers (*Art Therapy*), disability studies scholars Colin Barnes ("Effecting Change") also critique art therapy for employing an individualized approach, which depoliticizes and decontextualizes disabled people's

cultural expressions. Such criticisms ring true when disability is viewed from a medical model of deficiency that needs to be managed, rehabilitated, or simply cured.

It thus behooves art therapists to question the prerequisites mandated for admission to an Art Therapy Master's Program approved by the American Art Therapy Association (AATA). Among other academic credits, a course in "standardized human growth and development," such as developmental psychology and abnormal psychology, is required prior to applying for admission to any art therapy program.

During their training, students learn to use the Diagnostic and Statistical Manual (DSM) of Mental Disorders as a main reference. And all too often the majority of employment sites, such as hospitals, rehabilitation centers, shelters, psychiatric wards, special education schools, and correctional facilities require art therapists to assess, manage, and treat the client/patient's presenting issues.

Ethical principle 7.1 of the American Art Therapy Association (AATA) states on their website that "Art therapists do not discriminate against or refuse professional service to anyone on the basis of age, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, socioeconomic status, or any basis proscribed by law". At the same time, AATA largely ignores "disability" as a multicultural community. This is problematic as the organization strives to emphasize multiculturalism in shaping its organizational structure, ethical standards, and accredited training programs. Art therapists have spent over 40 years working with people with disabilities, but there have been few articles within the field's professional journals citing concepts and literature from disability culture and/or deaf culture perspectives. Such as Susan Spaniol's work in working with people with mental illness ("Exhibiting Art"); Susan

Spaniol and Mariagnese Cattaneo's work in discussing art therapeutic relationships, and Mary McGraw's practice in a hospital serving people with physical disabilities. Indeed, only a handful of educators are addressing issues of disability beyond the scope of medical and counseling frameworks. Susan Hedley approaches creative art therapies by addressing the issues of the dominant narratives and asks therapists to examine their complicity in creating harm within the dominant culture. Art therapy educator, Savneet Talwar argues for critical thinking in art therapy practice (*Creating Alternative Public Spaces*; "Culture, Diversity, and Identity").

Talwar also argues from a feminist perspective and calls for decolonizing art therapy's European-American tradition. ("Decolonization") The primary leaders and educators in art therapy have mostly been white, middle-class, and non-disabled people (Junge and Asawa; Kapitan) The majority of trained art therapists come from privileged socio-economic, cultural, and educational backgrounds. By contrast, a large number of clients/patients with disabilities who are surviving in the current mental health care system are people of color living on the margins. Thus, their quality of care is more likely to be compromised due to race and poverty (Mcguire and Miranda). Rabinow uses Foucauldian theories to illustrate the mechanism of discipline that art therapists need to be aware of. This includes how their professional roles are part of a system to regulate and reinforce sexism, classism, and racism. Art therapists need to be cautious of reinforcing ableist social norms that rely on stereotypical representations of the disabled as vulnerable people who need to be "helped" or "rescued." It is imperative that the art therapy curriculum and post-graduate training focus on being attuned to gendered and

racialized economic power structures. It is especially important to understand how disability is entangled within the web of identity and difference.

# 6.5 **Disability Culture, Disability Art, and Identity**

What can a cultural identity-based approach of disability offer art therapists working in an ableist society? All individuals, if they live long enough, will experience disability at some point in their lives. However, not all of them will seek out and bond with other disabled people. Disability culture grew out of the International Disabled People's Movement in the 1960s and 70s, when disabled people worked on raising consciousness and fighting for access and civil rights ("Effecting Change"). As a human manifestation that has been likened to a tool (Levin and Siebers), culture can change society. Disability culture is a set of values, shared histories, customs, and ways of being associated with a collective experience. As a minority expression, disability culture reflects disabled people's group consciousness through shared systemic and collective oppression, language, identity, and lifestyle. It is a community response growing out of social injustice, institutional isolation, and segregation. Often, an individual may grow up as the only person with a disability in his/her/their family, so meeting other disabled people, who know what oppression feels like, can be a transformative emotional experience (Garland-Thomson, "Becoming Disabled").

In her work, *A Psychological View of Disability Culture*, disability studies scholar and psychologist Carol Gill describes disability culture as the emotional unity of disabled people. Disabled people form a peer support network for each other at community gatherings and political engagement meetings, where they share knowledge and resources, process their experiences, and come up with strategies to confront stigma

and discrimination. Connecting with fellow disabled people has thus created a society, and subculture, where participating members forge alliances: brotherhood, sisterhood, and what we might even call "Criphood." As a defense mechanism against oppression, isolation, and discrimination (Barnes, "Effecting Change"; Kuppers, "Performing Determinism"), disability culture is a phenomenon that reflects disabled people's self-determination, empowerment, and a growing political strength leading to positive changes.

Disability culture is a process of reshaping and redefining the existing social rules and overturning the measures that have excluded and alienated disabled people. It is a relational process of building an interactive, communicative, and responsive system of care-relationships for bodies that do not conform to society's expectation of "normal" and "functional." To disrupt the history of hiding and shaming disability, it is often necessary for people to come out as disabled. This is not only a sign of self-acceptance, but also a desire to reveal the truth through stories and the multiplicity of disability narratives. In *Disability Culture and Community Performance: Find a Strange and Twisted Shape*, Keppers discusses that when the arts are presented in the context of disability politics, they can become a bonding agent and advocacy platform for fellow-disabled people to "undo the history of exclusions" (4) and use the arts as an agent to cultivate community and solidarity.

Disability Art, as a genre and an art movement, is the work of artists who explore the multiple meanings of disability on a personal, interpersonal, collective, political, and artistic level (Sandahl, *Disability art*). Art that falls under the category of Disability Art examines and critiques traditional representations of disabled bodies. It claims visibility

for disability and may also challenge what access means through artistic expression. Emotional engagement, and accessibility, are central concerns of the disabled artist and disability culture in general (Cooley and Fox). Disability Art and public events centered on disability culture require accessibility as part of the audiences' participation. Accessibility and disability accommodations intervene in ableist spaces and social structures through physical and sensory changes to spaces from which disabled people are usually excluded. In this way space and accessibility become a way to rescript cultural and social practices by shifting pathology to identity (Garland-Thomson, *Disability, Identity and Representation*).

Many of the artists who associate themselves with the Disability Art movement are often inclined to self-identify as "disabled" or even "Crip" as an identity category (Sandahl, "Queering the Crip"). Unless people have access or exposure to other politicized individuals who identify as Disabled or Crip, disability may remain a stigma, perceived pathology, taboo, or label. Disability is a collective experience and a fluid construct when it comes to identity. Feminist disability studies theorists illustrate the parallels between gender and disability as concepts permeating all cultural and social structures (Garland-Thomson, *Disability, Identity and Representation*; Hall). Unlike other biologically inherited or ethnic identities, disability is often reclaimed as a relational identity, not an isolated attribute, or a singular issue/experience. It is interconnected with other identities, (such as race, class, gender, and sexuality, among others) as a sociopolitical reality. It is imperative that we recognize how disability is produced as part of the ideological system that has marginalized disability identity (Garland-Thomson, *Disability, Identity and Representation*). Identity politics with regard to disability,

therefore, helps to formulate a sense of belonging and solidarity. Examining the social construction of disability from a feminist lens expands the knowledge of disability identity and its multiplicity of interpretation and analysis.

# 6.6 Disability Art and Culture Projects at Access Living

Garland-Thomson (*Disability, Identity and Representation*) argues that disability culture intervenes in ableist structures and rescripts cultural and social practices by shifting pathology to identity. How would community organizers facilitate such a shift at a grassroots level? At the beginning of my artist-in-residency with the Arts and Culture Project at Access Living, one of the core partners of Bodies of Work (BOW): Network of Disability Art and Culture, I was recovering from my encounter with Dr. B, and was seeking a space to heal and create personal connections outside of institutionalized mental health care services. I launched several exploratory projects that were in line with the independent living and disability culture philosophy at Access Living (www.accessliving.org/). Here, I discuss an advocacy photobooth project and a disabled youth self-advocacy workshop as examples of how the arts can support and cultivate a sense of disability belonging and identity affiliation, and give a voice to disability culture.

#### 6.6.1 Advocacy Photobooth Project

Access Living's International Women's Day celebration in 2013 focused on the intersection of disability and women's issues. With help from the Empowered FeFes, the Access Living advocacy group mainly comprising disabled women of color, we made props for a photobooth and invited people to pose with the props as a way to contribute to disability advocacy by making personal statements (Figures 25-26, Appendix A). Some props were generic—lips, glasses, crowns, mustache, or hearts. Others were

more topically focused: a uterus, a megaphone, a microphone inscribed "speak out," a steering wheel with "consumer control," the iconic ADAPT symbol (grass-root disability rights organization's design of wheelchair user ripping off handcuffs), and a solidarity fist. There were also a few blank thought bubbles for people to write in their own messages. Participants in the photobooth sessions, mostly consumers (a word reclaimed by the disability rights movement to denote control over services received as a self-directed participant; (DeJong), staff, and a few walk-ins, posed for the camera using the props.

Many participants quickly recognized the fun and entertaining aspects of a photobooth. After I introduced the activism themed props to the participants, many of them would pause for a moment as they inspected and drew personal connections to the props. Then they shared with me:

"Oh, I love the steering wheel, 'consumer control' is what disabled people like me need!"

"It took me a long time to speak up, but I am learning."

"How do you spell power? A-D-A-P-T!" 15

The photographs were then organized into an online album for public viewing.

This project lasted only two weeks, but as a part of the larger Arts and Culture Project it sparked the growth of other projects (Figures 25-26, Appendix A).

#### 6.6.2 **Disabled youth self-advocacy workshop**

In 2015 the ADA marked its 25th anniversary. One of the programs that the youth advocacy organizers launched at Access Living was working on self-advocacy with

<sup>&</sup>lt;sup>15</sup> It is a popular chant that disabled people use when protesting with ADAPT, a National disability rights organization.

students with disabilities from the Chicago Public Schools. This project was cofacilitated by two art therapy graduate student interns from the School of the Art Institute
of Chicago, Claudia Angel and Amelia Thomley. A group of high school students in
special education made four visits to learn about disability culture and disability
accommodations as their rights under the ADA. They visited Access Living's permanent
Disability Art collections and learned about my photographic portraits wearing body
adornments prior to meeting with me. "Oh, you're THE disabled artist! I saw your art on
the wall!" a student identified me excitingly. For our first art workshop together, I decided
to use the props from the photobooth to explore self-representation and self-advocacy,
which require attending to the self and to social relationships with fellow disabled
people.

Drawing on the approach adapted from the work of drama therapist Josephine

Lin, a multi-disciplinary artist in Taiwan, I initiated a conversation about a "touch free"

zone as the work involves physical interaction with each other's bodies. All of us, the
facilitators, students with various physical, developmental, and/or emotional disabilities,
and four special education teachers, were active participants. Before the exercise, we
created group agreements and encouraged students to express their needs, including
leaving or asking for personal space during the group activity. The workshop began by
honing in on participants' physical and emotional senses through a partnering exercise
in which students took turns creating gestures by positioning another person's body. We
reminded students to check in with their partners about appropriate and acceptable
physical touch, and to give space and time if their partners used mobility or
communication devices.

In the following group performance practice, students began to strike a pose on stage, one by one, without announcing what narratives they intended to create with their bodies. The group exchanged feedback about the "human sculptures." Their collaboration was intuitive and spontaneous. At the end of the exercise, we discussed the experiences and observations, both as audience and as performers. The conversations provided an opportunity to create a dialogue about the interpretation of bodies. Through this process, we re-envisioned the meaning of displaying disability, identifying personal needs and projecting and receiving stares. This exercise allowed the youth to gain knowledge about disability terminology and to name different ways disabled bodies are represented socially.

For the closing activity, participants paired up and shared a secret inspired by the group activity. I asked them to make a "helping space" by being empathic and non-judgmental towards each other. After a moment of silence, Maria (pseudonym) said, tearfully, that she did not like her disability. Jamie (pseudonym) interjected her passionate encouragements. I recognized Jamie's kind intentions, but I asked her to hear Maria's pain before offering something that she considered more positive. Jamie lowered her head, tears ran down her cheeks, and she did not want to engage with me. By then, it was time to wrap up the session. I offered myself as a resource to Jamie. A teacher followed up with her and later confirmed that she was fine. While the interns and other teachers rounded up the students for their bus, a few female students formed a circle around me and said they were afraid that other people would find out about their (non-apparent) learning disabilities. I responded, "It can be scary to experience it alone,

let's explore ways to talk about disability in art next week!" Students revealed a sense of relief as they dropped their tight shoulders, smiled, and said goodbye.

The final performance workshop entailed everyone taking turns with a chosen prop and striking poses to express their disability needs. The group then created narratives for what they saw and offered interpretations. During discussion, students got to see how their peers' and teachers' choices of self-expression varied. Many students got excited and kept raising their hands for a chance to speak. The special education teachers later commented on how surprised they were to see students taking the initiative and discussing their ideas about disability. In the end, this project served to help disabled students give a voice to their everyday experiences of disability and build a relationship with their disability activist community (Figure 27, Appendix A).

# 6.7 Towards a Social Justice Based Art Therapy

Earlier in the chapter, I discussed the stigmatization of interventionist, medical model approaches in art therapy, and the negative connotation that disabled people's art and cultural products must serve rehabilitation purposes. Sandahl (*Disability Arts*) discusses the lack of quality arts education for students with disabilities, and art therapy is often the only opportunity for them to make art, generally while staying in rehabilitation centers and hospitals. While it is certainly my interest to address the lack of access to creative arts within the disability community, it is also to confront the construction of disability as a taboo.

As illustrated in my artist-in-residency at Access Living, art making was made accessible to the consumers at a physical, emotional, and conceptual level. By creating images and representations of disabled people moving their bodies and declaring their

needs in public spaces, the two projects sought ways to explore the meaning of self and communal care as activism for social change. At the same time, it was also an opportunity to mine the everyday experiences of disabled people, especially the rhetoric of staring.

Garland-Thomson, in *Staring: How We Look*, discusses staring and its dynamics in creating identities. All people experience staring, both as the one looking and the object of the sustained gaze. It constructs meaning about disability when non-disabled people encounter disabled people. Staring can be a convergence with the unexpected and extraordinary, and it can be a form of communication, perhaps a demonstration of dominance, but it may also stigmatize the object of the stare (Garland-Thomson, *Staring*). It is a cross-cultural phenomenon. Most parents will tell young kids seeing disabled people to "stop staring". But this imperative never stops the human impulse to do so, since it arises from a desire to know when engaging with the unknown. It may shame the individual's behavior, but, significantly, it carries the implication that disabled bodies are not to be looked at. Disabled people spend a lot of time dealing with ableist staring, but rarely, do disabled people get to spend time looking at each other as a community. Thus, the two projects were about bringing visibility to the often silenced and hidden performative desire of disabled people.

# 6.8 **Practicing self-reflexivity**

Feminist philosopher Judith Butler, who coined the term "performativity," suggests that "language, gesture, and all manner of symbolic social sign" (519) create a social reality in which each individual performs his/her/their identity. Social justice practice requires art therapists to be transparent with regard to their own performativity

through multiple identities, including race, gender, class, sexuality, and ability/disability, among other markers of difference. How does the hybrid nature of art therapy speak to therapists' ability to determine what social scripts to follow when working with clients with disabilities? Can art therapists discern the nuances of their social reality in an ableist world and understand how their own performativity intersects or conflicts with a client's/patient's disability?

As a self-identified Crip artist of the disability community, I see working with a young generation of disabled students as an opportunity to model the process of naming and claiming disability. My training and sensitivity as an art therapist enable me to stay reflexive as I work with fellow disabled people with whom I share the memories and living history of oppression. Reflexivity is an intra-dynamic processing skill for community organizers and therapists who center their work in a social justice framework. It is not about exercising counseling techniques to provide descriptive solutions as help. Rather, reflexivity requires us to understand how issues of disability impact our personal lives and what sort of social norms surrounding disability we have absorbed. Reflexivity is like a scanner that captures and analyzes the decisions that therapists make when interacting with disabled people, including how and when they ask consumers questions, how they listen and take in information from their consumers. Reflexivity is akin to opening a door, to observing and recognizing how each of us is part of a matrix of power relationships (Collins and Bilge).

#### 6.9 Conclusion: Res(crip)ting disability narratives

Rather than writing this chapter as conventional "case studies" for an art therapy audience, my intention was to create snapshots of how we build disability culture and

activism as a continuation of the larger disability justice movement at Access Living. Disability narratives in history and contemporary culture have shaped the way art therapists understand disability, but art therapists have also played a role in scripting disability narratives. When art therapists present case studies to illustrate the effectiveness of interventions and results produced for specific "populations," they do so by focusing on symptoms and diagnoses along with other demographic markers. Art therapists need to recognize how their portrayals of disability paint only "what's wrong" and "what intervention works" when illustrating the individual's story. In the context of institutionalized therapy, disability narratives have become forbidden tales, erasing disabled people's self-representation. Art therapists must commit to seeking alternative ways to represent disability narratives.

If art therapists want to embrace a social justice framework informed by a radical social model of care, they will need to become equal partners with the disability culture community and fellow activists, shedding the clinical role of the expert. As art therapists, we must keep a versatile practice and begin thinking about ways to make contributions to the Disability Art and Culture movement. Disability culture events are about cultivating a site for disabled people to feel comfortable enough to come out as disabled people. As allies, art therapists can help disabled clients use art to talk through their feelings about the disablement, stigma, and shame they often feel in an ableist society. Art therapists can help connect disabled clients to disability culture communities and support them to develop their own cultural identity by organizing outings and attending disability art and culture events with their clients. Finally, as therapists use self-reflexivity in human engagement, and include an intersectional approach when

examining their own uncomfortable feelings about disability, they will have begun the work of deconstructing the ableist myths often held about disabled people. This, in turn, will allow art therapists to use their skills as cultural workers and social practitioners to res(Crip)t their dialogues with people with disabilities and their cultural representation.

# 7. DEMYSTIFYING THE INDIVIDUALISTIC APPROACH TO SELF-CARE: SEWING AS A METAPHORICAL PROCESS FOR DOCUMENTING RELATIONAL AND COMMUNAL CARE IN DISABILITY CULTURE

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# 7.1 **Background**

Getting discount massages through Groupon is often one of my top choices for self-care. That is, if the first 5 minutes could go by without receiving comments about my physical disability. I call the first 5 minutes of massages "the anxious five." I lie face down on a massage table. A white sheet covers my body, and I am wearing nothing but underwear. I never know how the massage therapists are going to react as soon as they discover that I only have two fingers on each hand and two toes on each foot under the sheet.

Massage Therapist (MT): "How is the pressure?"

Me: "It's okay; I can take more though."

I continue to keep my eyes closed as I feel tension release from the increased pressure on my tight shoulders. The therapist then moves her hands from my shoulders to my arms and then to my wrists. It is no surprise that more questions follow:

MT: "Did you have an accident?"

Me: "Um... no. I was born like this."

MT: "But you still function alright, right?"

Me: "Uh... yeah, pretty much..." (I answer with sleepy eyes.)

A few moments later...

MT: "So, what do you do now?"

Me: "...Um... I teach and I am working on a PhD in disability studies." (Am I being interviewed in the middle of a massage?)

MT: "Oh, good for you! You made it this far, and you can help other people with disabilities!"

Some massage therapists might not ask about my impairments, but the way they touch, hold, and put pressure (or don't do any of the above at all) on my hands and feet reveals how they feel about my body. The purpose of receiving a massage is to be in a judgment-free space where one feels accepted, pampered, and well taken care of. The last thing that I want to think about is how I can help others when lying down on a massage table for some *me time*. So, I decided to join group yoga, where I would not be the only one seeking self-care. At the end of my first Kundalini yoga session in a new studio, the teacher approached me after class.

Yoga teacher (YT): "It's wonderful that you came! I saw the way you move with your hands and feet—you can do a lot!"

Me: "Um... I have practiced yoga before."

YT: "Were you born like this?... What do you do now?" (asked with much enthusiasm)

Me: "Yes... I was. I am an art therapist and I'm working on a PhD."

YT: "Oh, that's very nice of you! You help disabled people...you must be so patient... Now, you can give back to society. You can show others that nothing can stop people like you."

"People like me?" People like me, who were born with or acquired a disability, desire to pamper our bodies and minds when we are tired, frustrated, and defeated because we often experience microaggressions on a regular basis. We are turned into "inspiration porn," a term coined by late disability activist Stella Young (2014), meaning that we are considered to be doing something extraordinary when we are simply doing something mundane, such as going to school or work, shopping, or taking a yoga class. We are constantly expected to prove ourselves and show our productivity and worth as model citizens who can take care of ourselves so we don't become burdens to society. But when we try to relax and have fun after a long week of hard work, people remind us that we have the responsibility to inspire and help others "despite" our disabilities. People like me, who realize that "nothing can stop people like you" is a false superhero tale.

#### 7.2 **Introduction**

People who choose to become mental health care providers, as I have, often have the personality and innate ability to relate to others' pain and struggles. We are prone to compassion fatigue because we are ethically bound to support others who have experienced trauma, harm, and the unbearable (Hinz). We are seen as people with enough patience for working with "those" disabled people, whose needs are stigmatized as "special" and "hard to deal with." Society often prizes our work with the disability population as charity and us as saints and saviors. Does the same stigma

and expectation apply to people like me who are both disabled and therapists? How do we, disabled and ill therapists, make sense of the stigma and deconstruct the savior syndrome, so we not only survive ableism but also thrive along with our disabled and ill clients/patients?

# 7.2.1 Critiquing Self-Help and Self-Care

In the United States, independence and self-determination are the ideal attributes for a person's success. In other parts of the world, personal success depends on "saving face"—not shaming your family name and bringing prosperity to honor your ancestors. The individual's accomplishments reflect how well they meet the social expectations and take care—to recharge and maintain—their productivity in comparison to others. In other words, success depends on individuals' efforts to help themselves first.

The mentality of "pulling yourself up by the bootstraps" deeply impacts the way we think about self-help and self-care in a capitalistic society (Gordon; Ward). The same "pulling yourself up by the bootstraps" mentality also impacts art therapists, who must present themselves as professional workers in front of clients/patients and colleagues with whom they work—especially when the field of art therapy strives to be recognized as an esteemed helping profession among other mental health care fields. It often requires art therapists to perform an authoritative presence and demonstrate "I've got it handled!" The individualistic norms shaped by neoliberalism have inevitably cultured art therapists to employ a capitalistic approach, focusing on individuals' responsibility for their own well-being (Gipson, "Challenging Neoliberalism");). As art therapists aim to serve clients/patients and keep up with the demanding capitalistic

mental health care industry; art therapists don't always do a good job of asking for help when we are the helpers. How we handle stress, burn out, or countertransference through self-care often becomes an individualized responsibility that takes place behind closed doors.

The emphasis on individual efforts and ability to overcome challenges or setbacks without help has further cultivated a class-based, ableist culture where disability is considered an individual problem and a burden on the social welfare system. Professional mental health care providers inherit an interventionist model (Yi, Res(Criping) Art Therapy) when working with people who experience any sort of disability or illness. An interventionist approach is based on the medical model that disability resides within the individual person who does not fit the norm and cannot fully participate in society; therefore, such a person needs to be "normalized" or make adaptations by receiving clinical and mental health intervention from professional experts.

#### 7.2.2 <u>Internalized Ableism</u>

It is inevitable for art therapists who are disabled and/or ill themselves to internalize ableism, especially when disability culture community is absent from their lives. Some of us may choose "passing" as a survival skill and detach ourselves from disability. Those who can, may "pass" by concealing their impairments and their need for help to avoid disability stigma. Those who can may also fall into an overachieving "supercrip" narrative in which their accomplishments are seen as proofs for ridding their disability (Clare, *Mountain*; Schalk). They hold positive "cando" attitudes and present themselves as overcomers to inspire non-disabled people

without examining or addressing the existing systematic and environmental prejudice against disabled people. They may make attempts to be accepted as "normal" by blatantly denying or rejecting their disability identity and affiliation even if their disabilities are apparent.

# 7.2.3 Chapter Thesis Statement

I examine the role of disability culture in self-care through the lens of disability studies. I engage the theory of complex embodiment (Siebers, *Disability Theory 22*) as I challenge existing self-care strategies: Through retelling an earlier period of my practice, where I first shifted from making art about disability as a personal struggle to a shared cultural and political alliance with fellow disabled women artists, I reflect on the power that the metaphor of sewing and the act of repairing has on disability narratives. I argue that knowledge of disability culture is fundamental for art therapists' professional development. Below I will use examples of my artwork to illustrate a precursor of a collective care model for a sustainable self-care practice for art therapists, especially for art therapists who have experienced disability and/or illness. I hope to offer this chapter as a way to complicate the meaning and practice of self-care for the field of art therapy.

#### 7.3 **Self-Care: A Personal Disability History**

In *Disability Theory*, Siebers called attention to the complicated nature of disability by locating the bodymind in the social, cultural, economic, and political contexts the disabled bodymind inhabits. Instead of seeing "body" and "mind" as separate entities within white, Western culture (Clare, "Writing a Mosaic"),

"bodymind" refers to how mental and physical states process lived experience as one unit (Price).

Examining how disability is often seen as merely an individual's tragedy, loss, or defect, Siebers encouraged readers to recognize the multiple social realities and meanings that shape one's disability experience and identity. The "Supercrip" is a term used by disability rights activists and disability studies scholars. It is defined as the representation of people with disability or illness who conquer their "limitations" by succeeding beyond societal expectations. This representation is problematic because it focuses on the individual person's willpower to overcome difficulties without examining how ableist society sets up a negative discourse around disability. Its use of positive language to portray disability, such as "overcoming their disability in spite of being a disabled person," fails to recognize the low societal expectations for disabled people. It also sets up a non-realistic expectation for all disabled people to attain the same level of success without considering each person's access to resources. The theory of complex embodiment therefore leads us to engage in a conversation beyond the stereotypical rhetoric of disability. Complex embodiment often requires unpacking one's own internalized perspectives and stereotypes regarding disability and care. This was certainly a necessary part of my learning as an art therapy student.

Before the age of 25, I was estranged from the disability community and my disability identity. I was taught not to see my body as disability, but only as "differences." People around me saw my passion and skills in art, and I proved to be evidence of how "disability did not hold her back." My ambivalent relationship to

disability became further entangled when I took "Exceptional Child, Exceptional Art" (Henley), a special education class taught by an art therapist during college. I was able to connect class material to my own experience of being "different." I unconsciously avoided naming my experience as "disability" due to the stigma attached to disability and my internalized ableism, and I was applauded for my refusal to see myself as "broken." My interest in becoming an art educator in special education somehow rewarded me as a "warrior" who would model for and perhaps "make other disabled people's lives better."

I first learned about the concept of "self-care" in art therapy graduate school back in 2003. I learned about response art (Fish) and I was taught to "make art about it!" whenever I felt drained or defeated by the presenting issues, difficult feelings, or conflicts from working with clients. I was constantly challenged to use art to explore what I was learning during graduate school. Sometimes, I was frustrated by the "illustrative" nature of images created in the context of art therapy. I felt pressured by the expectation to master art for self-care because I felt I needed to show my readiness to compete with other mental health care providers. When not making art to process issues, I felt I was not working on my training! At times, I felt like a hypocrite when I found making art as self-care, especially when I was exploring disability in an ableist dominated culture.

During an in-class presentation on self-care, I revealed that I was struggling with a personal memory and I was not able to make art about it. What I had done was cut up my Taiwanese disability ID card with scissors the night before. It was an old ID card that had framed my very existence as an impaired person with an "untreatable" diagnosis

from doctors, and as a benefit taker by the social welfare system. I cried as I talked about the emotional process that cutting the ID card had been and my desire to be seen as "just a person." Cutting my disability ID card along with claiming my personhood was regarded as self-liberation and self-care. I received strong support and empathic responses from my art therapy community. I value and am grateful for the opportunity to engage in such a cathartic experience. However, my internalized oppression and understanding of disability remained unchallenged. It had never occurred to me or to the people around me that disability is a social construction that is continuously shaped by a neoliberal ideology. Self-care is conceptualized as an individualized process without the integration of social, cultural, and political context.

# 7.4 **Disability and Helping Relationships**

The paragraphs above show how I experienced internalized ableism. My understanding of disability was further challenged when I began working for charity-based institutions, which made me examine the existing dynamics within the helping relationship that many disabled people experience. The charity model positions disabled people as the helpees on the receiving end. Although the charity model is very well intentioned, it often represents disabled people as victims. The charity model seldom focuses on disabled people's self-determination and self-representation. In training, art therapy students are eager to learn skills to help clients/patients by asking, "What can I do?," "What's my job?," and "How do I serve?" It is a priority to train future therapists to examine their role in the helping relationship; the "I" in each question inevitably draws focus on the position and value of the helper. Helpers do not always recognize the power positions they take on as the givers, as the presumably

"normative" people, and as those who have social capital. The savior syndrome instilled in the helpers often places emphasis on the virtue of helping. In *Bodies in Commotion: Disability and Performance*, Sandahl and Auslander point out that the relationship between the non-disabled helper and the disabled helpee is shaped and determined by helpers' internal "moral barometer" (3): how good of a person they are depends on how much they help or save disabled individuals.

The notion that "I gain more than I give when I help disabled people" shows the rewarding experience of helping others. At the same time, it mirrors the individualistic mentality that neoliberal ideology constructs by rewarding people who are able to contribute to others in society. It daunted me that I had been in the position of the helpee as a disabled person in my life; now as I became an art therapist who assumed the power position of a mental health care professional, I asked, "Where do I position myself as a disabled art therapist of color? Why am I drawn to work with disabled clients/patients?" I realized I needed to sort out my own connections to disability as I entered a helping relationship with a fellow disabled person.

#### 7.5 Sewing as Storytelling: The Meaning of Sewing and "Repairing"

Storytelling is a thread that connects people. In most cultures, the use of needlework has existed to portray and archive political movements, individual life events, marriages and family trees, life achievements, and social status (Baker; Boone). The embellishment of embroidery work shows wealth, taste, and style, and reflects the political climate and social values that existed within the time depicted. The pictorial

nature of embroidery and quilting composes narratives, such as the arpilleras<sup>16</sup> created by Chilean women during Pinochet's dictatorship and Hmong women's creation of story cloths<sup>17</sup>. Sewing provides a physical representation of lineage for people to trace back to their heritage and family of origin. Sewing physically ties human connections.

Sewing has been my way to tell stories. I have been drawn to sewing and craft making since I was a young child. Any kinds of crafting techniques that required fine motor skills— which doctors and occupational therapists worried I would live without— always attracted me madly and dearly. Perhaps it was the watchful strangers, who nervously monitored the way I manipulated thread and needles, who trained me to be skillful at using my hands efficiently under time pressure. I remember myself as a child, with sharp focus and sweat on my hairline, determined to do well and to achieve perfection in arts and crafts with my hands. Looking back as an adult, I realize that my perfectionism came from a desire to stop people from intervening and helping me before I even had a chance to try.

Repair is a verb that has torn me apart in different ways. Many of us who live with disabilities and/or illness often are told that we need to be fixed. Repair suggests that we are broken to begin with. In undergraduate school, I began exploring sewing as a process to trace and track the history of my bodymind, particularly through the surgical scars between my fingers. In the Gloves for Two series (Figures 28-29, Appendix A), I made three sets of gloves for my hands, indicating the three stages I went through as I

<sup>&</sup>lt;sup>16</sup> *Arpillera*s were used in Chile to represent pastoral scenes until Pinochet's regime, when they were then used to surreptitiously document the human rights violations of the regime. They are colorful patchwork cloth pictures depicting life hardship because of hunger, fear, and violence.

<sup>&</sup>lt;sup>17</sup> Hmong story cloths are often stitched with war and village life scenes. They can be seen in clothing and household decorations.

learned about my experiences of receiving stares from others: rejection of the norm, self-contemplation, and celebration of being different (Yi, *From imperfect*). For the purpose of this chapter, I will only discuss the first pair of gloves. I cut the "extra" six digits off of a pair of store-bought gloves, leaving only four to match my two fingers on each hand. I repaired the now-two-fingered gloves with surgical thread, following the actual scars on my fingers. The scars recorded the stitches that I once had from reconstruction surgeries.

The *Gloves for Two* series was made as the result of my frustration with the lack of fashion accessories, including glove, on the market for me. The process of repairing a pair of "perfect five-fingered gloves" was a defiant gesture against the normative measure of what qualifies as a "full" and "complete" human body. Sewing has become my way to investigate the mixed messages I've received, which are often overloaded with people's emotional responses to my body, and to examine how ableism and sexism shape people's understanding about disability. *Repair* began taking another form after I came out as a disabled person. *Repair* now means pairing up with a fellow disabled person and creating disability culture narratives as a collective.

## 7.6 **Are Art and Therapy for Self-Care Enough?**

The power of "witnessing" in group work helps individuals get a sense of "I am being seen" or "I am not alone" through the energy of group dynamics (Block et al). I made art alongside fellow graduate students during my training and with colleagues in professional supervision sessions after graduation. I saw therapists for individual therapy for self-care, and terminated therapy after I achieved my treatment goals. My therapists were helpful, but the treatment-focused nature of our therapy sessions

together meant that their presence was periodical. I felt that there was always something missing in my self-care routine. At that moment in my life, when I used art as self-care it felt like an individual lonely path and I was fighting against bias and oppression all alone because my disability was talked about as a singular personal struggle, an adversary story. Later, when I discovered the disability activist community, I realized that what I had been missing was a community of people who share similar disability experiences and who talk about disability from a politicized perspective.

In 2006, I began working in Taiwan as an art therapist. I received a traveling artist grant for collecting stories about children and adults who shared my particular disabilities. I departed for the trip with the mindset of an art therapist who wanted to bring the healing power of art making to my interviewees. When I met them, I realized that they were not interested in making art. They took care of me during my visit. They wanted to know about my stories as someone who was born with an apparent disability, over tea or at the dinner table where homemade meals were served. As I immersed myself in the disability activist community in Taiwan, I realized that I needed to set the institutional practice aspect of art therapy—contractual therapy relationships between a therapist and a client/patient—aside and relearn the meaning of "care" from my community. I learned that most people in the disability community considered art a luxury, a career path reserved only for people in middle and upper classes. I felt out of place when I made art about my feelings for self-care. This is not to say that art making no longer had value to me. Rather, the reality of Taiwanese culture made me realize that eating and sharing food with disabled people is also the art; strategizing demands and slogans for protests are the craft for creating

relationships in disability community. Mending broken wheelchair seat cushions and sleeves torn by pushing manual wheelchairs, dreaming up and sewing sexy lingerie with disabled sisters, and cleaning and decorating mobile devices such as walkers or canes is what connects people.

In 2009, when I left Taiwan and landed in the San Francisco Bay Area to pursue an MFA degree, I began participating in local and national disability rights rallies through ADAPT, a grassroots disability rights organization. I was also involved with Sins Invalid, a disability justice-based performance project with a focus on the experiences of disabled artists who are people of color, queer, and/or trans. On the one hand, the disability rights movement opened my views about fighting for equality: I learned negotiation skills, lobbying strategies, and ways to build community at the frontlines. As single-issue activism, disabled people's independence is portrayed as "we can and we want to be productive members of the society." On the other hand, my participation as an artist-in-residence with Sins Invalid cultured me to see independence as interdependence because disability is not the only identity.

It was then that I began conversing with other disabled people who share a mutual passion for arts, activism, and disability culture. A few fellow disabled sisters and I formed a bond through our shared disability and artist identities. I became increasingly interested in their experiences with coming out as disabled, their fashion choices, and how the medical procedures and rehabilitation interventions they experienced shaped their lives. Self-care began taking place when we hung out with each other over snacks, coffee, or a stroll; we told our stories and found resonance. We were tired of people positioning us as "courageous" artists because of our

impairments. We desired critical art critiques based on the merit of our concepts rather than its potential value to encourage others to feel good about their non-disabled status. We exchanged secrets for making ourselves feel pretty, not despite our disabilities but because of them. Most importantly, we were seen as having fun in public. As disability studies scholar Petra Kuppers once said at a performance workshop, "[disabled people] having fun in the public is an activism" (Kuppers, Introduction). We simply use the presence of our bodymind and state, "we exist, and we are living our lives."

#### 7.7 Self-Care With and Within Disability Art Community

My Crip<sup>18</sup> artist sister Sunny Taylor talked about her experience of getting braces to correct her L-shaped wrists. Her memories of the frustration and pain from the correctional therapy regime invited me to retell my story: the pain, fear, and also humor about getting correctional aids. We explored the connections of sensuality and impairment as we dreamt up fun ideas for prosthetic and assistive aids that would embody an individual's personality and style. Another Crip artist sister, Sadie Wilcox, and I processed our experiences of coming out Crip and explored the way we balance our bodies when walking, standing, and sometimes (but rarely) running. As I listened to Sadie share about her burn experience and the surgical procedures she went through, I was drawn to the suturing processes that she and I had both endured. Together, Sunny, Sadie, and I accompanied each other and went down memory lane where

<sup>&</sup>lt;sup>18</sup> Crip, a self-reclaimed identity used by many politicized disabled people, came from the word *cripple*, which was once a derogatory term that non-disabled people gave to disabled people in the past. With knowledge of this piece of disability history, and the influence from fellow disabled artists in the San Francisco Bay Area, I began embracing my "Crip" identity as an artistic choice and style—art with a focus on Crip people's lived experience and narratives as design elements.

disability culture and the sense of disability identity did not exist to support us when we needed them.

#### 7.7.1 Self-Care Example: *Em-Brace*

In response, I created *Em-brace*, a set of L-shaped, white plastic braces sculpted with organic contours and stitched with French knots on the top sleeve of the braces (Figure 30-33, Appendix A). The braces are tailored to Sunny's wrist curves and angles. Unlike the braces she had to wear as a child, Sunny expressed how comfortable these braces are as they support her in staying in her most natural physical state. People in society often demand to know "what's wrong with you?" when encountering a disabled person; the demand of full disclosure of disabled bodymind narratives shows the viewers' desire to assess the oddity, the disabled. When Sunny wears the braces, viewers do not get to see the inner linings, which are embellished with French knots. The intricacy and the softness of the inner linings is reserved only for Sunny. The silky and fine fabric decorated with embroidery holds Sunny's wrists as if it is crowning disability on our own terms, as we reserve intimacy and joy only for us as Crips.

#### 7.7.2 Self-Care Example: *Dermis Footwear*

To create *Dermis Footwear* (Figure 34-36, Appendix A), I cast the scars on Sadie's legs with latex and created a pair of open-toed boots based on her stories of trauma and her formation of disability identity. I researched the surgical suturing techniques used by surgeons and imitated them as I stitched the latex scar pieces to form the walls of the boots. The boots flare out on the top like layers of flower petals blossoming, which speak to the formation of disability identity. When Sadie tried these

boots on for the first time, she looked down and paused a moment, then commented on how the flaring petals look just like when her skin was peeling off during the fire.

But this pair of boots now represents a new meaning about the burn experience for her.

During the process of making these two couture pieces, Sunny, Sadie, and I each maintained a studio practice as professional artists individually. My studio functioned like a couture shop where I took their measurements. I maintained an element of surprise and only revealed the final designs to them at the last fitting. Our disabled bodymind narratives jointly cultured a liberating and therapeutic experience, which made me feel alive and held by the co-existence of fellow Crips. These two pieces were a part of my MFA thesis exhibition in 2011. Since then, this project has become a pilot project for a Crip Couture manifesto, which I am currently working on for my PhD dissertation in fashion, intimacy, and disability heritage.

#### 7.8 **Reflection and Discussion**

Throughout history, many craft practices have been deeply rooted in documenting domesticity, women's roles in society, and women's resistance (Robertson; Parker). Instead of documenting history with a pen or through typing, crafters use repetitive and time-consuming needlework to write and to create history. Crafters are instigators who explore and reveal hidden issues. As a disabled woman artist of color, I have used sewing as a way to trace, document, and create a shared disability family history. The slow stitches of care about disability narratives contrast the high-speed production that capitalistic society demands from all of us. I enacted the

suturing process (emblematic of doctors in power) and created holding spaces/garments to house my Crip sisters' bodymind histories. I touched, held, and measured my Crip sisters' bodies and adorned them with art sewn by my hands. Their Crip bodyminds rejuvenated me and answered my desire to be seen and to be touched as well. This Crip haptic intimacy is something that I would not gain from massage or yoga.

#### 7.8.1 <u>Disability Culture-Informed Care Practice</u>

What does the experience described above bring to my work as an art therapist? Tanya Cvetkovich critically examined the way in which society positions depression under the domain of medical disease in her 2012 book, Depression: A public feeling. Cvetkovich analyzed artists' and crafters' fiberwork and argued that mental illnesses, such as depression, should be seen as cultural and social phenomena. She stated: "The goal is to depathologize negative feelings so that they can be seen as a possible resource for political action rather than as its antithesis" (3). Before I was exposed to disability culture and disability activism, self-care meant a clinicians' skill. It helps increase insights about my clients/patients and countertransference— my own unresolved "issues" about disability. When defining disability solely within pathological terms, such as "personality issues," "mal-adjustments" (in an ableist world), or "psychological problems," we see "disability" as symptoms, as the targets for elimination that require coping skills and treatments. When self-care is done in connection to disability culture, it reframes my relationship to disability and the meaning of self-care as an art therapist. Sewing, as a metaphor, turns surgical procedure from fixing to archiving our shared body and emotional experiences. Crafting about disability narratives is an action to document and envision disability as social, cultural, and political entity. Self-care is no longer about the individual self, it now means a collective living process, which has the potential to generate Crip coalitions and disability self-representations.

In You Want to Be Well? Self-Care as a Black Feminist Intervention in Art

Therapy, Tillet and Tillet point to the limitation of feminist art therapy when race is left
out of the discussion on gender. The authors discuss black feminist self-care strategies
as advocacy tools for raising critical consciousness, cultivating agents of change in
young black women, and creating community care. To further enrich feminist
approaches to art therapy, I would argue that disability must be considered an identity
category alongside race and gender. In disability culture, Mad culture, and Deaf
culture, people take on disability, self-claimed madness/psychiatric illness, and being
Deaf as identity and pride (as in countering stigma and shame) and create a sense of
communal belonging and cultural affiliation.

## 7.8.2 Art Therapists' own Disability Identity and Affiliation

Is disability shameful for art therapists to claim? Does the disclosure of disability or illness risk career opportunities for art therapists? As a disabled woman art therapist of color, I rarely encounter fellow art therapists who explore and integrate their own disability, Mad or Deaf identities in professional practice, let alone how these identities intersect with their race and gender. The absences of these cultural identifications in art therapy are concerning. I once guest lectured on disability culture. A white student with a visual impairment said to me after class, "Disability means nothing," and suggested that his rejection of disability was what had led to his life achievements so far. A non-

disabled woman student of color shared, "What if disabled clients end up not socializing and integrating with the rest of us [the non-disabled] because of disability culture?" Was the former comment a reflection of how the current dialogue, training philosophy, and curriculum of art therapy have not addressed art therapists' own intersectional disability experiences? Did the latter comment show the fear of losing control over disabled people as non-disabled therapists?

As art therapists and art therapy educators, we aim to provide "culturally appropriate" services to disabled and ill client/patients and students. When we do not recognize or educate ourselves about the complexity of disability, we often inappropriately see disability from a voyeuristic point of view while we claim to be the experts. Therapists' identity formation is essential to personal and professional development. The absence of disability studies and disability culture orphans disabled art therapists' experiences of learning and working in the field of art therapy. When therapists are disabled and/or ill, their Crip, Mad, and Deaf cultural identities are also critical for them to thrive professionally. When there is no support or care network for disabled art therapists to explore our disability identity and affiliations, the art therapy field not only reinforces the dichotomy and the power dynamics between "us" (nondisabled therapists) versus "them" (disabled patients), it also risks the readiness and quality of disabled art therapists' work. If there is no space for art therapists and graduate students with disabilities to "come out" and cultivate a sense of our own disability/Mad/Deaf belongingness, how can any art therapist be expected to exercise self-care and provide culturally and ethically appropriate support to disabled clients/patients in the future? If disability is only considered a treatment target that is to be removed, intervened, and helped, doesn't the field of art therapy perpetuate a neoliberal, ableist practice with respect to disabled, ill, Mad, and Deaf art therapists?

### 7.8.3 **Summary**

The concept of self-care informed by a disability culture perspective can deepen the work both disabled and non-disabled therapists provide to clients. Self-care strategies must exist in relation to collective solidarity for sustainability. As we demystify self-care, we must remind ourselves that our work will be a crafting process: it is personal, communal, relational, and political. As artists, crafters, and art therapists, our job is to facilitate a sense of public intimacy by challenging existing values and boundaries. I recognize that it is not a one-person job to challenge the existing definitions and frameworks of disability in art therapy. I hope that the mission for advocating for fellow disabled art therapy students and practitioners will be a community care effort in the field of art therapy in near future.

#### 8. CONCLUSION

#### 8.1 Crip Couture, an Artist-Scholar's Practice

Throughout this dissertation, I described and analyzed the elements of Crip Couture (Crip desire, Crip identity, Crip specificity, Crip relationality, Crip healing and Crip collective care) to show how together they constitute a homemade theory. I argued that Crip-specific, intersectionally informed personal narratives cultivated privately or in community harness the power of the erotic to create new aesthetics, artistic practices, and community formations as a disability justice initiative. I explored how Crip Couture creates disability art as a genre by identifying and repurposing disability representation. These representations are collected from visual culture, fashion, art therapy, and disability art. I show how Crip Couture can contribute to each of these representational archives through theory and practice. While Crip Couture's focus is on unique, specific personal narratives, it contributes to fostering disability community by creating a safe space, akin to *collective testimonio*, to critique dominant culture and stitch together new cultural formations from its constituent parts.

This dissertation process has enabled me to articulate how Crip Couture is a puzzle that I have had to take apart and reassemble to reveal it as a large picture, a picture of a valuable, thriving disability cultural community. Crip Couture is an example of how we can draw on complex embodiment, which is cultural, intersectional, contextual, and profoundly relational, to both represent and create ourselves. The Crip Couture Manifesto summarizes its values and practices to create a set of guidelines for others to follow. Crip Couture draws on and expands techniques derived from social justice-based art therapy to foster a more relational, reciprocal approach to design and

fashion production. Crip Couture is aspirational, setting trends for art and community building that are sustainable and imbued with self-care and collective care.

My own personal narrative showed how my training at the School of the Art Institute of Chicago (SAIC) shaped my identity as an artist in the early 2000s. I used my identity as an artist and later as an art therapist to distance myself from being identified through a medicalized view of disability. I later learned to combine these identities by claiming what it means to be a disabled artist in the context of disability culture and activism influenced by past work as a clinical art therapist. Over the years, I have continued my relationship with SAIC through providing artist's talks to students and mentoring art therapy graduate student interns at Access Living.

Although I have not worked as an art therapist for many years, I have come to value and make use of my background and training in the field. Over the years, I have shaped my practice as a disabled artist and disability community art facilitator through social justice art therapy and disability organizing. My current practice now merges art, art therapy, and disability culture. In 2018, I started working as a part-time lecturer at SAIC teaching undergraduate studio art, introduction to disability studies, and graduate-level art therapy fieldwork and ethics classes. In the fall of 2020, I began teaching a graduate-level class at SAIC in materials and media in art therapy. By Spring 2021, I was hired as an assistant professor in the department of art therapy and counseling at SAIC, where I started contributing disability studies informed knowledge and practice to departmental policies and curriculum design. I take the groundwork that this dissertation developed into my current projects. For instance, I established the Disability Culture Activism Lab, which provides opportunities for my art therapy advisees to experience

disability-justice informed art therapy (I will provide more detail below). My organizing activities include my involvement in the disability organizations: the activist organization ADAPT, which is the Chicago Center for Independent Living, Access Living; Co-Director of Bodies of Work: A Network of Disability Art and Culture. I have integrated these activities into my theorization of Crip Couture in that Crip relationality is the emphasis of my artist-scholar activist work. Crip healing is a concept I began formulating during the last two years of my doctoral degree training. Crip Healing is the next direction that I have started taking in making wearable art and body adornments. As discussed in chapter four, the Crip Couture Manifesto provides a precursor for theorizing Crip Healing. My efforts to continue further defining and practicing Crip Healing in my practice include the following two project endeavors:

### 8.1.1 Masks for Crips Project

Crip Couture has only created wearable art with, about, or for one individual disabled person at a time in the past. Crip Couture has operated on a slow, process-oriented production system, and it has not mass-produced products serving multiple wearers. Crip Couture experimented with a new production process in response to the coronavirus in 2020.

When Covid-19 began its global outbreak, many East Asian people across the United States experienced racial hate crimes because they wore masks as a preventive measure. As a Taiwanese disabled woman living in the States, I recognized the stigma against people of color and the assumed medical conditions of the wearers. In late March, the pandemic hit the United States; nation-wide crafters and sewers began producing homemade masks to mend the shortage of masks. Most of the online crafters

organized and distributed their masks to hospital personnel and residents who lived in the nursing facilities. During that time, reasonably priced cloth masks were not yet widely available online. I became concerned about disabled people's access to masks since many people that I know do not always have steady income and live independently in communities. I began brainstorming ideas to lessen the stigma of mask wearing and the medicalized association attached to disabled people's appearance. My erotic power told me to make sure that my disabled siblings had access to masks, not as another medical or rehabilitation-based gear on their body, but as a wearable item that met their access needs, preventive care, and personal styles (Figure 37, Appendix A).

My colleague, fellow PhD candidate Alison Kopit and I both shared the feeling that we should "do something about it" after we exchanged conversations about illness and disability representations during the pandemic. We eventually organized a mask mutual aid, received donations from our network and delivered homemade cloth masks to disabled people and their personal assistants in the greater Chicago area. Alison and I organically approached this project by following disability justice's principles: sustainability, anti-capitalism, and collective care. We focused on mask requesters' and delivery team volunteers' access and health needs. We checked in with each other (about our energy level, both physical and emotional labor) and modified our outreach and delivery plans almost on a weekly basis. Homemade theory manifested in our collaboration because the mainstream, able-bodied, and capitalist production strategies did not work for us, so we created our own. While the masks did not reflect the wearers' narratives as the body adornments I had previously produced, in this project, I applied

the concept of Crip relationality and focused on developing and executing a collaborative working plan to address the urgent needs in the disability community.

## 8.1.2 <u>Disability Culture Activism Lab (DCAL)</u>

I conceptualized and founded the Disability Culture Activism Lab (DCAL) in late summer of 2020. As Director of DCAL, I founded and instituted DCAL as a response to the disability community's need for mental health support during the Covid-19 pandemic. With funding from SAIC, I began working with art therapy graduate students to train and support future disabled art therapists and disability activist allies. DCAL collaborates with Access Living's Arts and Culture Project and the University of Illinois at Chicago's Bodies of Work to organize disability community-based art and culture events and workshops. I structure DCAL based on the values and guidelines from the Crip Couture Manifesto and disability justice principles. I arrived at the intersectional lens of disability justice through my artist-in-residency with Sins Invalid in 2011. My fellow disabled residents and I were led to integrate the ten disability justice values by naming each of our access needs and creating art, narratives, movements, and performances organically as a group. I learned disability justice by immersing myself in an environment where Sins Invalid leaders embedded the disability justice principles as a daily practice in organizing community engagements and producing performance projects. This is the practice that I expect myself to carry forward in directing DCAL. I also built my vision and projects for DCAL from the legacy of the Chicago-area's disability community-based work and disability art and culture. DCAL is a site where I practice Crip Couture Manifesto and model community care as a disabled artist-activist, which works in complementary ways with my role as a college level professor.

#### 8.2 **Conclusion**

Through the process of this dissertation, the power of the erotic served as the fuel for, not only my art practice, but also for creating Crip Couture as a homemade theory, an arts-based, creative research method. I built on Lorde's work and extended the meanings of the erotic to include Crip erotic, the desire for crip relationality, and crip specificity. I argue that crip relationality and crip specificity are the mechanism for firing up the fuel to produce visual and haptic knowledge about disability. Crip erotic is a desire to provide and facilitate access intimacy with and for other disabled people. The Crip Couture Manifesto lays out the roles and the expectations of Crip Couture makers and all participating parties. It also requires them to center access need check-ins as a part of the communication process, and a way to define and personalize the meanings of access intimacy.

Disability justice is the spine of Crip Couture's art-making and community-building practices. To fully honor disability justice's grassroots activism as I produce work in academia, I continue expanding and challenging my understanding and practice of disability justice through working with disability justice's founders. Sins Invalid's executive/artistic director, Patty Berne, one of Ford Foundation's Disability Futures Fellows and Sins Invalid's creative director, Nomy Lamm, invited me to collaborate with them and create an art piece, "KelpHelp," with a focus on disability justice and climate justice.

"KelpHelp" consists of 200 pieces of hand-cut, six-feet long, olive green felt fabric, which was manufactured with eco-friendly, recycled materials (Figure 38-39, Appendix A). Each KelpHelp strip ends with two large rabbit-ear-like shapes, which

were modeled after the shape of my hands. Each strip also has its sides cut into a smaller version of my hands, which is organically placed and no strip has the same design. It was mailed out to 200 participants with this statement:

This is a six foot-long kelp, here to help, produced by crip hands during the pandemic. You can use it to measure social distance. You can wrap it around your body. You can dance with it and sing to it. You can turn it into a bracelet, a necklace, a crown, or a sling, or cut the kelp into shapes that make you feel home.

KelpHelp was commissioned by Ford Foundation and was made available for participants at the Disability Futures Virtual Festival on July 19th and 20th, 2021. KelpHelp continues the "knowing-making" (Hamraie, "Building Access" 99) fashion of Crip Couture. The process of making KelpHelp--cutting the fabric into the shapes of my hands--enabled me to tap into the creative energy in working with art materials that I put on hold during dissertation writing. The blisters on my fingers and sprains on my wrist from cutting fabrics reminded me of my physical limitations and my tendency to not ask for help from others. Then, I understood why Patty instituted funding for hiring assistants for me if needed. I ended up recruiting three assistants who self-identify as people with disabilities. I chose them because I too wish to hold their hands when we need to social distance ourselves. Instead, having them create my hand shapes on fabric, metaphorically fulfilled our shared desires for holding each other during the pandemic. This knowing-making process made me realize that the "homemade" in the homemade theory is about treating our disabled bodymind as a home, and we need to provide maintenance to the home by accepting help, connections, care, and knowledge from

other disabled siblings and family members. Crip Couture, a homemade theory, is a site for forming Crip kinship. As we attend to each other's access needs, we model for fellow disabled people by resisting mainstream disability representations. We activate our authorship and rescript disability narratives by providing a home for Crip self-care and collective care.

In this dissertation, I discuss how I define and produce new meanings of disability through my creation of artwork and facilitation of community art workshops. These discussions are evidence of how Crip desire enacts itself to search and research for collective care as a method for sustaining disability culture. The projects described in this dissertation have helped me theorize Crip relationality, consent, and collective care within the disability community in virtual (and also material) space and time (with mail delivered to people's homes). This dissertation marks a knowing-making process, which pushed me to discover new terrains to continue and explore after this dissertation. New terrains include theorizing Crip healing as an extension of Crip Couture, and how cripspecific aesthetic approaches can serve as a foundation for mental health care and art therapy pedagogy. As I am putting the final revisions of this dissertation together, I wrap one of the six-feet-long KelpHelp fabric strips around my body to remind myself that my doctorate training began with a desire to understand my own complex embodiment through creating body adornments and community art engagements. Now, my crip desire, crip erotic, is not going to stop as this dissertation project is coming to an end. My Crip erotic will stay activated and sustained by nurturing the disability community connections which I have created with other disabled people in the past years. Together, we will continue and create more homemade theories collectively.

# APPENDIX A



Figure 1. Disability community art workshop signages

Image description: Colorful hand-painted signages and props, including images of a microphone, uterus, ear, crowns, and a solidarity fist. Texts read, "Free, Today, Speaking, Woman is here!"



Figure 2. International Women's Day photobooth project at Access Living
Image description: A biracial woman wheelchair user holds several props, including a magnifying glass,
solidarity fist, uterus and a "consumer control" steering wheel, in her hand and on her lap. She looks up to
the direction of the ceiling.



Figure 3. Embrace, 2011, plastic, fabric and embroidery thread

Image description: A close-up of a disabled woman model's hands wearing the braces and resting her hands on her lap.



Figure 4. "One of Us" used as a design element.

Image description: Hand-made greeting cards, the center card has an outline of a two-finger hand and encloses the text "One of us." In the back, cards have multiple lines of printed texts, "Gooble Gobble One of us."



Figure 5. *Blowfish*2002, handmade felt, sponge and fish bone

Image description: A soft, black ball sculpture (resembling a basket) with a sharp curved fish bone erecting upward.



Figure 6. *Blowfish* (with artist's hand)

2002, handmade felt, sponge and fish bone

Image description: A soft, black ball sculpture (resembles a basket) with a sharp curved fish bone erecting upward. A hand with two fingers inserted into the hole of the sculpture and the fish bone sits between the two fingers.



Figure 7. Metamorphisis (with artist's hand)

2001, sterling silver

Image description: A hand with two fingers wearing a sterling silver butterfly ring, which hangs a sterling silver cocoon pendant. A small, silver butterfly cuff rests on the model's wrist.

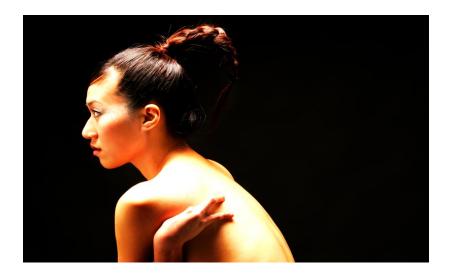


Figure 8. Armed and Beautiful Series, (series 1: I, alert)

2005, Digital photography

I knew you were watching me.

Your eyes were preying.

You made me sick... made me feel naked.

Image description: A profile image of a topless Taiwanese woman with a dramatically high ponytail looking straight ahead with a determined and fierce face against a pitch-dark background. She embraces her body by placing her hand with two fingers on her back.



Figure 9. *Armed and Beautiful Series*, (series 2: Animal Instinct) 2005, Leather, red oak, polymer clay & digital photography I thought, one day, I would grow up like a real woman.

I want to stand tall, stand still, like a real woman in her high heels.

So I can be strong and protect myself, I can fight you like a wild animal.

Image description: A pair of feet born with two curved toes wear high heel shoes with leather straps and sharp, white horns. The heels sit underneath the toes instead of the heels. Sharp horns are positioned snuggly in the negative spaces between the model's curved toes. Dramatic lighting on the model's legs and feet form a sharp contrast against the pitch-dark background.



Figure 10. Armed and Beautiful Series, (series 3: Armed and Beautiful)

2005, Leather, red oak, polymer clay & digital photography

I am ready for you! I imagine if I were really naked, I would be brave, I would look back at you with no doubts and no fears. It's a promise I made to myself. I will be strong, and I won't fall.

Image description: A disabled Taiwanese woman with two fingers wears only a pair of black capri pants and a pair of high heel shoes with sharp white horns. She squats down, leans her upper torso forward and rests her two-fingered hand on her waist on a white pedestal. She stares into the camera with a straight face.



Figure 11. Reclaiming Me (View 1)

2005, digital photography

Image description: A woman sits with her back facing the viewer. A masked doctor in his white gown sits across from the woman in a doctor's office room.



Figure 12. Reclaiming Me (View 2)

2005, digital photography

Image description: A close-up view of the doctor's hand examining the woman's hands in scrubs on a table.



Figure 13. Reclaiming Me (View 3)

2005, digital photography

Image description: A woman looks into a hand-held mirror. To her left, a doctor preps for a procedure with his back facing the viewer.



Figure 14. Reclaiming Me (View 4)

2005, digital photography

Image description: A woman crosses her arms and stares into the camera, leaving a doctor sitting at his desk in the background.



Figure 15. Gallery 901 storefront view

Image description: A glass-storefront gallery with a white wooden door. Two white banners with text and images each suspended from the ceiling inside the glass walls.



Figure 16. Project ImPerfect baby onesies on display

Image description: Two baby onesies on clothes hangers. The one on the left only has one long sleeve and colorful prints of various disabled people's hand and foot shapes. The one on the right has one long and one short sleeve. It has a print of an abstract line drawing in different shades of blue.



Figure 17. "Skinny," (work-in-progress documentation)

2014 ~ On-going, Skin flakes, silk organza, sewing thread, embroidery thread and lotion.

Image description: A small pile of skin flakes with various shapes and sizes sits next to a work-in-progress "pod" which is partly sewn with thread and sheer fabric and contains a pile of skin flakes.



Figure 18. "Skinny"

2014 ~ On-going, Skin flakes, silk organza, sewing thread, embroidery thread and lotion Image description: Three panels, each contains small sacs made with transparent/silky fabric. The shapes of the sacs vary organically. Tiny pieces of human skin flakes rest inside the sacs. They are embroidered with red, salmon colored and white threads.



Figure 19. Hair Undies artist book (studio production shot)

2019, Stamped images printed on paper

Image description: stacks of card size papers printed with texts and an image of a person's naked lower torso with two hands resting on this person's pelvic area. A notebook, ink pads, and a keyboard sit in the background.



Figure 20. Hair Undies artist book (Finished artist's books)

2019, Stamped images printed on paper

Image description: Stacks of artist's books with texts printed on their cover.



Figure 21. Hair Undies Letter

2019, Text and stamped image printed on paper

Image descriptions: Ten sheets of printed letters, each was signed and printed with a stamp at the bottom corner of the letter. The stamp design has a pair of long rabbit-ear-like shape, enclosed text reads, One of Us.



Figure 22. Hairy Undies (Series 1)

2019, Stretchy fabric, thread and donated hairs.

Image description: A full frontal shot of the lower torso of a woman of color, wearing an undie stitched with a cluster of dark hair on the pubic area. She has two fingers on each hand and two toes on each foot. Each of her hand rests by the hair cluster on each side. There is a small cluster of fine hair dropped on the floor right next to her toes.



Figure 23. Hairy Undies (Series 2)

2019, Stretchy fabric, thread and donated hairs.

Image description: A full frontal shot of the lower torso of a woman of color, wearing an undie stitched with a cluster of fabric balls on the pubic area. Fabric balls contain short pieces of hair. She has two fingers on each hand and two toes on each foot. Each of her hands cradles the pubic area on each side. There is a small cluster of fine hair dropped on the floor right next to her toes.



Figure 24. A tactile sample of Hair Undies made available at the exhibitions.

Image description: A pile of hair balls, wrapped inside sheer fabric. Some hairs stick out of the fabric, and some are scattered outside of the hair balls.



Figure 25. Photobooth project

Image description: Text reads, international women's day. Two black women each hold photobooth props, including a solidarity fist, a mustache and a large painted microphone labeled with "speak out" against a bright red drop cloth. They pose in the back of a Latina woman in a wheelchair. There is a partial view of the top of a gigantic heart in front of her.



Figure 26. Photobooth project: wheelchairs are sexy

Image description: Text reads, international women's day. Two disabled women in power chairs posing with a large heart-shaped prop, which says, "wheelchairs are sexy." Both press their lips together as in a pout and suck in their cheeks for a duck face camera shot.



Figure 27. Workshop with students

Image description: A group of students pose in both standing and sitting positions. Each of them holds photobooth props, including a watering can, a megaphone, red lips, a "POW" signage, a microphone, an eye and a bag with label "POWER SEED."



Figure 28. *Gloves for 2*, series 1

Studio documentation photographed in 2001, found object and thread

Image description: A pair of orange yellow gloves are sewn with black stitches for two-fingers against a dark purple velvet background.



Figure 29. Gloves for 2, series 1 Photoshoot

Studio documentation photographed in 2001, found object and thread

Image description: A Taiwanese woman with olive tan complexion resting her head on a wooden table, where her arms embrace. She looks at her hands wearing a pair of tailor-made orange gloves for her two fingers. A pair of metal scissors, black threads and five, cut-off glove fingers rest between her head and her hands.



Figure 30. *Em-Brace* (view 1)

2011, plastic, embroidery thread, and fabric

Image description: A light skin model in a coral-colored skirt and a beige bandeau takes up the left side of the photograph against a light background. The model wears a white, L-shaped wrist braces cradle her wrists, which naturally curve inwards. The L-shaped braces have a hard surface, but with organic, wavy edges close to the model's hands. The model's forearms are cuffed with soft and creamy fabric embroidered with clusters of white and pinkish French knots (tiny ball shaped stitches). A thin mesh fabric forms ruffles on the top of the braces.



Figure 31. Em-Brace (View 2)

2011, plastic, embroidery thread, and fabric

Image description: A light skin model in a coral-colored skirt and a beige bandeau sits on a chair wrapped in white frabric. The model wears a white, L-shaped wrist braces cradle her wrists, which naturally curve inwards. Her fingers curve and rest gently next to each other. The L-shaped braces have a hard surface, but with organic, wavy edges close to the model's hands. The model's forearms are cuffed with soft and creamy fabric embroidered with clusters of white and pinkish French knots (tiny ball shaped stitches). A thin mesh fabric forms ruffles on the top of the braces.

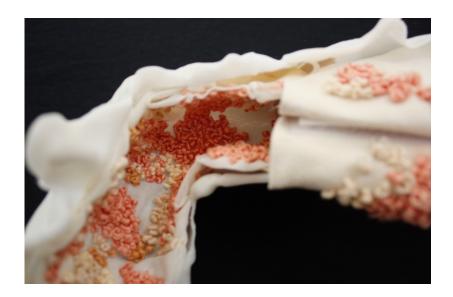


Figure 32. *Em-Brace* (detail view)

2011, plastic, embroidery thread, and fabric

Image description: A close shot of a L-shaped wrist braces with curvy plastic wedges. The braces' interior is lined with a soft and creamy fabric embroidered with clusters of white and pinkish French knots (tiny ball shaped stitches).



Figure 33. *Em-Brace* (detail shot from the side)
2011, plastic, embroidery thread, and fabric
Image description: A clusters of white and pinkish French knots (tiny ball shaped stitches) are embroidered on the inside wall of a plastic shell.



Figure 34. Dermis-Footwear

2011, latex, plastic, cast human scar, and thread

Image description: A light-skin model in a pair of open-toe, calf-height, latex and plastic boots. There is uneven skin-like surface, where thick scars form creases and bumps in brownish, orange and beige colors on the boots. Skin-like latex pieces lightly drape themselves like flower petals blooming on top of the boots. Large openings on the front and side of the boots reveal the model's burn scars. Black stitches are used to hold the wall of the boots together. The model's toes have turquoise nail polish. Parts of the soles were made with a layer of white plastic, which has an organic, fluid quality.

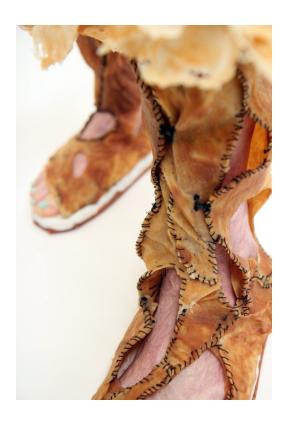


Figure 35. Dermis-Footwear (detailed view 1)

2011, latex, plastic, cast human scar, and thread

Image description: A close shot of a pair of open-toe, calf-height, latex and plastic boots with uneven skin-like surface, where thick scars form creases and bumps in brownish, orange and beige colors on the boots. Black stitches are shown on the edges of the latex pieces.



Figure 36. Dermis-Footwear (detailed view 2)

2011 (detail shot), latex, plastic, cast human scar, and thread

Image description: Skin-like latex pieces lightly drape themselves like flower petals blooming on top of a pair of latex boots.



Figure 37. Masks for Crips Project (One of Us Mask)

2020, fabric and thread

Image description: A long black hair Taiwanese woman wearing an olive-green cloth mask with prints of multiple two-finger hands and text, "One of Us" enclosed inside the hand shapes.



Figure 38. KelpHelp

2021, felt

Image description: This is a photograph of about 12 unrolled olive green felt strips with bunny ear shapes modeled after the shape of the artist's two-finger hands. They lined up diagonally and almost fill the entire picture.



Figure 39. *KelpHelp* (production shot)

2020, felt

Image description: A few rolls of olive green felt strips with bunny ear shapes modeled after the shape of the artist's two-finger hands. Parts of them are rolled and parts are unrolled.

#### **APPENDIX B**

Chun-Shan Yi 1529 S. State Street, Apt 18G, Chicago, IL 60605

January 9th, 2021

Meghan Moe Beitiks The Center for Sustainable Practice in the Arts 3805 Los Feliz Blvd, #5 Los Angeles, CA 90027

Dear Ms. Beitiks

I am a Ph D candidate in the department of Disability and Human Development at the University of Illinois at Chicago (UIC). I am requesting permission to use the following material in my dissertation. The dissertation will be made available to the public on the web via INDIGO, UIC's online institutional repository. I wish to include the following:

Reprint CSPA Quarterly, issue 18, 2017 Work title: Skinny (Page 48-51)

Your signing of this letter will confirm that The Center for Sustainable Practice in the Arts owns the copyright to the above-described material. If this request meets with your approval, please sign this letter where indicated below and return it to me digitally. Thank you very much.

Sincerely,

Chun-shan Yi

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE:

My signing of this letter confirms that The Center for Sustainable Practice in the Arts owns the copyright to the above-described material. Chun-shan Yi (Sandie Yi) is permitted to reprint **Skinny** in her dissertation.

Chun-Shan Y

#### **APPENDIX C**

Copyright statement from *Wordgathering: A Journal of Disability Poetry and Literature* website:

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#### APPENDIX D

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Chun-Shan Yi 1529 S. State Street, Apt 18G, Chicago, IL 60605

May 18th, 2020

Amanda Devine Routledge, Taylor & Francis Group 605 Third Ave., 21st Floor, New York, NY 10158, USA

Dear Ms. Devine,

I am a Ph D candidate in the department of Disability and Human Development at the University of Illinois at Chicago (UIC). I am requesting permission to use the following material in my dissertation. The dissertation will be made available to the public on the web via INDIGO, UIC's online institutional repository. I wish to include the following:

Reprint Chapter 8 in Art Therapy for Social Justice Radical Intersections (edited by Savneet Talwar, 2018)

Chapter title: Res(Crip)ting Art Therapy: Disability Culture and Art as a Social Justice Intervention

Your signing of this letter will confirm that Routledge, Taylor & Francis Group owns the copyright to the above-described material. If this request meets with your approval, please sign this letter where indicated below and return it to me digitally. Thank you very much.

Sincerely

Chun-shan Yi

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#### **APPENDIX E**

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Chun-Shan Yi 1529 S. State Street, Apt 18G, Chicago, IL 60605

May 18th, 2020

Amanda Devine Routledge, Taylor & Francis Group 605 Third Ave., 21st Floor, New York, NY 10158, USA

Dear Ms. Devine,

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Chapter title: Demystifying the Individualistic Approach to Self-care: Sewing as a Metaphorical Process for Documenting Relational and Communal Care in Disability Culture

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- Yi, Chun-shan, and Savneet Talwar. "Disability, art, and art therapy." *Disability in American Life: an Encyclopedia of Concepts, Policies, and Controversies*, edited by Tamar Heller et al., vol. 1, ABC-CLIO, an Imprint of ABC-CLIO, LLC, 2019, pp. 40–44.
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### **VITA**

# Chun-shan (Sandie) Yi

**Education:** 

2011-2022 Ph D Candidate in Disability Studies, University of Illinois at Chicago

2011 Master of Fine Arts, University of California Berkeley

2005 Master of Arts in Art Therapy, School of the Art Institute of Chicago

2003 Bachelor of Fine Arts, School of the Art Institute of Chicago

**Credentials:** 

2020 - Present Board-Certified Registered Art Therapist (ATR-BC)

Art Therapy Credentials Board

2007 - 2020 Taiwanese Registered Art Therapist (TRAT)

Taiwan Art Therapy Association

**Academic Appointments:** 

2021- Present Assistant Professor

Art therapy & Counseling, School of the Art Institute of Chicago Courses: Materials and Media in Art Therapy; Disability Studies (Art Therapy/Visual & Critical Studies); Community Practice & Helping Relationships; Professional Development & Career Counseling

2019-2020 **Lecturer** 

Art therapy & Counseling & Contemporary Practice, School of the Art

Institute of Chicago

Courses: Research Studio I & II (Contemporary Practice); Fieldwork I & II; Ethics I & II (Art Therapy); Disability Studies (Art Therapy/Visual & Critical

Studies); Materials and Media in Art Therapy

2014-2018 Graduate Teaching Assistant Instructor

Disability and Human Development, University of Illinois at Chicago

Course: Disability in American Film

Fall 2010 Graduate Student Instructor

Department of Art Practice, University of California Berkeley, CA

Course: Introduction to Visual Thinking

Spring 2010 Graduate Teaching Assistant

Department of Art Practice, University of California Berkeley, CA

Course: Art, Medicine and Disability

Spring 2009 Instructor

Taipei National University of the Arts, Taipei, Taiwan

Course: Creative Arts Therapy (co-taught with Weng-Fan Tsai, ATR-BC)

Fall 2008 Instructor

National Taipei University of Education, Taipei, Taiwan

Course: Art Therapy and Disability

2007-2009 **Lecturer** 

Center for General Education, Taipei Medical University, Taiwan

Course: Humanities and the Arts

2007-2009 **Instructor** 

Taipei Fine Arts Museum, Taipei, Taiwan

Course: Introduction to Art Therapy

2007-2009 Lecturer

Mackay Memorial Hospital, Taipei, Taiwan

Course: Gender, Ethics & Differences for Resident I

## **Clinical Experiences:**

2013 **Facilitator** 

Disability Art and Culture Group, Taiwan Access for All Association

Responsibilities: Provided community-based, expressive peer support group through creative arts. Facilitated group experience and conversations about personal expression and collective activism. Participants included disabled

adults, disabled college students and disabled activists.

2012-2015 **Community Art Group Facilitator** 

Access Living, Metropolitan of Chicago, Chicago, IL

Responsibilities: Develop, coordinate and facilitate community art workshops and art classes, focusing on disability culture, disability peer support, Independent Living and community cohesion. Participants include disabled youth and adults,

staff and the general public.

2008-2010 **Disability Community Organizer** 

> Informal, grassroot community organization; facilitated individual and group peer support to raise disability consciousness and skills in self-advocacy. Conducted informal participatory-action research. Provided peer mental health support.

Taipei. Taiwan

2006~2009 **Art Therapist** 

> Childhood Burn Foundation of the Republic of China, Taipei, Taiwan Responsibilities: Coordinated and co-designed clinical creative arts therapy program for the annual summer camp. Provided art therapy in-service and disability sensitivity training course to staff, volunteers, and social workers; designed and implemented creative arts therapy program, based on the social inclusion model for children and teen burn survivors. Collaborated with social workers and medical professionals.

Fall 2008 **Art Therapist** 

Taiwan Spinocerebellar Ataxia Association, Taipei, Taiwan

Responsibilities: Provided mental health support through art therapy group work

to care-takers of patients diagnosed with spinocerebellar ataxia.

2008 Art Therapist

Hospice Foundation of Taiwan, Taipei. Taiwan

Responsibilities: Coordinated and developed an expressive arts therapy program for children and adults. Co-facilitated expressive arts therapy with a team of therapists. The traveling program provided intensive art therapy workshops in several cities in Taiwan. Provided mobile "teaching-workshops" on art therapy and hospice to school teachers and hospital personnel in Taiwan.

2007-2008 **Art Therapist** 

Resource Center, Shih-Chien University, Taipei, Taiwan

Responsibilities: Developed and facilitated art therapy workshops for college students and groups with emphasis on disability identity for disabled college students. Groups included gender-specific groups and cross-disability groups. All groups utilized multisensory-based art making and writing as a part of the

psycho-social process work.

2007-2008 **Art Therapist** 

Good Shepherd Social Welfare Services, Single Parents Center and Adoption

Center, New Taipei City, Taiwan

Responsibilities: Provided emotional and psychological support to a children's group. Provided support and education to family and parents. Provided individual therapy to a disabled child in the adotion program. Implemented art-based assessment and supervised an art therapy graduate student and a social work

student.

2006-2008 **Art Therapist** 

Kuan Ching Foundation (Disability Organization), Taipei, Taiwan

Responsibilities: Facilitated Art as Activism groups for adults with disabilities. Group themes included: Body image, self-expression and personal fashion statement. The groups focused on self-advocacy and the use of the disabled

bodies in art and performance to build dialogues with the society.

2005-2006 **Art Therapist** 

Department of Recreational Therapy and Child-Life

Shriners Hospitals for Children, Chicago, IL

Responsibilities: Provided individual and group art therapy to both in-patient and

out-patient. Facilitated art therapy workshops and assessments.

2005-2006 **Art Therapist** 

Jane Addam Hull House, Chicago, IL

Responsibilities: Provided after-school art therapy programs for elementary school, middle school and high school students. Groups addressed behavioral,

emotional and psychological needs

Fall 2005 **Contract-Based Art Therapist** 

Connection Arts Chicago (Revised name: Art & Soul), Chicago, IL

Responsibilities: Provided community base art therapy program for children,

youth and families.

**Contract-Based Art Therapist** Fall 2005

Rehabilitation Institute of Chicago, Chicago, IL

Responsibilities: Provided art workshops for children with physical disabilities.

2004-2005 Art therapy Intern

Anixter Center and Anixter School, Chicago, IL

Responsibilities: Provided group art therapy for adults with disabilities in the Wellness Program. Provided art therapy group for students (ages 14~21) with behavioral, emotional, or developmental disabilities at the therapeutic day school.

Supervised by Angela Lyonsmith, ART-BC

Summer 2004 Art therapy Intern

Mackay Memorial Hospital, Taipei, Taiwan

Responsibilities: Provided art therapy to out-patient and In-patient at the Burn Center and the department of Social Service. Supervised by Suellen Semekoski, ATR-BC

Spring 2004 **Art therapy Intern** 

> Pilsen Little Village Mental Health Community Center, Chicago, Illinois Responsibilities: Facilitated Open Studio Process and horticultural therapy; provided support to adults with psychiatric disabilities. Supervised by Deborah Gadiel, MAAT

**Professional Practice:** 

2021- Present Co-director

Bodies of Work: A Network of Disability Arts & Culture, Chicago

2021- Present Review Board Member, Journal of American Art Therapy Association

2020-Present Program Director

Disability Culture Activism Lab, Department of Art Therapy and

Counseling, School of the Art Institute of Chicago & Access Living

2008 **Disability Film Festival Curator** 

Kuang-Ching Foundation, Taipei, Taiwan

2010-2019 Thesis Second Reader

Dept. of Art therapy & Counseling

The School of the Art Institute of Chicago

Leadership & Services:

2021- Present The Art Therapy Collective Advisor

Department of Art therapy and Counseling School of the Art Institute of Chicago

2021 Award Juror Panel, selecting emerging artists for the Emerging Awards

Unlimited, London, UK

2020- Present Committee Member

Workplace Accessibility and Accommodation Committee

School of the Art Institute of Chicago

2020 Co-chair

Workplace Accessibility and Accommodation Committee

School of the Art Institute of Chicago

2019- Present Access & Inclusion Consultant

National Theater & Concert Hall, Taipei, Taiwan

2019 Selection Committee Member

Wynn Newhouse Awards, NYC, New York

2017 Conference Co-organizer

Museum Conference on Inclusion and Accessibility, Taipei, Taiwan

2013-2015 **Steering Committee Member** 

Chicago Cultural Accessibility Consortium, Chicago, IL

2013 **Disability Culture Advisory Committee Member** 

University of Illinois at Chicago

Winter 2010 **Disability Activism Training Facilitator** 

Co-Facilitator: Rahnee Patrick, Director of Independent Living, Access

Living, Chicago

The League of Welfare Organizations for the Disabled, Taipei, TaiwanProvided disability conscious-raising materials and training programs for emerging disability activists. Organized a local protest and

provided participant-centered peer support.

**Publications: Edited Journal** 

Yi, C. S., & Moon, C. H. (2020). Editorial: Art Therapy and Disability Studies (C. S. Yi & C. H. Moon, Eds.). Art Therapy: Journal of the American Art Therapy Association, 37(2), 59-61.

### **Publications: Referred Article**

Bridger, M., Erlikh, S., & Yi, C. S. (2021). Reverberation! A New Wave in Disability Art. *Canadian Journal of Disability Studies*, 10(2), 7–26. https://doi.org/10.15353/cjds.v10i2.784

Yi, C. S. (2016). Disability Culture, Social Justice and Power in Museum Service and Accessibility Practices. *Journal of Museum & Culture*, (12), 5–42.

### **Publication: Invited Book Chapter**

- Yi, C. S. (2020). Demystifying the Individualistic Approach to Self-care: Sewing as a Metaphorical Process for Documenting Relational and Community Care in Disability Culture. In
- L. Leone (Ed.), Craft in art therapy: diverse approaches to the transformative power of craft materials and methods (pp. 72–89). essay, Routledge.
- Yi, C. S. (2018). Res(Crip)ting Art Therapy: Disability Culture and Art as a Social Justice Intervention." In S. Talwar (Ed.), Art Therapy for Social Justice: Radical Intersections (pp. 161–177). essay, Routledge.
- Yi, C. S. (2010). From Imperfect to I Am Perfect: Reclaiming the Disabled Body Through Making Body Adornments in Art Therapy. In C. H. Moon (Ed.), *Materials and media in art therapy: Critical understandings of diverse artistic vocabularies* (pp. 103–117). essay, Routledge. Publication: Invited Works
- Yi, C. S. (2020). The Crip Couture Manifesto. *Wordgathering: A Journal of Disability Poetry and Literature*, 14(2). Retrieved from <a href="https://wordgathering.com/vol14/issue4/disability-futures/yi/">https://wordgathering.com/vol14/issue4/disability-futures/yi/</a>.
- Yi, C. S., & Talwar, S. (2019). Art Therapy. In T. Heller, S. P. Harris, C. J. Gill, & R. Gould (Eds.), *Disability in American Life: An encyclopedia of concepts, policies, and controversies* (Vol. 1, pp. 40–44). essay, ABC-CLIO, LLC.
- Yi, C. S. (2017). <u>Art for Social Impact: Aging & Disability Research in Taiwan</u>. [Unpublished document], British Council in Taiwan. (in English and Chinese)
- Yi, C. S. (2017). Skinny. CPSA Quarterly (The Center for Sustainable Practice in the Arts), 48–51.
- Yi, C. S. (2017). 殘缺與性慾: 畸怪身體的「殘」美學 [Disablement and Sexuality: Crip aesthetics of the disabled body]. *ArtPlus Magazine*, (64)47–49.
- Yi, C. S. (2017, October). 表演藝術無障礙: 文化平權政策與劇場無障礙的美學 [Accessible Performing Arts: Cultural Rights Policy and the Aesthetics of Theater Accessibility]. *PAR: Performing Arts Review*, 94–95.
- Yi, C. S. (2017). *Claire Cunningham's Give Me a Reason to Live*. Taipei; National Theater and Concert Hall.
- Yi, C. S. (2016). Reading disability in film, Me Before You. *Yuan Ze University Cultural News*, 55.

Yi, C. S. (2012, Winter). Self-supervision and continue education for art therapists. *Taiwanese Art Therapy Association Newsletter 17, 3.* 

Yi, C. S. (2008). 殘酷兒 [Crip Queer: Disabled and Queer Identity in Action]. In P. Wong & Y. R. Chen (Eds.), 2008 認識同志手冊 [2008 Learn about LGBTQ Handbook] (pp. 104–107). essay, Taiwan Gender/Sexuality Rights Association.

## **Publications: Commentary & Review**

Yi, C. S. (2017, June 28). Review of *劇場再現身心障礙的反思《看不見的視界》[Reflection on Disability Representation in Theater in World Unseen]*. Retrieved from https://pareviews.ncafroc.org.tw/?p=25096.

Yi, C. S. (2007, December 9). Project ImPerfect: Disability Identity. China Times, p. 8.

### **Publications: Interview**

Green, C. (2020, April 1st). Disability Culture\_Crip Ally Care Exchange with Sandie Yi. (No.26) [Audio podcast episode] In *Storyminders*. Pigeonhole. <a href="https://soundcloud.com/storyminders/ph-26">https://soundcloud.com/storyminders/ph-26</a>

Schmit, C. & Vyn, J. (2019, March 26th). Chun-Shan (Sandie) Yi (No. 17) [Audio podcast episode]. In *DisTopia*. DisArt. <a href="https://www.disartnow.org/podcasts/episode-17-chun-shan-sandie-yi/">https://www.disartnow.org/podcasts/episode-17-chun-shan-sandie-yi/</a>

### **Publications: Book Cover Art**

Kim, J. B., Kupetz, J., Lie, C. Y., & Wu, C. (2021). Sex, identity, aesthetics: The work of Tobin Siebers and disability studies. University of Michigan Press.

O'Toole, C. J. (2019). Fading scars: My queer disability history. Reclamation Press.

Millett-Gallant, A., & Howie, E. (2017). *Disability and art history*. Routledge.

Wendell, S. (2013). *The rejected body: Feminist philosophical reflections on disability.* (J. Y. Kang, E. Kim, & J. S. Hwang, Trans.). Greenbee.

Moon, C. H. (2010). *Materials & Media in art therapy: Critical understandings of diverse artistic vocabularies*. Routledge Taylor & Francis Group.

#### **Solo Exhibitions:**

- 2019 Rethinking Fashion Through Disability (Solo exhibition), Pique Gallery, Covington, Kentucky
- 2006 It's meant to(Two) be... EXTRAART Gallery, Prague, Czech Republic
- 2006 Project Imperfect, Open Studio Project Gallery, Evanston, IL

### **Group Exhibitions:**

- 2021 Dis-an exhibition highlighting the advocacy work of Artists with Disabilities, Chicago Printmakers Collaborative, Chicago, IL
- 2021 Indisposable: Structures of Support After the ADA, Ford Foundation
- 2020 Recoding CripTech, SOMArts Cultural Center, San Francisco, CA

- 2020 Rapid Response Mask Collection Project, Center for Design and Material Culture, University of Wisconsin-Madison
- 2020 Chun-Shan (Sandie) Yi's "Crip Couture," East Window, Colorado
- 2019 Disability and Perspective, Museum of Contemporary Art, Chicago
- 2019 Wynn Newhouse Award Exhibition, Lubin House, Palitz Gallery, New York City
- 2018 <u>Process and Presence: Contemporary Disability Sculpture</u>. Frederik Meijer Gardens & Sculpture Park, Grand Rapids, Michigan
- 2018 Chicago Disability Activism, Arts, and Design: 1970s to Today. Gallery 400, University of Illinois at Chicago, Chicago, IL
- 2018 <u>RE/Configurations: art, disability, identity</u>. Newhouse Center for Contemporary Art, New York
- 2015 <u>Transforming Community: Access, Community Art, Disability, Diversity, Ecology and Spirituality. Westbesth Gallery, NYC.</u>
- 2014 MAAT 30th Anniversary Celebration Exhibition, The LeRoy Neiman Center, The School of the Art Institute of Chicago, Chicago, IL
- 2014 <u>Senses of Care: Mediated Ability and Interdependence</u>, Gallery@calit, University of California, San Diego, CA
- 2014 Out of the Basement: This is Our Art, Jane Addams Hull House Museum, Chicago, IL
- 2013 Fashion Forward, Annual Benefit of the Tellin' Tales Theatre, National Hellenic Museum, Chicago, IL
- 2013 Disabled by Normality, DOX Cetre for Contemporary Art, Prague, Czech Republic
- 2013 Humans Being II, Women Made Gallery, Chicago, IL
- 2013 The Small, Dark Room. Erasing the Distance. Chicago, IL
- 2012 What Can a Body Do? Cantor Fitzgerald Gallery, Haverford College, Haverford, PA
- 2011 <u>Medusa's Mirror: Fears, Spells & Other Transfixed Positions.</u> Pro Arts Gallery, Oakland, CA
- 2011 Resident Alien, the Sins Invalid Artists In Residence Show. Mission Cultural Center for Latino Arts, San Francisco, CA.
- 2011 <u>"Inarguably Uncertain,"</u> the 41st Annual University of California, Berkeley Master of Fine Arts Graduate Exhibition, Berkeley, CA
- 2010 Footnote7. Worth Ryder Gallery, University of California, Berkeley, CA
- 2009 A Matter of Course, Swell Gallery, San Francisco Art Institute, San Francisco, CA
- 2008 Myth Of Differences, Gallery project, Ann Arbor, MI
- 2006 Ways To See, International Festival of Inclusive Arts, Hong Kong, China
- 2006 Human Being: Disability in Contemporary Art, Chicago Cultural Center, Chicago
- 2006 Navigation/Negotiation Exhibition, Gene Siskel Film Center, Chicago, IL
- 2006 Expression of Ability: Community Artists Speak from Within, Jane Adams Hull House, Chicago, IL
- 2006 Expression of Ability: Community Artists Speak from Within, Jane Addams Hull House, Chicago, IL
- 2005 Fashion Show, The School of the Art Institute of Chicago, Chicago, IL
- 2005 Art in Action: Artists, Healers, Educators Take Action Through Art Making, ARC Gallery and Educational Foundation, Chicago, IL
- 2005 "Call me disabled? Look at me again!"—MAAT Thesis Exhibition, Woman Made Gallery, Chicago, IL
- 2005 Art of Connection: Signs Along Shared Paths, Gallery 2, The School of the Art Institute of Chicago, Chicago, IL
- 2003 Making It In Metal, California College of Arts and Crafts, San Francisco, CA

2003 Bachelor of Fine Arts Graduate Exhibition, Gallery 2, The School of the Art Institute of Chicago, Chicago, IL

# **Collaborative Art & Community Projects:**

- 2021 Kelp Help with Sins Invalid
- 2020 "What time is it?" with Irina Zadov. Radical Intimacy: Extending our Care
- 2018 Make-Up Art for Rebirth Garments, Evanston Art Center
- 2017 Audio description in Mandarin Chinese Claire Cunningham's performance "Give me a reason to live" National Theater and Concert Hall of Taiwan
- 2014 Extreme Embroidery (Metamorphosis) Series with Beth Schnellemberger
- 2010 Costime Design for *Lab Run*. Directed by Ph.D. students at Theater, Dance and Performance Studies, University of California, Berkeley.
- 2010 Bare Bones Butoh, "Invagination and the Beloved" with Neil Marcus, and Petra Kuppers, May 8th, Studio 210, San Francisco, CA
- 2009 Participating Artist in Olimpias Performance Research Project, Subterranean Arthouse, Berkeley, CA Director: Petra Kuppers

## Residency:

- 2018 <u>Unlimited International Placement, London, UK</u>
- 2015 Disability Culture Symposium Fellow, University of Michigan, Ann Arbor
- 2013 Access Living—Independent Living Center, Chicago, IL
- 2009 Artist-in-Residency with Sins Invalid, San Francisco, CA

### **Invited Lecturers, Panels, and Presentations**

- 2022 Disability Power Series: A Conversation on Art, Disability and the Body. February 10th,
- 2022 [Panel Discussion] Disability Lead, Chicago, IL
- 2021 Cripping Style: Disability & Design, Fashion Studies [Panel Discussion], Fashion Studies, Columbia College, Chicago, IL
- 2021 Co-Strugglers: Creative Arts Therapies, Critical Pedagogy, and Ethical Response/ability. April 9th, 2021 [Panel Discussion], Art Therapy Spring Conference, Southern Illinois University, Edwardsville
- 2021 *Crafternoon for co-strugglers*. April 9th, 2021 [workshop, co-facilitator], Art Therapy Spring Conference, Southern Illinois University, Edwardsville.
- 2021 Exploring Disability, Bias & Access, Consciousness-centered graduate school for counseling and art therapy. [Invited Panel Discussion] Art Therapy/Counseling department, Southwestern College & New Earth Institute.
- 2021 <u>Panel Discussion, Craft in Art Therapy: Diverse Approaches to the Transformative Power of Craft Materials and Methods</u>. January 16th, 2021. [Panel Discussion] Fuller Craft Museum.
- 2021 <u>Unlimited Discusses... International Perspectives</u>. January 15th, 2021 [Panel Discussion] British Council
- 2020 Art Activism: Visual & Performing Arts as Vehicles for Change. [Panel Discussion] Crip Camp Impact Campaign.
- 2019 *Crip Couture: Disability & Art.* [Invited Lecture] Disability and Design Class, Department of Comparative Human Development, University of Chicago
- 2019 *Disability and Art.* [Invited Lecture] Department of Occupation Therapy, Rush University, Chicago, IL

- 2019 Disability and Democracy. [Invited Presentation] Faculty Meeting. Department of art therapy and counseling, School of the Art Institute of Chicago
- 2019 Representing Disability: Strategies for Arts Practitioners Seminar. [Invited Keynote] Arts with the Disabled Association, Hong Kong
- 2019 Refiguring the Cultural Contours of Embodiment: Recent Work in Disability Arts. [Panel Discussion] International Health Humanities Conference, DePaul University, Chicago
- 2018 <u>Equality: Disability, intersectional identities and the arts</u>. September 4th, 2018. [Panel Discussion] Unlimited: The Symposium, Unicorn Theatre, London, UK
- 2018 Body Adornment and Disability Culture. [Invited Workshop] Claire Cunningham Project, London, UK
- 2018 Artist Talk: Meeting Artist Sandie Yi. Process and Presence Contemporary Disability Sculpture, Frederik Meijer Gardens, Grand Rapids, MI
- 2018 *Disability and Art.* [Panel Discussion] Critical Discourse Panel, Process and Presence Contemporary Disability Sculpture, The HUB Soundstage, Grand Rapids, MI
- 2018 *Disability Activism & Strategy*. [Invited Workshop], East Asia Disability Studies Forum, Taipei, Taiwan
- 2018 Intervening Ableism: Disability Culture and Creative Strategies for Disability Activism. [Invited Keynote] East Asia Disability Studies Forum, Taipei, Taiwan
- 2018 Accessibility Training. [Invited Workshop] Taiwan Traditional Theatre Center, Taipei, Taiwan
- 2018 *Disability and Fashion.* [Visiting Lecture] Department of Chinese Literature, National Tsing Hua University, Hsinchu City, Taiwan
- 2018 *Disability and Helping Profession.* [Visiting Lecture] Department of Social Work, Asian University, Taichung Taiwan
- 2018 *Disability Fashion and Disability Aesthetics.* [Invited Presentation] Eslite Bookstore, Taipei, Taiwan
- 2018 *Disability and Art Therapy*. [Visiting Lecture] Introduction to Art Therapy Class, Department of Art Therapy, The School of the Art Institute of Chicago
- 2018 *Disability and Body Adornment*. [Visiting Lecture] "Stitch by stitch" class, Department of Art Therapy, School of the Art Institute of Chicago
- 2017 *Disability Studies and Performance Studies.* [Invited Presentation] Disability Studies Working Group, Taipei University, Taipei, Taiwan
- 2017 Examining Disability through the lens of Art. [Visiting Lecture] Department of social work, Asia University, Taichung, Taiwan
- 2017 *Disability Art.* [Visiting Lecture] Introduction to Art Therapy class, Department of Art Therapy, School of the Art Institute of Chicago
- 2017 Disability Art. [Visiting Lecture] Research Studio Class: Interrogating Normal, Department of Contemporary Practice, School of the Art Institute of Chicago
- 2017 Art Therapy for Social Justice: Radical Intersections. [Panel Discussion] Department of Art Therapy, School of the Art Institute of Chicago
- 2017 Art as Activism. [Visiting Lecture] Disability Activism Class, Department of Disability and Human Development, University of Illinois at Chicago
- 2017 Advocacy, Activism & Art. [Visiting Lecture] Group Art Therapy class, Department of Art Therapy, School of the Art Institute of Chicago
- 2017 Outside In, Inside Out: Crip Art and Resistance. [Presentation] Disability as Spectacle Conference, UCLA
- 2017 "Outsider Art" Meets Crip Resistance. [Panel Discussion] Disability as Spectacle Conference, UCLA

- 2017 *Disability Art.* [Visiting Lecture] Stitch by stitch class, Department of Art Therapy, School of the Art Institute of Chicago
- 2016 *Disability Issues in Taiwanese Culture.* [Invited Presentation] Café philo at Chicago,
- 2016 Disability Activism, Disability Art and Culture.
  [Invited Presentation] Café Philo Taipei, Taiwan
- 2016 *Disability Art and Culture.* [Visiting Lecture] Graduate Institute of Interdisciplinary Art, National Kaohsing Normal University
- 2016 Coming Out Crip. [Invited Presentation] Taiwan Access for All Association, Taipei, Taiwan
- 2016 Introduction to Disability Studies. [Visiting Lecture] Department of Social Work, Soochow University, Taipei, Taiwan
- 2015 Disability Aesthetics. [Invited Presentation] Ministry of Social Welfare, Taipei, Taiwan.
- 2015 *Disability Art and Culture as activism.* [Invited Presentation] Comparative Literature Annual Conference, Taipei, Taiwan
- 2015 *Crip Couture: Disability and Fashion*. [Visiting Lecture] National Kaohsiung Medical School, Kaohsiung, Taiwan
- 2015 Disability and accessibility [Invited Presentation with co-presenter Jacky Hsu] Asia University, Taichung, Taiwan.
- 2015 Accessibility in the Arts and Culture Venues. [Invited Presentation] National Taiwan Museum of Fine Arts, Taipei Taiwan
- 2015 *Crip Couture.* [Invited Presentation] Disability Activism: From the Local to the Global class. Department of Disability and Human Devlopment, University of Illinois at Chicago.
- 2015 *Crip Couture.* [Invited Presentation] Department of Contemporary Practice, School of the Art Institute of Chicago
- 2015 Disability Art as Activism. [Invited Presentation] Grinnell College, Iowa.
- 2015 Crip Couture. [Invited Presentation] Grinnell College, Iowa.
- 2015 Disability Awareness Training (for elementary school student)s. [Invited Presentation, with co-presenters from Access Living] Gems World Academy, Chicago, IL
- 2015 Creating Accessibility in Arts and Culture Venues. [Presentation+Workshop] Taipei Artists' Village, Taipei, Taiwan
- 2015 *Disability Culture and Community.* [Visiting Lecture] Department of Special Education, National Taipei University of Education, Taipei, Taiwan
- 2015 Disability & Body Image. [Invited Workshop] Crip and Queer Support Group, Taipei, Taiwan
- 2014 *Crip Couture: Disability and Art Making.* [Visiting Lecture] Anthropology/human development class. School of the Art Institute of Chicago
- 2014 <u>Unexpected Anatomies</u>: Extraordinary Bodies in Contemporary Art. October 18, 2014. [Invited Presentation] Art, Anatomy, and the Body: Vesalius 500 Festival, The Center for the History of Medicine and Public Health, NYC, New York.
- 2014 Lost in Translation? Understanding, accessing, and representing disability in Art Therapy. [Invited Workshop] Illinois Art Therapy association.
- 2014 <u>Pleasure of the erotic body chaos: Disability Culture, Crip Couture and Fashion Justice.</u> March 26th, 2014. [Art Therapy Faculty Search Public Presentation], Department of Art Therapy and Counseling, School of the Art Institute of Chicago
- 2014 Disability Arts and Culture and Art Therapy. [Visiting Lecture] Materials and Media in Art Therapy class. Department of Art Therapy, School of the Art Institute of Chicago

- 2014 Advanced Conversations about Disability Culture and community. [Visiting Lecture]
  Human Growth and Development and Family Art Therapy. Department of Art Therapy,
  School of the Art Institute of Chicago
- 2014 *Crip Couture & Body Adornment.* [Visiting Lecture] Mold Making and Casting class. Department of Sculpture, School of the Art Institute of Chicago
- 2014 Debates. Crip Couture and Fashion Justice in Disability Art. March 29th, 2014 [Panel Discussion] <u>Access All Areas: Live Art and Disability (NYC edition)</u>, Abrons Art Center, New York
- 2014 What's social model of Disability? Arts and Culture Perspective on Disability and Social Work. [Visiting Lecture] Department of Social Work, Asia University, Taichung, Taiwan
- 2013 Disability Arts and Disability Culture: The Chicago Experience. [Panel Discussion, co panelists, Tsao-Fu Hsu, Li-chi Yo, Hsiu-tzi Yu and Ling Chang] Taiwan Access for All Association, Taipei, Taiwan
- 2013 Disability and Art. October 23rd. [Visiting Lecture] Materials and Media in Art Therapy class. Department of Art Therapy, School of the Art Institute of Chicago
- 2013 Art Therapy as Public Practice. June, 2013. [Invited Lecture & workshop with Dr. Pat B. Allen] Taiwan Art Therapy Association, Taipei, Taiwan.
- 2013 Accessible Chicago and Disability Arts and Culture." June. [Invited Presentation] Taiwan Access for All Association, Taipei, Taiwan
- 2013 Intersection/intervention, disability in museums. [Invited Panel Discussion] Jane Addams Hull-House Museum, Chicago, IL
- 2013 What is Disability Studies?—Disability Studies through the lens of Disability Arts. May 31st, 2013 [Invited Presentation] Disability Studies Round Table Symposium, Taipei University, Taipei, Taiwan
- Disability Studies, Disability Arts and Art Therapy: A Social Justice Framework. April
   19th, 2013. [Invited Presentation, co-presenter, Cathay Moon] Annual Spring Art
   Therapy Symposium. Poesis: Forming, Performing, Transforming, Mount Mary College
- 2013 Art Therapists as Culture Makers Within Disability Community. March 24, 2013 [Invited Workshop] Territories of Encounter: The Art Therapy Assemblage: a symposium on interdisciplinary, community-based arts practices, School of the Art Institute of Chicago
- 2013 Art, Social Change and the Public sphere. March 24, 2013 [Panel Discussion] Territories of Encounter: The Art Therapy Assemblage: a symposium on interdisciplinary, community-based arts practices, School of the Art Institute of Chicago
- 2013 Couture and Fashion Justice. [Invited Presentation] "In the Loop," Lecture series on design, innovation and entrepreneurship, Illinois Institute of Design, Chicago, IL
- 2012 *Disability Arts and Art Therapy.* [Visiting Lecture] Materials and Media in Art Therapy class. Department of Art Therapy, School of the Art Institute of Chicago
- 2012 The Art of Art Therapy. [Invited Presentation] College of Nursing, University of Illinois at Chicago
- 2012 From the doctor's office to the art gallery: Sandie Yi's radical Vision of Beauty. March 31st, 2012. [Invited Presentation] de Young Museum, San Francisco, CA
- 2011 *Disability Awareness, Disability Identity and community.* [Visiting Lecture] Introduction to Art Therapy class. Department of Art Therapy, University of Taipei, Taiwan
- 2010 Made in Taiwan? Made in USA? Re-examine the USA cultivated disability identity in Taiwan. June 2010. [Presentation] Society for Disability Studies, The 23rd Annual Conference, Philadelphia, PA.
- 2010 *Disability Awareness, Disability Identity and community.* [Visiting Lecture] Introduction to Art Therapy class. Department of Art Therapy, University of Taipei, Taiwan

- 2009 Disability Awareness, Disability Identity and community. [Visiting Lecture] Introduction to Art Therapy class. Department of Art Therapy, University of Taipei, Taipei, Taiwan
- 2008-2009 Traveling Presentation: *Project ImPerfect.* Wanderer's Project. Various locations in Taiwan
- 2008 *Disability Awareness, Disability Identity and community.* [Visiting Lecture] Introduction to Art Therapy class. Department of Art Therapy, University of Taipei, Taiwan
- 2008 Artful and Therapeutic Camp Experience. [Invited Presentation, co-presenter Wen-Fan (Tiffany) Tsai and Balas King]. Creative Arts Therapies Symposium, National Taipei University of Education, Taipei, Taiwan
- 2008 Making Body Adornments for the disabled body as art therapy. June 2008. [Invited Presentation] Concern for Mental Health 208: Open the Heart in Arts, Symposium on Arts and Mental Health, Hong Kong, China.
- 2008 Body Image, Body Adornment and Art Therapy. [Keynote Presentation] Concern for Mental Health 208: Open the Heart in Arts, Symposium on Arts and Mental Health, Hong Kong, China
- 2008 Therapeutic Art Making in Building Positive Body Image. [Invited Workshop] Concern for Mental Health 208: Open the Heart in Arts, Symposium on Arts and Mental Health, Hong Kong, China
- 2008 *Cross-Cultural Supervision*. [Panel Discussion, co-presented with Dr. Barbara Fish and Erin Redmond] 37th Annual Conference of the American Art Therapy, New Orleans, I A
- 2007 Art Therapy in Taiwan. [Panel Discussion,with Li-wen Wong, Ming-Fu Wu, Chiaoling Su, and Wen-Fan (Tiffany) Tsai] Art Therapy Symposium National Taipei University of Education, Taipei, Taiwan
- 2006 Call Me Disabled? Look at Me Again!': An Art Therapist's Use of Body Adornments and Photographic Self-Portraits as a Means to Revise the Hurtful Gaze and Reevaluate Disability Identity. November, 2006 [Invited Presentation] International Conference of Creative Arts Therapies, Tokyo, Japan
- 2006 Call Me Disabled? Look at Me Again!': An Art Therapist's Use of Body Adornments and Photographic Self-Portraits as a Means to Revise the Hurtful Gaze and Reevaluate Disability Identity. [Presentation] The 8th European Art Therapies Conference: Grounding the Vision to advance Theory and Practice, Rethymno, Crete, Greece.
- 2005 Call Me Disabled? Look at Me Again!': An Art Therapist's Use of Body Adornments and Photographic Self-Portraits as a Means to Revise the Hurtful Gaze and Reevaluate Disability Identity. August, 2005 [Presentation] IVSA Conference: Re-Viewing Bodies: Embodiment, Process, and Change International Visual Sociology Association, Trinity College, Dublin, Ireland.
- 2005 Call Me Disabled? Look at Me Again!': An Art Therapist's Use of Body Adornments and Photographic Self-Portraits as a Means to Revise the Hurtful Gaze and Reevaluate Disability Identity. April 2005. [Invited Presentation] Aliens of Extraordinary Ability: A symposium on immigration, alienation, and contemporary art, Center for the study of Race, Politics and Culture, University of Chicago, IL.

### **Recognition: Awards, Nominations & Grants:**

- 2021 (Project lead at Access Living) ECLIPSE Grant Project with Shirley Ryan Ability Lab, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Washington D.C.
- 2021 Make a Wave, 3Arts, Chicago, IL
- 2021 Nomination for 3Arts Award for Visual Artist, 3Arts, Chicago, IL

- 2021 Nomination for the 2022 USA Fellowship, United States Artists, Chicago, IL
- 2021 Faculty Enrichment Grant Recipient, The School of the Art Institute of Chicago
- 2020 Faculty Enrichment Grant Recipient, The School of the Art Institute of Chicago
- 2018 Wynn Newhouse Awards 2019, New York City, NY
- 2014 Nomination for "Everyday Sheroes", National Asian Pacific American Women's Forum
- 2013 Study Abroad Education Scholarship, Ministry of Education, Taiwan
- 2013 Anne Hopkins Scholarship
  Awarding researches in Disability and Sex, Relationships and Dating; Social Model of
  Disability and Social Entrepreneurship, University of Illinois at Chicago recipient & 3E
  Love, LLC, Batavia, IL
- 2010 Eisner Award—The highest creative achievement of the year—University of California Berkeley, CA
- 2009 DeBatz Fellowship Award, University of California Berkeley, CA
- 2007 Wanderer Project Artist Grant Recipient, Cloud Gate Dance Theater of Taiwan, Taipei, Taiwan
- 2006 Disability Arts and Culture Honor, The Disability Pride Parade Planning Committee, Chicago, IL
- 2006 Sandra Rosenberg Memorial Fund Award Recipient, Open Studio Project, Evanston, IL
- 2005 Graduate Fellowship Award Recipient, The School of the Art Institute of Chicago
- 2003 Trustee Scholarship for the Master of Arts in Art Therapy Program, The School of the Art Institute of Chicago, Chicago, IL
- 2002 Peer Encouragement Award, The School of the Art Institute of Chicago
- 2002 Outstanding Collaborative Effort Award, The School of the Art Institute of Chicago
- 2001 Leadership Award, The School of the Art Institute of Chicago

### **Bibliography:**

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Cachia, A. (2017). Disabling Surrealism: Reconstituting Surrealist Tropes in Contemporary Art. In A. Millett-Gallant & E. Howie (Eds.), *Disability and art history* (pp. 132–154). essay, Routledge.

Marien, M. W. (2015). Nature and the body politic. In *Photography: A cultural history* (pp. 477–486). essay, Pearson.

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Kuppers, P. (2014). Studying disability arts and culture: An introduction. Palgrave Macmillan.

Lindgren, K., Cachia, A., & Kelly, G. (2014). Growing Rhizomatically: Disability Studies, the Art Gallery and the Consortium. *Disability Studies Quarterly*, *34*(2). <a href="https://doi.org/https://dsq-sds.org/article/view/4250/3590">https://doi.org/https://dsq-sds.org/article/view/4250/3590</a>

Tabone, J. (2014). Regard: a research through history, culture, anthropology and artists on the power of the stare: an attempt to challenge the starer in overcoming the awkwardness between the starer and staree (dissertation).

Cachia, A. (2012). What can a body do? *Wordgathering: A Journal of Disability Poetry and Literature*, *6*(3). Retrieved from https://wordgathering.syr.edu/past\_issues/issue23/arts/cachia.html.

Ware, L. (2011). When Art Informs: Inviting Ways to See Disability. *Learning Disability Quarterly*, 34(3), 194–202. <a href="https://doi.org/10.1177/0731948711417557">https://doi.org/10.1177/0731948711417557</a>

Millett-Gallant, A. (2012). Disarming Venus. In *The disabled body in Contemporary Art* (pp. 25–49). essay, Palgrave Macmillan.

Elisová, J. (2006). Interview with Chun-Shan (Sandie) Yi . *Art Therapy: Journal Czech Art Therapy Association, Focusing on Art Therapy, Music Therapy and Drama Therapy*, (12), 46–48.

### Press & Media:

Greer, B. (2021, November 16). *5 adaptive fashion creatives you should know about: Spoonflower blog.* Spoonflower Blog, Custom-printed fabric, wallpaper and home decor. Retrieved from https://blog.spoonflower.com/2021/11/5-adaptive-fashion-creatives-to-know/

Wu, C. (2021, August 26). *從大門之外到舞台之上,表演藝術的共融心願景 [Inclusive Performing Arts: Intention and Vision]* National Theater and Concert Hall. Retrieved from <u>shorturl.at/efnNO</u>

Wright, N. (2021, February 1). *Curation highlight: Rapid response mask collecting project*. Center for Design and Material Culture. Retrieved from <a href="https://cdmc.wisc.edu/2021/02/01/curation-highlight-rapid-response-mask-collecting-project/">https://cdmc.wisc.edu/2021/02/01/curation-highlight-rapid-response-mask-collecting-project/</a>

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Bruno, G. (2020, February 26). *The disabled artists using Tech to defy their bodies' boundaries*. Dazed. Retrieved from <a href="https://www.dazeddigital.com/art-photography/article/48044/1/the-disabled-artists-using-tech-to-defy-their-bodies-boundaries-criptech">https://www.dazeddigital.com/art-photography/article/48044/1/the-disabled-artists-using-tech-to-defy-their-bodies-boundaries-criptech</a>

Westin, M. (2020, February 24). *In "Recoding CripTech," artists highlight the vital role of hacking in disability culture*. ARTnews.com. Retrieved from <a href="https://www.artnews.com/art-in-america/aia-reviews/recoding-criptech-hacking-disability-sara-hendren-1202678282/Seikaly, R. (2020, February 12). *Recoding Criptech proudly asserts disability as an identity and culture*. KQED. Retrieved from <a href="https://www.kqed.org/arts/13874625/recoding-criptech-somarts-review">https://www.kqed.org/arts/13874625/recoding-criptech-somarts-review</a>

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Wu, S. (2019, July 11). 藝術共融》「身心障礙者過去是被隔離的」 兩廳院推文化平權拆心牆 [Inclusive Arts, "Disabled people have lived in isolation." NTCH's Cultural Equality policy is tearing down the wall]. Yahoo! News. Retrieved January 12, 2022, from <a href="mailto:shorturi.at/fsul8">shorturi.at/fsul8</a>

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Cronin, Linda J. (2012, June). YI's Crip Couture and Wearable Art. Wordgathering, 6 (2). Retrieved June, 29, 2012, from <a href="http://www.wordgathering.com/issue22/art/yi.html">http://www.wordgathering.com/issue22/art/yi.html</a>.

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Lo, Y. (2009). Dream Makers: Girls chasing their dream journeys. Vogue Taiwan, (150).

#### **Professional Affiliations:**

2018- Present Chinese Associations of Museum, Taiwan 2016- Present Taiwan Society for Disability Studies 2011- Present Society for Disability Studies 2003-2017 American Art Therapy Association Illinois Art Therapy Association