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Reimagining Disability: Expressive Arts Therapy as an Empowerment Tool

Capstone Thesis

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Abstract

A quarter of the U.S. adult population is disabled. Current expressive therapies' approaches are rooted in a medical-interventionist model of disability over a social model of disability. In utilizing the connection between disability arts and creative arts therapies, this capstone thesis explores the tools found within the field – such as photovoice – to examine the impact of hierarchy in therapeutic spaces. Mental health practices are also often rooted in individualistic models of self-care, over community care. Through examining the practices of disabled art, music, and drama therapists, this literature review seeks to imagine new therapeutic spaces and realities for disabled clients. By utilizing liberation psychology and crip theory, disabled clinicians and clients alike, might rebuild expressive arts' therapeutic practice to adapt to the imminent needs of multiple marginalized populations. Creative arts therapists must realign themselves as professionals allied to community over professionals allied to medicine. Without attending to these needs, creative arts therapists may continue to unintentionally perpetuate harm against clients as disabled clients are required to adjust to an ableist world. The Expressive Therapies can be re-shaped as a tool for empowerment.

Keywords: expressive arts therapy, disability arts, crip theory, disability, chronic illness, chronic pain

The author identifies as a straight-passing, queer, asexual, disabled, white, Jewish person from the Southern United States.

Reimagining Disability: Expressive Arts Therapy as an Empowerment Tool

Introduction

How do we make Creative Arts Therapies a space built for disabled people? In my exploration of how we think of and perceive disability, I have found it is mired in a few themes: over-medicalization of the disabled body, hyper fixation on impairment, and the necessity of rehabilitation. Bridger et al. (2021) recalled Maggie's experience of attending the conference, *VIBE: Challenging Ableism and Audism Through the Arts:*

> I am always aware of my body, but the awareness shifts in spaces built by and for disabled folks. Typically, my focus is split between the internal and the external. I ask constant questions of my body as I move through life to adjust for pain and fatigue. How is my stomach? Particularly tight today, I should avoid anything that might intensify that into actual pain. I regularly bend and extend fingers, toes and ankles to check on joint stiffness and inflammation. I live my life split between caring for my body and performing the external tasks required of it, but I never go too far inside if I can help it. While in the general public, my internal attention extends only far enough to maintain productivity. To fully focus on the internal, to actually understand my body fully in every moment, would take my full attention in a world not built for bodies to know and care for themselves. (p. 13)

The problem precisely is that this world is not built for disabled bodyminds. Maggie's experience is one in which I relate deeply too. My "non-apparent disabilities" weigh heavily on the ways in which I navigate the world we all live in (Price, 2011, 2015, as cited in Bridger, et al., 2021, p. 14). I live with multiple chronic illnesses – endometriosis, adenomyosis, and fibromyalgia – all of which impact the ways my bodymind moves through these internal and

external worlds. My own personal experiences as well as a curiosity to improve my own future clinical work have compelled me to commit further to this research given. My time in this program has significantly laid the foundation for the work researched as a part of this thesis. I acknowledge my inherent privileges around race and socioeconomic status. I am a straight-passing, asexual, queer, disabled, Jewish, educated, white person from the South. I grew up in a middle-class/upper-middle-class household with access to significant education. I exist in a minority-marginalized space as one of the only Jews in my community. I am not visibly disabled, and am ambuantly disabled. My disability did not present itself until later life. I have been sick since I was in elementary school.

This literature review will examine the ways in which current treatment is structured for disabled clients within the Creative Arts Therapies. Greater research on disabled experiences is imperative as we examine the over-medicalization of disabled bodies in therapeutic spaces. There must be greater room for the spectrum of beliefs and lived experiences of disabled people. In this research, I hope to learn about the intersection between Expressive Arts Therapy and Disability Arts. Similarly, I hope to further examine the autoethnographic research of disabled artists and therapists alike to understand the unique challenges the field contends with in solidifying a clear identity as a professional field. In writing and researching this paper, I utilized the work of diverse disabled writers and researchers. For accessibility reasons, a glossary is included in this literature review's appendix. This capstone thesis project will view disability through the lens of liberation psychology, critical disability theory, and crip theory.

Literature Review

Defining Disability

Disability is an expansive term that touches the lives of many. It often encompasses experiences including chronic illness and chronic pain, and it exists at the intersections of various markers of identity and oppression. The way in which individuals define themselves allows them to better define their relationships with the world in sociopolitical realms and in community. Okoro (2018, as cited in Kattari, 2020, p. 1170) stated that "Almost 26 percent of adults in the United States identify as having one or more disabilities or impairments." This makes disabled people the largest minority in the United States (Dunn, D.S. & Andrews, E.E., 2015). With this substantial population, it is valuable to examine contrasting perspectives on lived experience. How does one view difference, and how does one view disability? Kalenderidis (2020) utilized first person language to define their disability

> My use of first person language for me symbolizes for me a reclaiming of power that has been historically seized from people with disabilities. This grab at power is aligned with the concept of "claiming" disability as a significant part of one's identity. This claim brings disabled voices to the forefront of the dialogue, celebrates our shared identity and calls for collective action against systemic oppression, akin to the Charlton (2000) notion, "Nothing about us, without us." (p. 2)

This arts-based researcher examined a sample set of disabled music therapists in Australia and inquired about how the therapists chose to identify. The only outside participant in the study, one music therapist, chose to not disclose their disability to their clients (Kalenderidis, 2020). While the size of the sample challenges the validity of the arts-based research, the exploration further brings to the forefront the question of disability identification.

Peers & Eales (2017) understand disability dissimilarly, as part of a performance, existing in community spaces and cultures alone (p. 106). In this context, performance might be understood as a new way of understanding and dismantling how the able-bodied world perceives disability. In its essence, performance is antagonistic, it requires a disposal of normative and medicalized thinking where the disabled bodymind is something that needs repair or fixing. Peers & Eales (2017) wrote:

> … "crip," refers not to someone who is disabled, but rather, to how some people do disability in ways that, to quote Kelly Fritsch (2013): "both destabilize it as a concept and open up desire for what it disrupts" (intro). Crip is thus, at heart, a set of embodied practices or performances. (p. 106)

Peers & Eales (2017) suggested that performance fractures able-bodied understanding of disability as community aims to: "… generatively re-imagine and re-make disability, and to share, practice, and perform these knowledges together" (p. 107). Similarly, Bridger et al. (2021) understands disability through a political and social lens, conceptualizing it as "constantly emerging in relationship to surroundings, environment, and other bodies" (p. 9). Prior perceptions of disability are less important and rather contend that disability in artistic spaces must be more than an afterthought. (Bridger, 2021)

Significant nuance exists in disabled and chronically ill realms. Giving definitions and accepting identities holds significant political power. Gurza (2021) wrote:

> I struggle a lot with the realization that my disability activism often isn't the same as others. Telling my stories as a disabled person, knowing that some in my own community don't agree with me or even like me is hard, but it's okay. I have learned that disability isn't a monolith the hard way.

Throughout greater analysis of these researchers' work, it becomes imperative to understand that disability is not one thing, nor does it exist individually. Rather, disability and disability art develop a "collective consciousness." This creates new languages, pathways, art forms, and communities of care (Barnes 2003; Cameron, n.d.; Peters, 2006 as cited in Bridger et al., 2021, p.10). In other words, the disability community encourages interdependence and solidarity (Beck, 2020). This is done through shared lived experiences and the development of new languages. Disability creates new identities as the term disability refers to societal oppression of the bodymind, thereby society itself creates disability. Bogart et al. (2015) stated that self-identification within a minority group can have a beneficial impact on the individual's mental health understood through Social Identity Theory (p. 555). The resources provided by these communities of care may also aid in further supporting disabled people by providing them with relevant access needs or appropriate policy changes. Expressive Arts Therapy is built on an anti-oppressive framework, and as such, applicable work should be studied to determine the efficacy of experientials and therapeutic goals and objectives.

Systemic Inequalities in Disability/Perceptions of Crip Community

It is imperative to examine the role intersectionality plays in the disabled experience. It is supposed that "disability—like gender—is a concept that pervades all aspects of culture: its structuring, institutions, social identities, cultural practices, political positions, historical communities, and the shared human embodiment" (Garland-Thomas, 2002, p. 4, as cited in Macdonald, 2020, p. 4). Cross-viewing is valuable in understanding how able-bodied people might interact with disability, not only through their own political experiences but also the experiences of others in the space (Manning, 2004, as cited in Bridger et al., 2021). In other words, able-bodied people may only understand their relationships with disability when sharing a

space with a visibly disabled person (Bridger, 2021). For example, an able-bodied individual can be in a restaurant filled with ambulant people, except for one person in the restaurant who has an invisible disability. In this instance, the able-bodied person likely would not consider their ability. Therefore, if the disability is not obvious to the able-bodied gaze, the able-bodied person will still live in ignorance. However, the following week, the able-bodied individual is at the same restaurant. They see a disabled person come into the restaurant with an assistive device. Suddenly, they may become more aware of the fact that they have certain abilities that others might not have. The same person had not reflected on this the week before. Now, they have a heightened awareness. Bridger et al. (2021) stated: "disabled people constantly live their lives aware of bodily differences, the non-disabled art viewing masses only become aware of this difference when they see it embodied" (p. 15). This literature review seeks to provide a critical examination of Expressive Arts Therapy as a field in relation to disability. Expressive Arts Therapy is unlike its related Expressive Therapies disciplines, and in fact, the field practices in the "wild zone" (Ardener, 1975l Candelaria, 1993 as cited in Estrella, 2018, p. 1-2). Estrella (2018) noted: "… expressive arts therapy is an interdisciplinary/transdisciplinary multimodal practice that promotes radical inclusivity, one grounded in an approach that embraces a use of all arts" (p. 2). If the field is a space that encourages difference and acceptance, how do we integrate the work into our practice? We focus on a language we can all understand – the arts.

There are many ways in which Expressive Arts Therapists can create spaces where the inequalities disabled people face can be more adequately examined. Photovoice is a community based arts project used in the creative arts therapies that may work directly in line with this goal as well as advocacy initiatives. Photovoice – also known as phototherapy – is a therapeutic method that utilizes photographs and photographic collage to express one's lived experience for

identity development, advocacy, and community engagement (*AboutPhotoVoice, n.d.*). Understanding the systemic inequalities faced by disabled people is among one of the first steps in practicing improved care. How can clinicians better contextualize the lived experiences of their disabled clients? What barriers might also be identified outside of the therapeutic space? In my own interactions with Photovoice and disability grief, I wrote a poem that can be found in this literature review's appendix.

The ways in which I relate to the world, as well as the way others relate, often provides an even greater sense of grieving. Others' perceptions and society's systemic limitations prevent disabled bodyminds from access to their own basic needs – like rest. In the sense, visibility is a tool (Peers & Eales, 2017). There is a compulsory nature in able-bodiedness where individuals must in turn "perform" as able-bodied. Failing to pass destroys any hope of social mobility. However, choosing to utilize aids unleashes political mobility, or in other words, activism (Peers, D. & Eales, L., 2017, p. 113). The discomfort associated with the presence of mobility aids is based out of fear and a lack of creativity. This fear stems out from the idea that the human is dependent on the wheelchair to get around, and this reliance does not work in line with able-bodied ideals (Peers, D. & Eales, L., 2017). This perspective requires a re-imaging, a shift in long-held beliefs of what the body should do. Peers and Eales (2017) wrote, "an assemblage is understood through how it might move, act, feel, breathe, create, relate, assemble, disassemble, reassemble, explore, and desire otherwise." (p.118). In other words, there are many qualities and purposes where aids serve a function that is intrinsic to our understanding of the human body. This must be viewed more imaginatively so clinicians can make space for the multiplicity of client narratives.

Even greater, what happens to disabled people who cannot mask? Severely mentally ill (SMI) individuals face systemic discrimination, exclusion, and a lack of empowerment. SMI individuals are often at risk of severe food insecurity. Coleman-Jensen & Nord (2013, as cited in Weinstein et al., 2019) wrote that "a person with a disability would require more than two and a half times the income of a person without disabilities to have the same likelihood of food security" (p. 162). Weinstein, et al. (2019) elaborated:

> A human rights framework holds substantial potential to improve the understanding of the complexity and interrelatedness of these multilevel issues in the public and policy sectors by explicitly linking the problem of poor health in people with SMI to the right to health, the right to food and the rights of people with disabilities. (p. 162)

It is imperative to understand that the challenges SMI individuals face are systemic in nature. The qualitative study aimed to utilize photovoice as a method to provide SMI individuals with the space to be heard, to educate through first-person experiences, and to advocate for access to basic rights – such as physical care and health care. Photovoice or phototherapy is a therapeutic method that utilizes photographs and photographic collage to express one's lived experience to support identity development, advocacy, and community engagement. (*About PhotoVoice,* n.d.). In theory, the work also acts as an impetus for social change by creating photo exhibits and meetings with changemakers. Out of 21 potential co-researchers, eight showed interest and attended the first session. The research study consisted of seven separate sessions, with the first four focusing on photography prompts and discussion regarding weight loss. The following three sessions focused on choosing photographs for a community presentation and developing advocacy skills (Weinstein, et al., 2019). Participants were then invited to participate in four advocacy sessions. These sessions included meetings with city public health officials,

with a senator, and in collaboration with a non-profit. Co-researchers could also share work as part of an exhibition (Weinstein, et al., 2019). This qualitative study provided greater skills through the arts and narrative while also encouraging the development of self-advocacy skills. One of the primary limitations of the study remains in the significant changes in power dynamics between university researchers and co-researchers (Weinstein, et al., 2019). However, this study was rooted in liberation psychology. Weinstein et al. (2019) writes:

> Our hypothesis was that participation in the PhotoVoice process would result in community advocacy activities such as presentations and policy recommendations to influential private and public mental health organizations and these advocacy activities would support study participants in acting as change agents in their own lives. (p. 163)

This study could benefit from further research on intersectionality in relationship to severe mental illness. Similarly, this research might benefit from utilizing additional social justice resources beyond Photovoice.

Photovoice has also been shown to be beneficial with gaining greater clarity specifically in relation to how women are perceived within physical disability – highlighting the value of clinicians in engaging with disability in an intersectional manner. Disability in fact has a unique relationship with women's issues. "… disability—like gender—is a concept that pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment (Rosemarie Garland-Thomas, 2002, p. 2 as cited in Macdonald, et al., 2020, p. 4). In structuring disability as a point of discourse, led and constructed by disabled people, understanding the experience of disability might become more understandable and provide greater clinical reference for providers. Macdonald et al. (2020) protocol paper gleaned insight from various angles by

encouraging the photovoice project to not only be a space of empowerment, but to also raise awareness for systemic challenges faced by disabled people, specifically disabled women. The work itself highlighted a specific subgenre of work a "sophisticated and nuanced portrait of female disability that could contribute to feminism's intersectionality" (Macdonald, et al., 2020, p. 5). These contributions by co-researchers can only broaden the scope of the way disability might be understood. While the utilization of photovoice is increasing, it often fails to include disabled co-researchers as valuable contributors (Macdonald, Dew, & Boydell, 2019 as cited in Macdonald, et al., 2020, p. 4). In the spirit of understanding the impact of disability, the study was also conducted by putting accessibility first. Selected co-researchers to the study were given access to a "large accessible space," and the workshop took place on Saturdays as to not exclude women who worked full-time jobs on the weekdays (Macdonald, et al., 2020, p. 8). Macdonald et al. (2020) encouraged co-researchers to examine their experience of identity through the following lenses: "1. politics of appearance, difference, and the body; 2. exclusion, inclusion and visibility in the community, 3. femininity, sexuality, relationships and reproductive rights, 4. equality, power and power imbalances" (p. 9). Utilizing this work through a feminist lens provided a way to differentiate the experiences of disabled women and make it both a part of and separate from pre-existing research. This qualitative research also aimed to expand beyond the realm of disabled women and envision the impact of the work in a public space. The study sought to place photographs in a city library (Macdonald, et al., 2020). The significance of this kind of exhibition differs from that of another arts-based exhibition as it creates space for marginalized communities to share their stories and advocate for themselves in a space that they create as a source of empowerment. While the study was limited because those constructing the protocol themselves are not disabled women, it shows the ability for progress the field holds. In

viewing the research through a feminist lens, the researchers were able to develop a similar language and a way in to better understanding the world of disability (Macdonald, et al., 2020). This is a step in the right direction and is a necessary one for all Expressive Arts Therapists. However, the work only begins to examine the world disabled, chronically ill, and chronically-pained people live in.

Chronic illness and disability disrupts self-concept. It is imperative that therapeutic work is adequately able to explore and integrate new visions of self. A qualitative research study took place at the Soroka Medical Center Lupus Clinic. Fifteen women who lived with Systemic Lupus Erythematosus (SLE) participated in the study. Researchers engaged in work to determine the mental representation of the illness to better understand the inner workings of the clients' worlds and others like them (Schattner, Shahar, & Abu-Shakra, 2008). Similarly, they examined the participants' "affective states and behaviors" (Schattner, et al., 2008, p. 466). The researchers viewed this through the lens of object-relations theory, and they concluded that sufferers approach their illness in one of two ways. Schattner et al. (2018) writes: "In the first, the illness is experienced as a persecutor, the self as its victim. In the second, the illness is an adversary, a trial to be overcome, and the self is the hero facing it" (p. 470). The research found that several anxiety themes arose because of being in relationship with illness (i.e., issues with intimacy, shame). Coping with illness and healing arose in several different ways (Schattner, et al., 2008). The research encourages the connection with the body as the narrative. This research was only tested on a small group of women with SLE. Further research is required to make conclusions about other experiences with chronic illness (Schattner, et al., 2008,. There is significant value in understanding the relationships between the individual and illness or disability.

What motivations make individuals identify more strongly with disability identification? Bogart et al. (2017) concluded: "Stigma and severity were the largest predictors of disability identification, and stigma mediated the relationship between severity and identification" (p.553). The qualitative study took place as a part of a large internet study. Guidelines were determined by the International Classification of Functioning, Disability and Health (ICF). Recruited by Amazon Turk, the initial 1,105 participants were reduced to a final dataset of 710 with identified impairments (Bogart et al., 2017, p. 556). Bogart et al. (2017) contends results were "gender-balanced, geographically distributed, racially and ethnically representative, and representative of the disabilities in the US (p. 556).

Researchers applied an open-ended approach to examining disability identification. For example, efforts were made to not limit the context of disability or impairment. Researchers gave participants a list of 86 impairments, accompanied by empty fill in the blank boxes which granted participants autonomy to decide what conditions are in fact disabling (Bogart, et al., 2017). The qualitative study also highlighted: "Stigma predicted identification over and above impairment and personal factors…. This finding supports the validity of the social model of disability from the perspective of people with impairments, suggesting that disability is at least somewhat socially constructed" (Olkin & Pledger, 2003 as cited in Bogart, et al., 2017, p. 559). This conclusion further supports this thesis' theoretical approach. This research works from a medical model approach of disability, one which works against the political/relational model (a radical social model) of disability this writer supports. Bridger (2021) wonderfully articulated the challenges of understanding disability as impairment alone:

> Disability representations are polarized. The mundane, physical, mental, and emotional
>
> ups and downs, and the systematic [systemic] barriers that everyday disabled people

remain unseen or intentionally sealed off. On the other hand, impairments can be overemphasized to the point where they are seen as the only things in a disabled person's life. (p. 20)

However, the data provided shows further attempts to understand the roots of disability identification and encourages disability identification. Further research must be conducted within different more racially diverse and global communities. Another limitation of the study includes its limitation of the intellectually disabled as well as communities without access to computers (Bogart, et al., 2017).

There is so much value in centering the lived experiences of disabled, chronically ill, and chronically pained individuals. Everyone approaches the topic of disability from different perspectives. Research into the use of the Expressive Arts Therapy with disabled folks must go beyond the therapeutic space and begin to ask more questions regarding the systemic oppression(s) of living with disability and its intersections.

Disability Arts & Creative Arts Therapeutic Practice

What might full participation in society look like for disabled folks? On June 30, 2022, *PURE JOY: 14 Disabled Visual and Performance Artists,* an art exhibition curated by Chella Man, a queer, disabled, Chinese, Jewish man, opened at Tribeca's 1969 Gallery (Fisher, 2022). Man said on the value of curating the exhibit,

> As a disabled artist, we are often asked to make work about our trauma and our struggles, and this is a way we are tokenized. The word "disability" rarely is paired with the word "joy." For that exact reason, I wanted to expand the stereotypes connected to the word disability and also just the connotations. (Fisher, 2022)

To further contextualize the value of the exhibit, Man spoke about the diversity of accessing the experience of joy. Some art centers around joy as something gleaned from the creative process due to the demoralizing nature of discrimination. A live performance entitled *Care Transitions* by artist, Panteha Abareshi, highlighted "how painful it is that the medical industrial complex has implemented pain to be such a financial, transactional act, rather than care being something born of love, something led by compassion and empathy" (Fisher, 2022). Disability arts is a world in its own. Disability arts understands disabled people as belonging to a minority culture. It separates the co-opted strains of art found in modern galleries and the "therapeutic gaze" (Bridger, et al., 2021, p. 10). Disability arts understands itself as fluid, where accessibility is viewed as the forethought. The field began in the 1970s as an art form for and by disabled artists (Bridger, et al., 202). Disability rights advocate, Carol Gill (1995) describes "disability culture as the emotional unity for disabled people" (Bridger, et al., 2021, p. 10). In other words, creating a community with individuals who can better relate to and understand experiences works as an antidote against isolation and alienation by centering the multiplicity of experiences. Similarly, disability arts and disability culture is rooted in "solidarity over charity" (Beck, 2020, p. 67). Disability culture understands community as a key to survival (Piepzna-Samarsinha, 2018 as cited in Beck, 2020, p. 67). Beck (2020) wrote: "In a profession that often emphasizes the importance of self-care, it is imperative that we learn from disability culture the limitations of self-care when divorced from community care" (p. 67). In challenging the medical model imposed on and by creative arts therapists, we can open greater pathways to understanding the expansiveness of the disabled experience and its unique connection to creative arts therapies.

Contributions to disability art and art therapy are numerous. An autoethnographic study conducted by Chun-Shan (Sandie) Yi detailed the weight of navigating bodies that deviate from

normative functions and expressions (Yi., 2010, p. 103). This is informed by social hierarchies

that impact how disabled people navigate the world. Yi (2010) wrote:

> When gaze turns into staring at a fellow human being for an extended period of time
>
> (longer than what is socially acceptable) the observer conveys that the perceived person
>
> is not being viewed as human, but rather as an object or animal, thereby establishing the
>
> viewer's dominance over the one being viewed. (Argyle & Cook, 1976; Marshall, 1983
>
> as cited in Yi, 2010, p. 104-105)

For disabled people, the body is the site of this otherness and oppression. Therefore, the site of

struggle is ultimately the access point of liberation (Fabre-Lewin, 1997, p. 119 as cited in Moon,

2010, p. 105-106). Yi utilized two projects to explore the disabled bodymind. The first project

examined the disabled bodymind and the impact of bodily adornments on able-bodied "gaze."

The second project utilized bodily adornments with clients as part of Yi's art therapy clinical

work (Moon, 2010). In understanding and articulating the concept of the "gaze" it is valuable to

understand the way in which this phenomenon extends into therapeutic practice. Like Man

(Fisher, 2022), Sandhal (2009) acknowledged "that gaining support for disabled artists is far too

often based in a charity framework and/or art therapy perspective, as if art making is meant to

heal the disabled artist from their distress" (Sandhal, 2009 as cited in Beck, 2020, p. 63). This

practice relies on a medical model of disability that pathologizes disability, thereby limiting the

expression of disabled artists and clients alike. Profound healing can only come in viewing this

experience through the social model of disability.

Beck (2020) conducted an autoethnographic study differentiating the values in practice

between the medical model and the social model in relationship with disability. The social model

of disability defines disability "as social oppression manifested through phenomena such as the

lack of access ramps into public spaces and disproportionately fewer employment opportunities, rather than individual medical cases" (Jordan, 2012, as cited in Beck, 2020, p. 63). Therefore, disability exists far beyond the language of *impairment* or *fixing*. Beck (2020) conducted her autoethnographic research through co-current internships at Access Living of Metro Chicago, a community-based organization for disabled people focused on racial justice, and at Jesse Brown VA Medical Center. As a result, the researcher was able to examine the presentation of the social model of disability and the medical model of disability side-by-side in a community setting and as an art therapy intern. At Access Living, Beck developed an art therapy community group that focused on interdependence and mutual aid (Beck, 2020, p. 64). Beck (2020) found that during her time at Access Living, community art making sessions took on an art therapy role given the collective work's ability to deepen relationships, navigate emotions, and grieve (p. 64). The researcher understood the importance of being in community as a disabled person, given her own experiences (Beck, 2020, p. 64). At Jesse Brown VA Medical Center, Beck noticed a significant shift in attitude regarding disability perception. Often, the discussions were marked by a loss of identity and ability (Beck, 2020, p. 65). Not only did Beck notice this perceptual shift, but she came to understand that some veterans did not believe in her capability to facilitate a group given her disability. Beck (2020) wrote:

> It was extremely hard to focus after that. It hit me in that moment how much disability is stigmatized here – that I could be a fellow disabled person, but when it came to me being a position of leadership, there was fear, skepticism, and stigma. "They don't know how to talk to you," he said. My heart sank, thinking about the pervasive internalized and attitudinal ableism. We are of course, in a hospital, and here disability is something that must be "fixed" or "overcome." (p.65)

It is apparent that the medical model is a societal mirror. Who is deemed as professional, responsible, and capable within our world is determined through a normative lens. When Chun-Shan (Sandie) Yi worked in a hospital, one of her colleagues, the chief plastic surgeon, approached her to look at her hands (Yi has two digits on each hand). She said of the experience, "I realized no matter how hard I worked for recognition as a professional. I would always be seen as a patient. The imposition of *overcoming narratives* did not end merely by refusing to see myself as disabled (Yi & Moon, 2020, p. 59). In many ways, the medical model imposes limitations on the disabled body, seeing it as something that requires *curiosity* or *fixing*, rather than existing as yet another variable to be proud of in community. As such, we can understand visibility as a tool against the medical model. Peers & Eales (2017) contended that the failure to pass as a form of political mobility. The decision to not pass, even for people who are ambuantly disabled, is a way to reclaim power.

Through her autoethnographic research, Beck (2020) built off her work at Access Living, she organized a Disability Arts Showcase. Beck (2020) concluded that the most significant supports for disabled clients were "community support and understanding, a safe place to authentically share one's story, and access" (p. 66). The space attracted around 70 individuals, many of whom accessed a "celebratory disability space for the first time" (Beck, 2020, p. 67). Unfortunately, this often fails to be the reality for many disabled people, clients, and patients. It is imperative that professional fields take an active role in understanding the impact of accessible and celebratory disability spaces. Similarly, they must make space for shifting attitudinal beliefs on disability.

Professional Competence in Community

Creative Arts Therapies are compatible with the experiences of disabled people, but the field requires a new perspective on what it means to be truly accessible. Beck (2020) wrote about necessary adjustments to therapeutic space to accommodate disabled clients:

When working within the disability community, a traditional clinical and/or medical-interventionist approach to art therapy is insufficient; however, that is not to say that disabled folks cannot benefit from art therapy. Practitioners must think critically about their treatment approach. That is, they need to consider whether they are asking clients to accommodate to a disabling society, or, alternatively, working from a transformative stance that helps clients recognize and resist a disabling society, become more knowledgeable about disability identity, and explore the psycho-social-emotional experiences associated with disability. (p. 68)

With this mindset, clinicians and clients alike can understand that disability is not a one-size-fits-all phenomenon. Careful consideration is necessary regarding an individual client's access needs and a consideration of intersectional identities – including race, ethnicity, gender identity, socioeconomic status, and religion. When effectively harnessed, disability knowledge develops self-concept and disability pride, tools for combating the ableist world we live in (Bogart, 2014 as cited in Beck, 2020). Individual access needs play a significant role in how disabled people navigate the world.

Kafer (2019) wrote about the steps clinicians can take to make therapeutic spaces accessible. Technology can be used as a tool against the medicalized *fixing* of disabled bodies. It can build relationships in the disabled community and support the development of self concept (Kafer, 2019, p. 1-2). Kafer (2019) recounted Yi's project entitled *Gloves for All*. Kafer (2019)

continued: "Rather than the typical orientations of 'accommodation' and 'retrofitting,' both of which include disabled people as afterthoughts (Hamraie, 2017), Yi (2010) anticipated and assumed the presence of disability, building it into her art practice 'from the beginning' (Yi, 2010, p. 14 as cited in Kafer, 2019, p. 2-3)." In this reframing and creativity, Yi's work holds space for community development or *crip kinship*. However, the alignment of the therapeutic field limits the development of equitable relationships and community building.

As previously discussed, a significant critique of creative arts therapy spaces is due to the field's alignment with the medical-interventionist model. Creative arts therapies including expressive arts therapy, music therapy, art therapy, drama therapy, dance/movement therapy, and beyond have struggled with professional recognition. Cameron (2014) wrote: "Taking on the trappings of pseudo-medical academic practice, in terms of, for example, the development of positivist research involves the entrenchment and stabilization of already formidable disabling barriers" (p. 7). As clinicians attempt to prove the benefits and efficacy of the field, they in turn limit the true reality of the population researched and served. Beyond that, this approach not only limits understanding, but also contributes to active harm against disabled people. Yi wrote:

> It angers and saddens me that when disabled people seek help from mental health
> providers, we 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
> only reinforces able-bodied privilege. (Yi, 2019, p. 163)

When clinicians and those in the medical field view disability through the lens of impairment or the intent to *intervene* or *repair,* they in turn perpetuate beliefs of normality that harm disabled bodyminds (Kuppers, 2006 as cited in Yi, 2019, p. 166). Creative arts therapists often lack the critical understandings developed through lived experience or critical engagement in disability

studies, feminist theory, queer theory, and critical race theory. Sayre (2021) wrote: "... the training of drama therapists needs to recognize how power and privilege impact sociometry that can support the field in finding new ways to build community across differences, while reducing the negative bias and prejudice in diverse groups" (p. 2). Creative arts therapists can benefit from the development of critical consciousness of their identity and role. Similarly, they might learn from understanding the benefits of kinship, a practice disability studies actively pursues. Kafer (2013) wrote about the power of kinship as: "...reckoning with the ways in which kinship networks have been destroyed through slavery, mass incarceration, settler colonialism, and eugenics, kin is a site of power, friction, and potentiality" (Kafer, 2013, p. 5-6). Creative arts therapists must take responsibility for understanding the relational power in their spaces. This practice, known as *reflexivity*, captures the ways in which society positions our power in relationship to others (Collins & Bilge, 2016 as cited in Yi, 2019, p. 174) It is essential to revisit an entirely new set of beliefs reliant on professionals allied to community over professionals allied to medicine (Finklestein, 1999 as cited in Cameron, 2006). A re-envisioning of the field may allow creative arts therapists to see disabled people as partners (Cameron, 2006). In doing so, this eliminates unfavorable hierarchical frameworks that prevent disabled clients from accessing their own healing.

When able to create in studio spaces that are of their own, in community, disabled artists are able to thrive in new ways. Burlington (2021) wrote about the group show *A Consideration of All Bodies*: "The exhibition imposes on the able-bodied the very barriers ordinarily inflicted on those it platforms: those typically left on the outside looking in" (p. 1). The show features a performance piece with the artists engaging in discussion about the systemic inequalities found within the Irish healthcare system (Burlington, 2021). This work as a form of social advocacy

provides valuable messaging and practice, as a way for able-bodied or less marginalized people to begin to understand how society itself is the disabling element. Similarly, artist Sunara Taylor's *Wheelchairs on the Moon* depicted a wide variety of whimsical wheelchairs in their own environments. This particular watercolor image envisions five yellow wheelchairs on a blue moon. While laughable, these wheelchairs provide an important message. They take up space on their own while holding characteristics of their humans (Kafer, 2019). This imagery shows how the wheelchair is often an extension of the person (Belser, 2016 as cited in Kafer, 2019). Crip theory contrasts with the belief that humans are bipedal. Kafer (2019) noted an advertisement of empty wheelchairs by Ekso Bionics (p. 11). Kafer (2019) wrote: "... the photo echoes common images of evolutionary stages of Man, culminating in the upright white man as apex of progress. Such technologies are thereby rendered not only revolutionary but evolutionary, not only desirable but inevitable" (p. 11). However, crip theory suggests that technologies may not run in one direction but possibly in reverse (Kafer, 2019). This work fundamentally challenges societal conceptions of normalcy, by creating new visions of self-concept. It also attempts to create new conceptions of normalcy by replacing the understanding of functionality with creativity. Miller (2020) contended that the physical studio space itself is a beneficial site for artists with Intellectual and Developmental Disabilities (IDD). Art therapists tend to be drawn toward outsider arts as artists with IDD may receive recognition for their work. However, while approaching the topic from a positive intent, this often fails to recognize the ways in which disabled artists are not in charge in the studio space. Additionally, it fails to account for the potential loss of benefits artists with IDD might face if they do receive compensation (Miller, 2020). Shifting the space to reflect disability arts as a part of art therapy holds value. However, it begs the question: should able-bodied art therapists even inhabit these studio spaces? Perhaps,

these clinicians should practice self-reflexivity and employ curiosity to deduce whether their presence in the space is wanted. In community, disabled artists are able to share stories of their experiences and bodies others might not understand. This is a space creative arts therapists may welcome if they are willing to understand disabled artists as co-creators or partners. Similarly, what benefits may arise for disabled artists as disabled clinicians? Can these two identities exist at the same time?

Therapeutic value exists in working in community. As disabled therapists expand into spaces with disabled clients, new understanding, new futures, and new access are imagined. Sayre (2021) wrote: "What seems most consistently therapeutic for my clients is having their experiences with discrimination and stigmatization mirrored and having a role model to provide hope that a different future could be possible" (p. 5). However, what happens when that identity is not front-and-center? In searching for a therapist, Beck recollected her own personal challenges regarding culturally competent therapists. Beck noted her therapist engaging in the concept of "able-splaining" by which her therapist utilized assumption to speak for the disabled community. This in turn inspired her to become a clinician (Beck, 2019, p. 62-63). Yi (2019) reccounted a similar experience when she noticed her therapist gazing at her hands. Yi (2018) asked her therapist: "I noticed that you were looking at my hands. Disability is an important part of me; it's my identity, my politics, and activism. Are you comfortable with my disability? Have you worked with disabled people?" (p. 162-163). Yi's therapist went on to share an able-bodied narrative of *overcoming disability* and attempted to deny Yi's rebukes claiming her therapist's shock (p. 163). However, disability identity alone is insufficient. It is imperative to recognize the space for multiplicity of experience for those belonging to different identity groups (Beck, 2019, p. 68). There is no one singular experience of disability; clinicians and disabled folks alike must

make room for multiplicity. Additionally, clinicians must be willing to have their power taken away in the therapeutic space.

A disabled person reclaiming power is imperative for the therapeutic process. Friere (2014) wrote: "The oppressed are regarded as the pathology of the healthy society, which must therefore adjust these 'incompetent and lazy' folk to its own patterns by changing their mentality" (p. 74). In this way the oppressed, including disabled people, are seen as the problem to fix or conceal. This process of normalization works against the idealized approach of the arts. Expressive therapies attempt to support revolutionary praxis and subvert narratives. In this way, they work in line with liberatory practice. Friere (2014) explained: "The solution is not to 'integrate' them [the oppressed] into the structure of oppression but to transform that structure so that they can become 'beings for themselves' (p. 74). The crucial transformation must also be completed in the therapeutic space. In this way, in order to create Friere's dialogue in the therapeutic space, the arts must exist as the holding space. Fabre-Lewin (1997) notes that this fundamental shift comes in co-creation between two people – the therapist and the client (p. 122). In the practice of art therapy, the sheet of paper may be viewed as "territory" and the act of creation "'reinforces her [the client's] awareness of her power to create and give shape to herself and her life' (Ellis, 1989, p. 270 as cited in Fabre-Lewin, p. 122). This development of self-concept is critical through the lens of disability studies and disability arts as well (Beck, 2019; Bogart, 2014). Similarly, Boal's Theatre of the Oppressed utilizes psychodrama as a disruptive force, thereby focusing on how theatre play extends to community as a form of solidarity (Boal, 1985; Sajanani et al., 2021 as cited in Sayre, 2021). Creative arts therapists must extend their creative work outside of the therapeutic space to encourage social activism by holding the identity of an expressive therapist and a disabled person, co-currently.

While the field of Expressive Therapies can shift the field to a more equitable future, it may be possible that we must shed our identities as creative arts therapists. We must actively engage in understanding how the medical-industrial complex is in and of itself disabling. The labels of "therapist" and "client" inform hierarchical power structures that may be impossible to fully dismantle, even given the clinician's best efforts. Sayre (2021) suggested the possibility of "de-role" (p. 4). They even encourage to create "a space where artists and performers care WITH each other, instead of perpetuating systems where a therapist cares FOR a client." (Sayre, 2021, p. 4). While a therapist may ultimately shed the label of "therapist," Yi (2018) sugested a social model of care that requires creative arts therapists to work as allies to disabled people (p. 175). This process relies on establishing equal partnerships, utilizing art as a grounding force, connecting clients to community, supporting clients in development of self-concept, and practicing self-reflexivity (Yi, 2018, p. 175). In turn, these steps work in line with the community care inherent within disability arts and disability culture. With careful work and commitment from expressive arts therapists, this field can align with the practices of disability arts.

Discussion

Yi (2018) wrote: "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 truth through stories and the multiplicity of disability narratives" (p. 168). In practicing self-reflexivity, I understand the importance of naming identity and understanding how my identity impacts my clients. However, this development of identity is insufficient as our therapeutic work remains partially invested in the medical-interventionist model. In this model, disabled bodies are to be *fixed* or *repaired* rather than recognizing that society itself is disabling.

This literature review explored the expansiveness of disability and disability experiences, considering various identifiers including chronic illness and chronic pain to more fully explore the diversity of lived experience through the lens of liberation psychology and critical disability studies. It elaborated on the positive benefits of disability identification and what factors influence disability identification (including stigma) (Bogart, et al., 2017). Similarly, it viewed disability as a performance and examined how disability pervades our limited understanding of the world we live in and is in fact always being re-created in relationship with our surroundings. (Peers & Eales, 2017; Bridger, 2021).

It served as a guidepost to understand the many ways in which the Creative Arts Therapies utilize similar tools to serve as a radical form of community advocacy. The capstone thesis explored two photovoice projects, traversing intersectional identities including severely mentally ill individuals of low-socioeconomic status and disabled women. Continued exploration into the variation of disabled experiences is necessary. Community projects such as photovoice have significant potential to integrate the practices of disability arts. Given the project's focus on community and grounding in liberation psychology, they may be equipped to integrate disability arts more expansively.

The capstone thesis explored the works of disabled artists including Chella Man, depicting the limitations set on disabled artists, and highlighting the expansiveness of expression when creating in community with other disabled artists (Fisher, 2022). Similarly, it examined the value of creating studio spaces for Intellectually and Developmentally Disabled artists to encourage self-concept while disrupting the narrative that they must be run by able-bodied people (Miller, 2020, p. 93-94). It further explored autoethnographic research conducted by disabled art therapists, examining the impact of normative functions and expression on disabled

bodyminds by discussing the concept of the "gaze" and exploring the benefits of community support, solidarity, intersectionality, and representation within disability arts and creative arts therapy spaces (Moon, 2010, p. 104-105; Beck, 2020, 68-69). Disruptively, the "gaze" also extends into therapeutic spaces (Bridger, et al., 2021, p. 10).

The literature review explored the medicalized *fixing* of disabled bodies given the field's alignment with the medical-interventionist model. In fact, it argued that significant adjustments must be made to the spaces to accommodate disabled clients. Clinicians must ask if they are accommodating their clients needs within the creative arts therapy space or if they are asking their client to accommodate to the disabling society (Becker, 2020). Therapeutic practice is often centered on intervention and repair (Kuppers, 2006, as cited in Yi, 2019. The seizing of power from clinicians is a valuable part of the therapeutic process.

Expressive arts therapists often understand disability through the lens of disability narratives constructed by able-bodied voices. I strongly believe that things are beginning to shift in the field as we also notice dramatic shifts in the world we live in. The field's focus on symptoms and diagnosis limits the potential for the creative arts therapists to understand the fullness of any experience. An invitation to move beyond intervention and focus on community spaces, self-concept, and intersectionality are essential for shifting the field's focus toward true healing for disabled people. Creative arts therapists must consider the limitations presented by the role of the *therapist* identity.

In conducting this literature review, I found many resources within Art Therapy as well as some in Music Therapy and Drama Therapy, exploring the value of integrating Disability Arts into therapeutic practice. However, I had trouble finding published autoethnographic research by Expressive Arts Therapy peers. I would love to see this research grow within the field as we

continue to recognize and welcome more disabled voices into these spaces. As a disabled person myself, I'd like to create a therapeutic space for my clients that does not require further alteration of their bodyminds to fit the expectations created by the able-bodied world. I want the world to alter to fit their bodyminds. Samuels' (2020) wrote:

> For *crip time is broken time.* It requires us to break in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don't want to, even when we want to keep going, to move ahead. It insists that we listen to our bodyminds *so* closely, *so* attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honoring their words. (p. 192-193)

Despite the challenges of navigating this world, this program, I can imagine our futures. The futures where we listen to the words of our bodyminds over the expectations of the able-bodied world. *Crip time* teaches us to move more slowly, to honor, to unfold. I cannot imagine another future that is this rich with creativity.

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Appendices

<u>Glossary of Relevant Terms</u>
asterisked definitions are in line with the perspective of this writer, if applicable

- Person-first language: utilizing the identity of the person before the disability identity (i.e. person with a disability) (Dunn, D.S. & Andrews, E. E, 2015)
- Identity-first language*: utilizing the disability identity before the identity of the person (i.e., disabled person)/(i.e.. cont. Sick, Mad, Disabled) (Yi & Moon, 2020).
- Bodymind*: an explicit rejection of mind-body dualism (Price, 2015)
- Photovoice/Phototherapy a therapeutic method that utilizes photographs and photographic collage to express one's lived experience to support identity development, advocacy, and community engagement. (*About PhotoVoice,* n.d.)
- Crip: a performance, an embodiment of disability (Peers & Eales, 2017)
- Medical model: "(the dominant cultural perspective) that places the problem of disability on the disabled individual, which almost always leads the disabled individual to the medical industrial concept for *fixing*" (Beck, 2020, p. 63); often focused on *impairment* as a concept
- Social/political model*: "a conceptualization of disability as political and constantly emerging in relationship to surroundings, environment, and other bodies" (Kafer, 2013 as cited in Bridger, et al.., 2021).

Autoethnographic use of Photovoice: *Mourning*

Figure 1

Above: Photo featuring medical scans in the background and images of two babies, one in pink on their stomach (upper left image) and one in blue with a medical device (lower right image). Images of two sets of legs with a heating pad surround the distorted image of this writer. An ashtray, weed, and hand cover their mouth. A lighter exists on their lower right and a medical wand is floating above this writer's head. Writing listed in Figure 2.

Figure 2

mourning
finding the words
to fit
how long have i existed
in sickness
is it from the beginning
as in
always been there with me
encoded into my dna
afraid of me?

have i fought it?
won even?
oh, how you compound…
one, two, now three

maybe… i'll call y'all friends?
not yet
but even worse yet
is them
i exist, i create
(sometimes thrive)
alongside you all:
one, two, and three
each one of you challenges
me
they invalidate me
because they can't see
what i see so clearly

THESIS APPROVAL FORM

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