RECOGNIZING MY WHOLENESS THROUGH ART-MAKING





Creative Generation believes that youth create change. We are a values-driven global collective that collaborates with young creatives and those who cultivate their creativity to take local actions towards global changes in pursuit of a more just world. Founded in 2019, Creative Generation operates five signature programs: The Campaign for a Creative Generation, the Institute for Creative Social Transformation, The Academy for Creative Leadership, the Incubator for Creative Impact, and the Foundation for a Creative Generation.

Learn more at: www.Creative-Generation.org



The Institute for Creative Social Transformation produces new and honors existing forms of knowledge and ways of knowing, while dismantling systemic barriers to sharing and learning.

This report was authored by Audrey Maxner

Suggested Citation:

Maxner, A. (2022). Recognizing My Wholeness Through Artmaking. Creative Generation. DOI

©2022. Creative Generation and Audrey Maxner



This work is licensed under the Creative Commons Attribution-NonCommercial 4.0 International License. To view a copy of this license, visit http://creativecommons.org.

Table of Contents

Introduction: How Did This Start? 4	
Framing of Inquiries 5	
What is Disability Justice? 5	
Why Heuristic Inquiry? 7	
Why Arts-Based Research? 12	
What Was the Project? 15	
A Reflection: The Disabled Art of Play	33
Bibliography 38	

"Able-bodied people are shameless about really not getting it that disabled people could know things that the abled don't. That we have our own cultures and histories and skills. That there might be something that they could learn from us. But we do, and we are."
– Leah Lakshmi Piepzna-Samarasinha, Care Work: Dreaming Disability Justice ¹

Introduction: How Did This Start?

A multitude of emotions, weaved into ongoing and interconnected disabled experiences, have gone into the creation of this project. In reflecting back on the entire process, I am given the chance to revisit these emotions, to confront them, to examine them, and to question them. I ask myself: Where was I? What was I doing? How was I feeling? Why?

Disability itself can feel like living within a whirlwind of questions. Where is my bodymind?² How is it today? Will it be the same tomorrow? The day after? Will there be something new that happens that I need to plan for? Is there even a way to plan for it? But what happens if I don't?

When the summer began, I was sitting in this line of questioning and pondering the dissonance that it caused. Only two months prior, my partner had spent several weeks in the hospital, unable to eat and not receiving the care they needed from their doctors. The entire time, as their health declined further and further and we entered the new reality their bodymind and my own demanded, I wondered what this change would mean: How could we find care? Were we alone in this experience?

The following publication offers both my reflections and a report about my inquiry, process, project, and learnings. To start, I will share the discourse on the framing inquiries of my project and describe my process. Then, I will share the project itself and the work produced as a result. To conclude, I will summarize my learnings and offer a reframing to our approach of wellness in the field of practice.

Framing of Inquiries

As I reflected on my own living experiences from May through August 2022, I pondered the questions I shared in the previous section. As a current student and emerging professional working at the intersection of arts, education, and social change, I spent some time with the documented knowledge³ on a number of topics. Each of these topics framed my inquiry and shaped my final project. In the following section, I share the foundations I built on in my process.

² "Bodymind" is a term used by leaders of the disability justice movement to show that our bodies and our minds are connected. The usage of this term foregrounds the understanding that experiences of the bodymind are integrated and cannot be separated.

The term "documented knowledge" is used by Creative Generation to describe the type of review of knowledge that is documented in the field: broader than published literature, documented knowledge could be any type of knowledge that is shared by anyone with the lived experience or expertise on a topic, ranging from peer-reviewed published articles to blogs, interviews, or recorded dialogues.

What is Disability Justice?

In searching for answers, I surrounded myself with the words and knowledge shared by elders of the disability justice movement. The disability justice movement was launched in 2005 by disabled activists of color Patty Berne, Mia Mingus, and Stacey Milbern⁴ to "centralize the needs and experiences of folks experiencing intersectional oppression, such as disabled people of color, immigrants with disabilities, queers with disabilities, trans and gender non-conforming people with disabilities, people with disabilities who are houseless, people with disabilities who are incarcerated, people with disabilities who have had their ancestral lands stolen, amongst others." This movement and framework expands upon the Disability Rights Movement, which established civil rights for people with disabilities. However, as the Commission on Disability Equity writes, "While the disability rights movement did have 'many successes in advancing a philosophy of independent living and opening possibilities for people with disabilities . . . the lives of sick and disabled people of color (SDQTPOC) were 'invisibilized.' This means that the voices, perspectives, and contributions of SDQTPOC were often erased."

I am by no means an expert on disability justice and I do not wish to speak for the movement or to present this as a complete overview of it. There is a deep, intricate history connected to ableism and perceived normativity in the United States and the oppressive, interrelated systems that exclude, subjugate, and pathologize disabled people. In addition, disability justice is a living movement, shaped by the existing, emerging, and evolving leaders who have the capacity to drive the movement's work forward.⁸

Rather, I am approaching disability justice as a disabled, queer person of color grappling with what it means to be disabled, in a disabled relationship, and living a liberated disabled lifestyle. I have found comfort in the disability justice framework, which states that "all bodies are unique and essential; all bodies have strengths and needs that must be met; we are powerful, not despite the complexities of our body, but because of them; and all bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and we cannot separate them." Alongside this framework, I have found a set of principles which align with my way of being which I am learning to integrate wholly into my life. They are the guiding principles of this project and are as follows:

- Intersectionality "We do not live single issue lives" Audre Lorde. Ableism, coupled with white supremacy, supported by capitalism, underscored by heteropatriarchy, has rendered the vast majority of the world "invalid."
- **Leadership of Those Most Impacted** "We are led by those who most know these systems" Aurora Levins Morales.
- **Anti-Capitalist Politic** In an economy that sees land and humans as components of profit, we are anti-capitalist by the nature of having non-conforming body/minds.

^{4 &}quot;Disability Rights, Studies & Justice: Disability Justice," Hampshire College, June 9, 2022, https://resourceguides.hampshire.edu/c.php?g=759682&p=5447794.

⁵ "Disability Justice," Project LETS, accessed August 18, 2022, https://projectlets.org/disability-justice.

⁶ The acronym SDQTPOC stands for Sick & Disabled, Queer & Trans People of Color.

^{7 &}quot;What is Disability Justice?" CODE, accessed August 18, 2022, https://code.as.ucsb.edu/what-is-disability-justice/

⁸ To learn more about the disability justice movement, read "What is Disability Justice?" on the Sins Invalid website, doodle in the "Disability Justice from A to Z" coloring book, peruse writings on the blogs Leaving Evidence and Disability Visibility Project, listen to audiobooks produced by crip elders such as "Care Work: Dreaming Disability Justice," or watch Youtube videos such as "My Body Doesn't Oppress Me, Society Does" interviewing crip elders on the movement.

[&]quot;What is Disability Justice?" Sins Invalid, June 16, 2020, https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice.

- **Commitment to Cross-Movement Organizing** Shifting how social justice movements understand disability and contextualize ableism, disability justice lends itself to politics of alliance.
- **Recognizing Wholeness** People have inherent worth outside of commodity relations and capitalist notions of productivity. Each person is full of history and life experience.
- **Sustainability** We pace ourselves, individually and collectively, to be sustained long-term. Our embodied experiences guide us toward ongoing justice and liberation.
- **Commitment to Cross-Disability Solidarity** We honor the insights and participation of all of our community members, knowing that isolation undermines collective liberation.
- **Interdependence** We meet each others' needs as we build toward liberation, knowing that state solutions inevitably extend into further control over our lives.
- Collective Access As brown, black and queer-bodied disabled people we bring flexibility and creative nuance that go beyond able-bodied/minded normativity, to be in community with each other.
- **Collective Liberation** No body or mind can be left behind only moving together can we accomplish the revolution we require. 10

I slowly began this project towards the end of May. At first, I struggled to identify my topic of inquiry. Surrounded by so many dovetailing questions, which one did I most wish to explore? I started with what I knew: that I wanted to learn about myself, find community with others, and leave space for answers and themes to emerge over time. With this understanding, I searched for qualitative forms of research that might fit my needs and eventually landed upon heuristic inquiry.



Why Heuristic Inquiry?

Heuristic inquiry was originated by Clark Moustakas, initially as "an informal process of assessing and meaning-making rather than as a research approach."11 However, the methodology of heuristic inquiry became more formalized with the publication of Moustakas' book, Loneliness, in 1961. In this book, Moustakas used his personal experience and relationship with loneliness during his daughter's heart surgery to draw deeper insight into the human condition and the world we live in. 12

Heuristic inquiry brings together the subjective experiences of the researcher and of those with shared experiences in order to understand the nature of a phenomenon. Douglass and Moustakas describe heuristics as "a passionate and discerning personal involvement in problem solving, an effort to know the essence of some aspect of life through internal pathways of the self."13 This form of inquiry is focused on relational, intersubjective, empathetic discourse; holism, personhood, and what it means to be human; and process, rather than arriving at a particular truth or destination. It is the study of living experience and how our internal pathways connect us to ourselves, others, and to the world.14

¹⁰ Principles of Disability Justice," Sins Invalid, September 17, 2015, https://www.sinsinvalid.org/blog/10-principles-of-disability-justice. 11 Nevine Sultan, Heuristic Inquiry: Researching Human Experience Holistically (California: SAGE Publications, Inc, 2019), 2.

¹² Clark E. Moustakas, *Loneliness* (Pickle Partners Publishing, 2016), Kindle.

Lee Bach, "Chapter 7: Heuristic Scholar: Heuristic Inquiry and the Heuristic Scholar," Counterpoints 183, (2002): 91-102, http://www.jstor. org/stable/42976833.

Nevine Sultan, Heuristic Inquiry: Researching Human Experience Holistically (California: SAGE Publications, Inc, 2019), 8-9.

The descriptors and characterizations of heuristic inquiry, as outlined by Nevine Sultan, are as follows:

- Exploratory, serendipitous, and discovery-oriented
- Process- and content-focused
- Intuitive, introspective, and reflexive
- Experiential, embodied, and holistic
- Existential and humanistic
- Culturally embedded and emancipatory
- Relational, authentic, and participatory
- Imaginative and creative
- Nonlinear, fluid, and flexible¹⁵

In order to complete heuristic inquiry and embed it within personhood, Sultan outlines six phases of heuristic inquiry researchers should engage with. These are initial engagement, immersion, incubation, illumination, explication, and creative synthesis.¹⁶

In **initial engagement**, the researcher has a first encounter "with a topic of extreme interest through an autobiographical experience that, though it is internal and personal to [the researcher], is potentially of social and universal significance." Initial engagement may occur at multiple points throughout the study; it is an exploratory way of formulating a question that lingers with the researcher.

This leads to **immersion**, where the researcher embodies and lives the question fully, after it is identified and formed. Moustakas stated that by immersing a core question into every thought, feeling, and sensation in every sleeping and waking moment, the researcher begins to "live the question." This allows for the researcher to have ambiguous boundaries with the question and for the topic of inquiry to adapt to the researcher's emergent needs. Immersion therefore informs the process of inquiry and discovery while releasing any attachment to a specified goal, finding, or outcome.

To allow the knowledge collected during immersion to process and integrate, **incubation** brings the researcher away from the research. By disengaging from intense and focused attention on the question, the researcher allows the "tacit dimension" to be at work, generating knowledge unconsciously. This requires the researcher to truly surrender to the process and allow realizations to emerge serendipitously and unexpectedly.

Moving back and forth between immersion and incubation is central to heuristic inquiry. It permits the heuristic inquiry process to be "rooted in experiential time, not clock time." ¹⁸

This ultimately leads to **illumination**, where knowledge resurfaces into conscious awareness. In Sultan (2019), Moustakas writes, "Illumination opens the door to a new awareness, a modification of an old understanding, a synthesis of fragmented knowledge, or an altogether new discovery of something that has been present for some time yet beyond immediate awareness." ¹⁹

¹⁵ Ibid, 3.

¹⁶ Ibid, 93.

¹⁷ Ibid, 11.

¹⁸ Ibid, 11.

¹⁹ Ibid, 97.

Following the cyclical cycles of initial engagement, immersion, and illumination come explication and creative synthesis. **Explication** is the phase where a researcher explores deeply "what has come into awareness through indwelling, focusing, and self-disclosure."20 It requires the researcher to attend to their own awarenesses, feelings, thoughts, beliefs, and judgments to create an individual depiction of the core themes illuminated from the data collected. Once this individual depiction is formed, a composite depiction can be created showing a holistic depiction of the themes. This characterizes the universal themes of the overall study.

Creative synthesis, the final phase of heuristic inquiry, is then a "realization of the comprehensive essences of the topic of inquiry."21 Bringing the knowledge back into the individual, the researcher finds a creative way to generate an interpretation that accurately represents and depicts the experience of the inquiry. This can be through any number of different forms, such as drawing, storytelling, collaging, recordings, and more.

I chose this form of inquiry for this project because it was aligned with what I hoped to accomplish. I had no specific goal or destination in mind and no singular question to guide my research. Rather, I sought a type of inquiry which would take shape in an emergent and exploratory way throughout the research process. In addition, I recognized that my endeavor to understand disability in a deeper way came from personal experience and possessed personal significance to me. Heuristic inquiry's self-reflective and self-explorative framework, adaptable and discovery-driven nature, humanistic foundation, and non-hierarchical questioning fit into the exploration I was constructing. Sultan stated, "A heuristic researcher's final destination is often a seque into a new beginning."22

In reflecting on Sultan's statement, I discovered two questions of inquiry to guide this project:

How can I begin to liberate myself? How can I begin to liberate my art?

Ibid, 98. 21 Ibid, 99.

Ibid. 79.

Why Arts-Based Research?

Once I had established heuristic inquiry as my method for processing my two guiding questions, I contemplated which type of research would support it most effectively. Arts-based research came to my mind for several reasons.

- First, the final step in heuristic inquiry is the expression of the research findings and themes in creative ways. This naturally transitions into arts-based practices, which create tangible representations of the passages of time.
- Second, heuristic inquiry centers process, self-exploration, and cultural observation. Therefore, I needed a type of research that would allow immersion into my processes, provide space for self-reflection, and draw connections between the personal and the collective traits all inherent and available in artmaking.
- Third, my experiences with disability are entangled in artmaking. As a classical musician, I grew to realize my disabled identity as it interacted with my physical playing and performing capacities. In result, questions around capitalism, productivity, and the monetization of art seeped into my relationships with disability and art.

By delving into arts-based research, I realized I was able to confront the questions, "How can I begin to liberate myself," and "How can I begin to liberate my art" most directly.

Arts-based research (ABR) is a creative movement broadening research towards a deeper understanding conveyed through aesthetic creation, representation, and interpretation. It primarily began in 1980 alongside the postmodernism movement, combating the conservative, traditional, scientific definitions of research that had been established. Elliot Eisner, who first coined the term "arts-based research," stated, "Every methodology is a way of seeing the world – and every way of seeing is a way of not seeing."²³

ABR expanded through the 1980s and early 1990s towards what ABR is today. While there are still divergent thoughts around whether ABR is a paradigm or a set of methodological tools, there is consensus that ABR is the blending and blurring of boundaries between science and art. By engaging in arts-based practices during any or all phases of research, researchers "address research questions in holistic and engaged ways in which theory and practice are intertwined." They "actively form a new visual reality by *creating* images. The visual is not just a tool for recording, analyzing, or interpreting data; it has become a tool for creating data. The visual has reached a new dimension. It has become *generative*." Pamela Smithbell, a scholar who critically examined arts-based research, further states, this "opens new ways of doing and presenting research to broader audiences."

Melissa Cahnmann-Taylor and Richard Siegesmund, Arts-Based Research in Education: Foundations for Practice (New York: Routledge, 2008), https://www.routledge.com/rsc/downloads/9780805863802_Cahnmann-Taylor1.pdf.

Patricia Leavy, *Method Meets Art, Third Edition: Arts-Based Research Practice* (New York: Guilford Publications, 2020), https://ebookcentral.proguest.com/lib/aul/reader.action?docID=6268652.

²⁵ Pamela Smithbell, "Arts-Based Research in Education: A Review", *The Qualitative Report* 15, no. 6 (2010): 1597-1601, doi: 10.46743/2160-3715/2010.1363.

²⁶ Ibid, 1599.

To create this new data, researchers are required to be continuously reflexive and critical regarding the quality and rigor of their processes. Yet there is no definitive way to measure the quality and rigor of an arts-based researcher. Therefore, Smithbell concludes, "As new knowledge is generated, new and more complex questions develop. It is just this reflexivity, triggered by these new questions, that supports the rigor of arts-based research." In addition, researchers can extend beyond art mediums that are purely visual, including dance, drama, music, and other creative arts media to conduct rigorous, relevant, and insightful arts-based research.

²⁷ Ibid, 1600.

What was the Project?

This project became a heuristic, arts-based self-study connecting my subjective experiences with the shared experiences of others to gain deeper understanding about living as a disabled person in the world. Following the phases of heuristic inquiry and the methodology of arts-based research, I leaned into knitting as a non-textual medium for introspective processing, visual data creation, and welcoming the disabled experience.

Knitting is a ritualized practice which moves through six steps: collecting materials, winding yarn, casting on, knitting and tinking, casting off, and blocking. Each step is crucial to creating a knit garment. Collecting the materials allows the knitter to conceptualize and prepare for a project. Winding the yarn transforms a tangled skein into a usable, workable ball that a knitter can pull from. Casting on sets a project in motion – the first step to a garment being created. Knitting and tinking is the act of creating the garment. Casting off brings the knitting to a close, tying off any loose ends so the garment can no longer be worked. Blocking is the final step, adjusting the final shape of the garment and preparing it to be used or worn.

For this project, I created as many knit blanket squares as I chose within the given time parameters of the project. Each square represents where I was in my reflections through shifting circumstances as I gathered knowledge about disability and disability justice. The answers that emerged from these squares were unprecedented and the organic results of my heuristic inquiry. Rather than providing my research with directional goals, knitting offered me a reassuring space for practicing heuristic inquiry and engaging with my selfhood.

The start of each square acted as an initial engagement with a new question or theme, typically formed after delving into disability justice readings. To fully live the heuristic process and to relinquish control over any intended outcome, I used a random-number generator to select which square I would be knitting from a 60 Quick Knit Blanket Squares book. My only criteria were that the squares needed to be tightly woven to provide warmth; this eliminated any form of lacework, which incorporates the intentional placement of holes into the pattern. Once a square was selected, I immersed myself in the act of knitting – a repetitive and non-strenuous physical activity and allocation of time. This in turn provided designated space for my mind to either immerse into my research question or to incubate and move away from it entirely. I naturally flowed between these two phases, changing the location and external stimulus to support whichever phase I was in and what my bodymind needed.

As a square reached completion, I would enter the illumination and explication phases through active critical self-reflection. This took the form of composing narrative storytelling, re-examining my own poetry, and generating self-reflections about my experiences. These revealed the themes, guiding questions, and disability justice principles I had consciously or subconsciously been disentangling. I integrated these ideas into each of the knitting steps: collecting materials, winding yarn, casting on, knitting, casting off, and blocking.

The result was the creative synthesis and data production of knit blanket squares and accompanied writings which provided answers as I reminded myself of my questions of inquiry: How can I begin to liberate myself? How can I begin to liberate my art?

The Project

Square 1: What Am I Doing?

Collecting the Materials

Associated Disability Justice Principle(s): Leadership of Those Most Impacted

#10 Cartridge Rib Color: Blue Started May 23rd



Image Description: A twilight blue knit square, similar to the color of well-wom denim, is on a white background. Across the width of the square are eleven columns of vertical knit stitches evenly distributed from each other. These columns alternate with small sections of horizontal purl stitches which hold the square together. This creates a stretchy, elastic, and accordion-like texture.

Loneliness, Clark Moustakas' first book utilizing heuristic inquiry in a more formalized manner, begins, "I have experienced loneliness many times in my life but until recently I lived my loneliness without being aware of it." In homage to the originator of heuristics, I will begin in a similar way: I have experienced fear many times in my life but until recently I lived my fear without being aware of it.

When I first began recognizing my disability, fear was not the accompanying emotion. For me, it started out as an answer. I was still training as a classical musician at that point, building the skills to become either an orchestral violinist or a freelance musician and slowly collecting injuries preventing me from safely pursuing such a career path. My first inhibitive injury was at 15 years old, only one year after beginning my formalized endeavors as a violinist, in my left wrist. My next was at 18 years old in my second semester at conservatory – a slight twinge of what I now know is nerve pain in my left pinky. This quickly progressed into left cubital tunnel pain, which slowly degraded my nerve sensation and strength in my left arm. My shoulder responded next – at this point, I can't remember where that pain started – and then my neck got involved, bringing the rest of my body along for the ride.

Around the middle of junior year, I started growing afraid. Things had escalated to my shoulder by that point, but I'd realized the more outspoken I became about my physical wellbeing, the more resistance I'd face from the faculty and administration at my school. What would it mean if these injuries progressed further? What if I lost support because of it? What if I weren't able to play as well as I used to? What if I weren't able to play at all?

These questions and this fear sparked my next four years of physical therapy appointments, with a combined total of five separate physical therapists. Somewhere along the way, I learned that I have a genetic condition which affects the connective tissue in my body, which affects everything else. It means allergies which require a constant stream of antihistamines; soft, stretchy skin; hypermobility and accompanying flexible joints which like to regularly sublux and dislocate; and amongst

²⁸ Clark E. Moustakas, Loneliness (Pickle Partners Publishing, 2016), Kindle.

other things, a proneness to injuries. As a violinist, contorting my body into unnatural positions for many hours a day was not helping my cause. So, disability was an answer. Once I graduated from college, I stopped playing my instrument and pursued ways of helping my bodymind. I became accustomed to observing the shifting pains, locating the needed support team, and finding ways to self-manage. My partner, a couple of years ahead of me in the realization and diagnosis process, did the same. The fear faded into the background.

Until last Spring, when an unexpected onset of full-body pain brought my partner to the hospital, screaming. I stayed in the ER with them through the night, my second time doing this in our relationship, and only left the next morning when the nurses confirmed they were being admitted. It was heavy, hard, and scary.

I realized, upon reflection, that this was the moment I became aware of my fear. No longer was it hiding in the background – it was in full-force, present, and all-consuming. My response was to ignore it and push through as best I could, falling only slightly behind in my schoolwork.

But fear can't be ignored, and it has lingered. It is now something I am carrying within my own bodymind, an awareness of the pain and the struggle disabled people experience when navigating ableist systems. It is a fear of what can happen, what might happen, and the powerlessness when faced with an uncaring and unsupportive world.

I initially purchased the knitting book used for this project as an anniversary present to my partner, one month after they were discharged from the hospital. I did not have the idea of this project in mind at the time. Rather, the project took shape as I read the writings of Leah Lakshmi Piepzna-Samarasinha, Alice Wong, Patty Berne, Valerie Novack, and more. I began learning what disability justice is, what it means for them to live at the intersection of marginalized identities, and how they form community together in creative, adaptive ways. I realized that in order to be in right relationship with disability and with myself, I needed to confront the fear I had associated with it before I could begin offering care to anyone.



Square 2: Who Am I With?

Winding the Yarn

Associated Disability Justice Principle(s): Intersectionality, Collective Liberation

#30 Bonbons Color: Blue Started May 28th



Image Description: A twilight blue knit square, similar to the color of well-worn denim, is on a white background. Across the width of the square are ornate columns which lightly protrude from the square. These columns alternate between wide, open stitches and tightly wound twists to look like candies covered in plastic wrappings. Horizontally between each column are purl stitches holding the square together.

We're all on a board that won't be overturned Dictated by the die Fighting to be heard

We're moving in circles
Existing in pieces
Laughing at the joke
Till we all fall broke

It's not a monopoly,
Playing a part unhappily
Between the margin,
we share a line
Follow it and over time

Find new aim

Forget the game

We spin and we spin Each of us trying to win We spend all our money All our paper-thin skin

On an inkling, a word A construct we heard A lesson we suffered And eventually learned

Little did we know
That it twists as it grows
A shroud slowly spread
From our toes to our nose

Till thats all we see
That's all we know
It's part of our scene
It's part of our show

Dictated till we die Fighting to be heard We are all aboard An unfurled world

Share the line And over time Find new aim Forget the game

Square 3: Where Are We Moving?

Casting On

Associated Disability Justice Principle(s): Anti-Capitalist Politic, Commitment to Cross-Movement Organizing

#2 Moss Stitch Color: Blue Started June 21st



Image Description: A twilight blue knit square, similar to the color of well-worn denim, is on a white background. The square is uniform vertically and horizontally, with alternating flat knit stitches and bumpy purl stitches. This creates a chainmail-like appearance, while maintaining a soft feel like holding fish tank pebbles in your hand.

Say what you will in your soliloquy Your hand-crafted vision Of self-indulgent fantasy Where everything is as you believe Controlled, calmed, cleaned to a tee

I see her now, this girl, so pretty In the landscape you perceive She dances through the un-reality Kept safely in captivity, She lies untouched by any need

But she knows
And outgrows
This dream
And one day soon
She'll find herself freed.

Square 4: Why Do We Do This Work? Knitting and Tinking

Associated Disability Justice Principle(s): Recognizing Wholeness, Interdependence

#29 Hugs & Kisses Color: Gray Started July 1st



Image Description: A misty gray heather square, similar to the color of an overcast and stormy sky, is on a white background. Across the width of the square are eight columns evenly distributed from each other. Each column is constructed with thick, twisted cables that are woven together to look like alternating X's and O's. These columns protrude lightly from the background of the square, creating a bumpy texture.

The pressure building in my head
Is sounding the alarm again
He lives inside of me alone
A drummer marching me to bed

He is a watcher standing guard Hiding in sight amongst the loud Forgotten until a ghost appears And he is back, fully armed

We tried before to become friends But all attempts were abandoned To truly move through life as one We needed ways to make amends I showed my guard my armor's on My rosy glasses now long gone He answered back by ringing less And started trusting I knew best

I stopped pretending he wasn't there And he stopped asking to be shared Now I know when he comes by It's cause a ghost is in disguise

Like clockwork moving, in a sense He goes angry charge to empty rest To wind himself up until it happens again My mechanism of defense

Square 5: When Is There Change?

Casting Off

Associated Disability Justice Principle(s): Collective Liberation, Sustainability

#18 Lattice Color: Gray Started July 11th



Image Descriptions: A misty gray heather square, similar to the color of an overcast and stormy sky, is on a white background. Thick bars of yam which have been cabled and twisted together crisscross over each other to form a lattice design across the entire square. This creates bordered diamonds around the square's flat, knit background, similar to a fence laid out upon the ground.

The one disability justice principle I have repeated for two squares is "collective liberation" because I felt it needed further processing. The idea seems like this big, broad, impossible dream to liberate everyone, with all of their identities, and to not leave anybody behind. Given the cultural and political climates I live within in the United States, what would this even look like?

There is an entire page devoted to the topic of liberation on the Disability Visibility Project's website, and I have read and re-read the words of Alice Wong, Leah Lakshmi Piepzna-Samarasinha, Valerie Novack, and more. They each offer insight and understanding into their perceptions and experiences, highlighting places change is needed and offering ways for change to happen. In "Cripping The Resistance: No Revolution Without Us," Leah Lakshmi Piepzna-Samarasinha speaks about the concept of making crip resistance soup. They tell the story of how they had a dream one week after Stacey's unexpected death. In this dream, Leah asks Stacey, "Who's going to make the hand sanitizer to distribute via the crip mutual aid network now? I can't do it, I only got two bottles of rubbing alcohol before everyplace sold out, I'm afraid to leave the house. We're fucked." Stacey's response was, "You make soup. That's what you're good at. Make soup."²⁹

Leah's conclusion around collective liberation has stuck with me. They write, "The point I took from this wasn't that we should all literally make soup. I took it to mean, use what you've got. Make crip resistance soup out of whatever skills, resources, tactics and brilliant wild crip ideas you possess."

My partner was once again in the hospital during the creation of this square, while I was out of town traveling. In the spirit of making crip soup, we found ways of showing up for each other that worked for who we both are in all of our intersecting identities. I like to look at this square, with its lattice patterning, as a reminder of that.

²⁹ Leah Lakshmi Piepzna-Samarasinha, "Cripping The Resistance: No Revolution Without Us," *Disability Visibility Project* (blog), August 24, 2020, https://disabilityvisibilityproject.com/2020/08/24/cripping-the-resistance-no-revolution-without-us/.

Square 6: How Do We Get There?

Blocking

Associated Disability Justice Principle(s): Commitment to Cross-Disability Solidarity, Collective Access

#56 Sprouts Color: Blue Started July 23rd



Image Description: A twilight blue knit square, similar to the color of well-worn denim, is on a white background. The square is uniform vertically and horizontally, with clusters of stitches arranged like tile. Each cluster has several stitches extending upward like newly planted grass seeds sprouting in a new lawn.

- 1. COME SEE MY COLLECTION
 OF TIME-TRAVELING EMOTIONS
 SAFELY TUCKED BEHIND THE MASK
 STORED IN MEMORIES OF THE PAST
 - 2. They rest my devotions
 Those loves who later lied
 Making oceans
 Impossible to find
- 5. TIME TRAVELING EMOTIONS
 HIDING BEHIND THE MASK
 MESSAGES TO REMEMBER
 TRAVERSING THE PAST

- 3. THEY CHARGE THE NOTION
 THAT SLIPPED PAST MY PRIDE
 ANSWERS ALWAYS IN MOTION
 BECOMING MY GUIDE
- 4. LIKE BILLY PILGRIM
 UNSTICKING THROUGH TIME
 MELTING THE TUNDRAS
 HUGGING SPIRIT AND MIND

- 6. So while you are gone,
 And I am alone,
 I'll search the collection
 To find what has grown
- 7. THESE SEEDLINGS OF COMFORT
 ARE REMINDERS OF HOME
 FAITHFUL COMPANIONS
 UNTIL NEW ONES ARE SOWN

A Reflection: The Disabled Art of Play

The entirety of this project, from preparing yarn for the first square to blocking the last square, took a total of two months, three weeks, and four days. The act of knitting has allowed me to markedly observe, feel, and reflect on my processes within a container of physical time. As a result, each square has become a storage device for my disabled learning journey.

The first square, "What Am I Doing?" set me off to an energized, unexpected start. Although I initially planned to completely trust the random generator in selecting square patterns for me, this idea was quickly adapted. The first square the random number generator selected was from the "Combos & Unique Stitches" section of the book, where the most complex stitches and intricate patterns were consolidated. I was immediately disappointed and daunted. Some of these knitting charts include over a hundred rows of instructions, with few repeating patterns or sequences to follow. With no clarity on how long this project would take me, would I be able to complete a square of this complexity? What if I made a mistake and had to tink backwards, or worse, completely restart? Would I be spending my entire summer on one square?

There was a simple solution to assuage my stress: choose another square. This time, when the generator produced a number, it was for a square from the beginning of the book, where the simplest patterns and stitches were laid out. This is the square that I knit, joyfully, in five days: #10, Cartridge Rib. I still did not know exactly how the rest of these squares would turn out, but I had begun the process of bringing all my materials together.

Square number two, "Who Am I With?" followed the precedent set by the first square. This time, I ran the random number generator three times and selected the square I was most interested in creating based on aesthetics, knitting difficulty, and personal inspiration. At that point, I was beginning a new summer class, continuing an ongoing summer class, starting a summer residency, and teaching music part-time. Knitting this square offered moments of respite amidst a period of intense socialization and new environments. Like winding a brand-new ball of yarn, I began settling into this project, to the summer, and to the unknown.

The third square, "Where Are We Moving?" took a different turn. The pattern I landed upon, #2 Moss Stitch, was one of the easier patterns – only the second in the entire book. I expected it to progress similarly to square one: quickly, easily, and with gusto. Yet, this wasn't the case. To be honest, I don't much remember making this square. Maybe I had signed on for more than my disabled body could handle. Maybe I needed time to recover from the shock of navigating between multiple spaces at once; it had been several years since I attempted to live in constant motion. Maybe this is what caused my bodymind to no longer act as one, creating instead a vacuum of dissonance between where my body and my mind were supposed to merge. Maybe it was the weather – I've never much been able to handle DC's summer heat.

The square turned out too big – once I cast on, I forgot to stop. "It's okay," I told myself. "Time to move on."

Square number four, "Why Do We Do This Work?" is titled #29 Hugs and Kisses. Like its namesake, this pattern provided familiarity and comfort. Although it's not the most mindless

type of knitting, I've always found immense satisfaction in cabling – twisting the yarn together by crossing stitches in front of or behind each other. Cabling gives immediate gratification because it instantly shows the pattern unveiling as you knit. It also shows mistakes as they are made and provides the opportunity to quickly adjust, tink (knit backwards) to the mistake, and fix it. There aren't many other spaces where I ever feel quite so safe, just knitting and tinking, back and forth.

By the time I reached square number five, "When Is There Change?" knitting these squares had become routine. I no longer stressed when selecting a square, I was no longer daunted by the type of knitting it would need, and I no longer worried about completing a square in time. I had already made four; if they were all I produced, they would be enough. I simply continued going with #18 Lattice. Similarly, living my disabled life was beginning to fall into this routine. When I was traveling, I made sure to bring a hefty supply of antihistamines and a pillow. When my partner was back in the hospital, we texted frequently and Facetimed daily. The fear that had driven me in the beginning of this project was being cast off as we sailed onward, not towards a new normal, but towards the next rendition of our liberated lives.

The sixth and final square, "How Do We Get There?" showed me that forward motion is not always linear. At one point in #56 Sprouts, I found myself completely lost in the pattern. Somehow, without realizing it, my fabric had flipped. This meant I had been knitting the front of the pattern on the back, and vice versa. Bringing together what I learned from my previous squares, I tinked backwards. When I thought I'd reached the mistake, I began knitting again. Only to realize, I had not fixed the mistake. So again, I tinked back, only to begin once again knitting. . . for it to turn out I still hadn't fixed the mistake.

I can't say how many times this went on and how many days I spent working on two inches of the square. Eventually, I accepted that I was stuck in an idle cycle and all there was to do was change. This time, I tinked back well beyond where I believed the mistake to be, resituated myself within the pattern, and began anew. The square is likely imperfect; I'm sure I skipped a row or two without realizing it. But when I went about the final step of blocking it – soaking the square in wool wash and stretching it out so all the stitches are evened out – I was quite happy with the result.

My project has not turned out perfect. Some squares are arguably too large, and some are too small, according to my 15 inch by 15 inch guideline. I did not follow my given parameters of randomly selecting squares and instead eliminated squares based on personal preference. I made mistakes when knitting and did my best to repair them; but an astute eye might notice.

I see these changes and choices and mistakes as signifiers of one thing: through this project, I have learned the disabled art of play. This has meant adapting things to fit my needs in the ways that I need, through creative improvisation. It has meant embracing the movements of the process, pivoting to find new, better pathways forward. It has meant always continuing forward, even if that may feel like taking a step backwards or simply staying in place. It has meant providing space for imperfection and celebrating it when it arrives. It has meant dissolving fears into acceptance and joy.



It has meant liberation.

Bibliography

Bach, Lee. "Chapter 7: Heuristic Scholar: Heuristic Inquiry and the Heuristic Scholar." *Counterpoints* 183 (2002): 91–102.

Cahnmann-Taylor, Melisa, and Richard Siegesmund, eds. *Arts-Based Research in Education: Foundations for Practice. Inquiry and Pedagogy across Diverse Contexts.* New York: Routledge, 2008.

Clark E. Moustakas. *Loneliness*. 2016th ed. Pickle Partners Publishing, 1961. https://www.amazon.com/Loneliness-Clark-Moustakas-ebook/dp/B01M29KGFY/ref=sr_1_1?keywords=loneliness+moustakas&gid=1660849412&sr=8-1.

Project LETS. "Disability Justice." Accessed August 18, 2022. https://projectlets.org/disability-justice.

Lakshmi Piepzna-Samarasinha, Leah. "Cripping The Resistance: No Revolution Without Us." Disability Visibility Project, August 24, 2020. https://disabilityvisibilityproject.com/2020/08/24/cripping-the-resistance-no-revolution-without-us/.

Leah Lakshmi Piepzna-Samarasinha. *Care Work: Dreaming Disability Justice*. Canada: Arsenal Pulp Press, 2018. https://read.amazon.com/?asin=B07D5J6RWX&ref_=kwl_kr_iv_rec_1&language=en-US.

Leavy, Patricia. *Method Meets Art, Third Edition: Arts-Based Research Practice*. New York, UNITED STATES: Guilford Publications, 2020. http://ebookcentral.proquest.com/lib/aul/detail.action?docID=6268652.

Hampshire College. "Resource Guides: Disability Rights, Studies & Justice: Disability Justice," June 9, 2022. https://resourceguides.hampshire.edu/c.php?g=759682&p=5447794.

Smithbell, Pamela. "Arts-Based Research in Education: A Review." *The Qualitative Report* 15 (November 1, 2010): 1597–1601. https://doi.org/10.46743/2160-3715/2010.1363.

Sultan, Nevine. *Heuristic Inquiry: Researching Human Experience Holistically*. 2455 Teller Road, Thousand Oaks California 91320: SAGE Publications, Inc., 2019. https://doi.org/10.4135/9781071802632.

Sins Invalid. "10 Principles of Disability Justice." Accessed August 18, 2022. https://www.sinsinvalid.org/blog/10-principles-of-disability-justice.

Sins Invalid. "What Is Disability Justice?" Accessed August 18, 2022. https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice.

"What Is Disability Justice? | CODE." Accessed August 18, 2022. https://code.as.ucsb.edu/whatis-disability-justice/.

CREATIVE GENERATION

www.Creative-Generation.org