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A Tale of Two Art Programs: Art & Identity for People with Disabilities

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Sociology
College of Liberal Arts and Sciences
University of South Florida

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Dedication

This dissertation is dedicated to Theatre eXceptional, and the many ways those in the organization supported me. This project would not be the same without them and I am very thankful for the experience.

Acknowledgments

In the many years that it took for me to complete this dissertation, I could not have done it without the help and support of numerous others. The people mentioned in this section helped me both in terms of my dissertation and in helping my life to be enjoyable through everything.

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Table of Contents

Abstract

This dissertation explores the relationship between disability and art in individual and organizational narratives told in the context of art programs that are designed to provide meaningful and inclusive experiences for people with disabilities outside of "art therapy." Findings of narrative and thematic analysis of the websites of two non-profit disability centered arts education organizations, autobiographical sketches of disabled artists, and in-depth family history interviews with parents of people with disabilities suggest that the clear cut boxes created by scholarly and social movements narratives of disability do not map neatly onto the lived experiences of people with disabilities, their families, or the organizations that serve them. Rather, both organizational and personal narratives about disability and the arts examined for this dissertation were characterized by messiness and overlapping goals. For example, in attempting to empower artists with disabilities while also justifying the need for funding and services, the organizations cast themselves as sidekicks to heroic disabled artists engaged in the fight against the villains of inaccessibility and stigma. This is a more complex story than the traditional narrative of service organizations as heroes in the service of people victimized by the villain of disability itself. Individuals with disabilities, and their parents, also often used a complex mix of narratives, including aspects consistent with the medical, social, and crip/cyborg models of disability. The use of multiple narratives by people and organizations points to a need for more complex understandings of disability, art, and the relationship between the two in order to create meaningful social change for disabled people and their families. People with disabilities consistently engage with the arts for many complex reasons.

A simplistic assumption that the primary role of art for people with disabilities is therapeutic demeans the talent and artistic contributions of disabled artists, and masks other benefits that participation in the arts by people with disabilities can provide to individuals and communities. Just as art can take many unique forms, people with disabilities relate to art in a variety of ways.

Chapter 1: Introduction

Introduction

This dissertation explores narrative constructions of participation in the arts among people with disabilities. From early childhood to late adulthood, art spaces can be important sites of inclusion and exclusion. Though art classrooms and spaces are often the first supposedly integrated space where students with disabilities are "included," the term "inclusion" sometimes indicates the student is physically in the room rather than indicating true full participation. Unfortunately, people with disabilities are regularly excluded from art spaces that are not labeled as being "therapeutic," and have reported significant barriers to establishing careers in the arts (Bingham & Green, 2016; Green & Bingham, 2017). This denies people with disabilities the opportunity to produce their own art and presumes that the relationship between disability and art is a one-way relationship where art can help people with disabilities but people with disabilities have nothing to offer the art world. For this project, I explored two organizations that stand in opposition to this trend by including career connections and opportunities to produce high-quality art, for the sake of art, for people with disabilities.

The organizations that I studied are very different: one is state-wide and provides access, primarily to minors, through schools and juvenile correctional facilities. The other is a local non-profit theater group that works with adults with disabilities, many of whom have intellectual or developmental disabilities. Despite these differences, these two organizations stand out in that they emphasize their support for people with disabilities who seek to be professional artists in their mission statements. One of the organizations conceptualizes art as a possible source on income and includes a list of former students who are currently professional artists on their website (Allen, 2014; https://arts4allflorida.org). This contrasts with the formula story (Loseke, 2017) of art as a form of therapy or charity for people with disabilities (Cooley & Fox, 2014; Fox, 2015; Lenakakis, & Koltsida, 2017; Solvang, 2012).

In selecting organizations that specifically focus on aspects of art other than therapy, I am not arguing that art does not have therapeutic value, for those with and without disabilities. Some positive outcomes include increasing communication skills (Lenakakis & Koltsida, 2017) and in some cases, fine motor skills (Loesl, 2012). While these are important, they will not be the primary focus of this research, as I specifically chose sites that market themselves as offering career opportunities in contrast to organizations that focus primarily on therapy (Solvang, 2012).

I collected data in and about these two organizations to answer the following questions:

1. How do disability-based arts organizations that promote inclusion frame their identities in publicly broadcast narratives?
2. How do adult artists who advertise their work on organizational websites of disability-based arts programs that promote inclusion describe themselves and their art?
3. How do parents of participants in disability-based arts programs that promote inclusion view the work of the organization and its role in their children's lives? What facilitators and/or barriers do parents of program participants perceive in relation to the opportunities their children have had to participate in the arts at various points in the family life course?

The first research question is addressed in Chapter 2 through a narrative analysis of publicly available materials produced by Blue Butterfly Productions about its inclusive theater program Theatre eXceptional. The second question is addressed in Chapter 3 by analyzing self-descriptions of adult artists that can be publicly accessed through the website of Arts4All Florida. The final questions are addressed in Chapter 4 through an analysis of the transcripts of fourteen in depth, life course interviews with ten parents of participants in Blue Butterfly Production's inclusive theater program Theatre eXceptional.

Theoretical Underpinnings

While each chapter in this sandwich-style dissertation contains its own discussion of relevant theories and literatures, there are several theoretical perspectives that guided the overall project. The next section briefly outlines conceptual frames from which I will draw: the importance of narratives; social model of disability; stigma; and crip and cyborg conceptualizations of disability.

The Importance of Narratives

Narratives are a deeply embedded in of all levels of social life. Meaning is produced through stories, and shared meanings are important to individual and community identity (Loseke, 2019). Individual, organizational, and institutional stories both shape and are shaped by shared cultural understandings of the meaning of human experiences (Loseke, 2007). At all levels, stories have plots, morals, and characters - such as villains, victims, and heroes - which can either conform to or resist widely shared notions about what is and isn’t good, or even believable, about a particular kind of experience (Dunn, 2004; Loseke, 2007, Loseke, 2019). Some stories are acceptable in some circumstances and not in others. Storytellers sometimes construct their tales in very particular ways for pragmatic reasons – for example, to acquire desired outcomes such as services, support, and social approval (Loseke, 2019).

Loseke and Green (2020) argue that while it is not particularly common to do so, scholars can also be seen as storytellers and scholarly discourses can be viewed as narratives that shape and are shaped by shared public understandings. The systems of meaning constructed by academics can become part of the public imagination when they are championed through activism, influence public policy, and/or are incorporated into the self-descriptions, practices, and daily doings of organizations that serve the public. Through these channels, academic narratives can also shape the stories individuals tell about even the most personal aspects of their daily lives.

Competing narratives exist about the nature of both art and disability. In terms of art, there are differences of opinion as to who can create art (Chandler, 2017; Foucault 1965/1988; Fox, 2015; Solvang, 2012; Wexler & Derby 2015), the purpose of art, and who, if anyone, can evaluate what art is (Chandler 2017; Fox, 2015; Solvang, 2012). In terms of disability, there are tensions between medical and social views of what constitutes disability. Disability activists typically see "inclusion" to be the primary goal (Oliver & Barnes, 2012; Shakespeare 2014). Yet, there is also a pressure for art programs to be "exclusive" in order to be taken seriously and be considered more than therapy (Chandler 2017; Cooley & Fox, 2014; Fox, 2015; Fraser, 2013; Solvang, 2012). Understanding how art programs for people with disabilities manage to navigate these seemingly contradictory goals is a goal of this dissertation and an important step in designing truly inclusive art spaces.

In the next sections, I provide more detail about three types of academic narratives about disability that have entered the public sphere to at least some degree and that have relevance for the ways in which arts organizations and individual artists and their families might portray themselves and others in the stories they tell.

Medical vs. Social Model Understandings of Disability

Within the context of western capitalism and its associated narrative of individualism and self-sufficiency, disability is framed as a biomedical problem. This understanding focuses exclusively on what tasks a person cannot do (Coriale, Grant, & Robertson, 2012; Jung 2003; Oliver & Barnes 2012; Shah & Priestly, 2010; Shakespeare 2014). Critics argue that: "Working out of the medical model of disability, assumes that a deficit exists within the individual-something to 'fix, cure, accommodate, or endure" (Baglieri, Valle, Connor, & Gallagher, 2011; Andrews, et. al. 2000 pp 259).

Instead of emphasizing negative consequences of bodily impairments or neurodivergence, the Social Model calls attention to the negative consequences of social and physical environments that restrict the ability of people with impairments to participate in their communities (Jung, 2003; Oliver & Barnes, 2012). The Social Model not only shifts the focus to what people *can* do - it calls for the eradication of structural and attitudinal barriers that inhibit people with disabilities from fully participating in society. This shift in focus is a call to action, and has led to improved accessibility of public spaces, education, employment, housing, and all areas of social life, including art programs. Disability activists have fought for and succeeded in passing laws that mandate that spaces, particularly educational spaces, need to be accessible for people with disabilities (Oliver & Barnes, 2012; Patterson 2012; Rothstein 2014).

Despite improved access, however, people with disabilities still navigate institutions designed primarily for able-bodied/minded people (Kafer 2013; Oliver & Barnes, 2012; Shakespeare, 2014). This reproduces inequalities in institutions that are assumed to be meritocratic (Castagno, 2014; Egilson & Traustadottir, 2009; Kafer 2013; Oakes, 1982; Oakes, 2005; Oliver & Barnes, 2012; Ruben, 2006; Shakespeare, 2014; Weblow, Urick, & Duesbery, 2013; Wilson 2017). Despite the successes of these movements, society overall still values wage-labor and productivity as a measure of self-worth; and disability and illness are seen as deviant because they violate norms of productive capacity (Goffman 1963; Nowakowski 2016; Parsons 1951; Parsons 1964; Oliver & Barnes 2012; Welch 2017; Zola 1993).

Critics also argue that by focusing heavily on the built environment and legislation, disability scholars and disability rights activists have also fallen victim to the same problem they seek to solve. Not all people with impairments or disabilities benefitted equally from this movement or the laws passed. Shakespeare (2014) identifies some key issues that have not been adequately addressed by the Social Model: 1. nature, incompatibility between what is most accessible for different conditions; 2. practicality, the exorbitant cost and intrusion that would be necessary to make all spaces accessible; and 3. its inability to address issues related to impairments that cause distress, such as pain, psychosis, and shortened lifespan.

Many Social Model proponents have been responsive to these critiques. This is most easily exemplified by the steps taken in educational settings to accommodate neurodivergent students (Brigham, Morocco, Clay, and Zigmond; 2006; Wilson 2017). Schools that offer multiple ways of teaching and learning can help students with a variety of disabilities. For example, having written and auditory versions of instruction available in a way that it can be revisited can help students with sensory impairments, learning disabilities, and mental illness alike. Alison Kafer's (2013) offers up the concept of "Crip Time." "Crip Time," can be referred to as "a flexible standard for punctuality" rooted in the understanding that people with a wide range of disabilities may have difficulties with punctuality for a variety of reasons including but not limited to, inaccessibility of spaces and transportation, failing or malfunctioning technological equipment, and mental distortions of time and energy. Factoring Crip Time into places such as schools, workplaces, the theater, and social events can make places more accessible to those with disabilities, including those that are not visible, unpredictable, and/or not yet diagnosed.

The Stigma of Disability

In his book, *Stigma,* Goffman (1963) explores the ways in which some identities, including disability, are devalued though social norms and interactions. While Goffman's book was not explicitly about disability, it does reference disability frequently and is one of the earliest works to treat interactions between individuals with and without disabilities as a phenomenon worthy of serious scholarship. Goffman (1963) argues that when someone has a “spoiled identity” or a negative label, all of their actions are interpreted by others through the lens of that label, (Goffman, 1963; Link & Phelan, 2001). For example, in a mixed-disability-status theater group, directors expressed concern about including people with disabilities because actors with disabilities forgot lines or became distracted, even though this happened to all of the actors, with or without disabilities (Lenakakis & Koltsida, 2017).

Goffman (1963) describes “discredited stigmas,” or easily visible sources of stigma, and “discreditable stigmas,” which can be hidden. While discreditable stigmas may seem easier to navigate on the surface, people with discreditable stigmas run the risk of being labeled as “deceptive” or “untrustworthy” if that stigma is discovered by others (Goffman 1963). Yet, some people find that when they hide or downplay their symptoms, they are then accused of being manipulative for not seeming “sick enough” (Bilderbeck et. al., 2014; Maconi, Green & Bingham, 2019; Venville, Street, and Fossey, 2014).

Stigma does not always arise from malicious intentions. In fact, often times, it is well-meaning professionals and members of the community who continue to perpetuate stigmatizing and paternalistic ideals (Charles & Bentley, 2014; Dunn, 2004; Green, 2007; Loseke, 2007; Oliver & Barnes, 2013; Shakespeare 2014). Professionals and educators who work with people with disabilities (whom Goffman calls “the wise”) do not necessarily hold less stigmatizing views about disability compared to the general population. Their well-intentioned attempts to advocate for and help may even exacerbate stigma (Black et. al. 2011; Charles & Bentley, 2014; Green, 2017; Lund, Andrews, & Holt, 2014).

Goffman's concept of stigma offers a useful way of addressing the socially constructed aspect of disability, without denying the salience of experiences that arise from the impairment or condition itself.

Crip Theories and Cyborgs: A Story of Both/And

The theoretical dichotomies between the Biomedical and the Social Models of disability (Oliver & Barnes, 2012) fails to resonate with the lived experiences of many individuals with disabilities and their families (Blum, 2015; Green, Darling, & Wilbers, 2017). Manago, Davis, and Goar (2017) found that parents of children with disabilities found it useful to use both the Social Model *and* the Biomedical models in order to advocate for their children. Thus, A more nuanced approach is needed to address the sometimes, contradictory experience of disability that many people live.

The emerging narrative of the cyborg experience is one attempt to problematize the narrative divide. Kafer (2013) borrows from Donna Haraway's (1985) concept of the cyborg, which does not address disability outright. Rather, it zooms in on seemingly contradictory relationships that thrive- such as the idea that environmental ecofeminism could recruit members and disseminate information via technology. This concept of the cyborged self, particularly in its celebration of contradiction, resonates with many people with disabilities in ways that the Social Model on its own sometimes lacks. Steven Kurzman for example, described himself as a cyborg, stating,

> *"I stand and walk with the irony that the materials and design of my leg are based in the same military technology which has blown the limbs off so many other young men, … I am not a cyborg simply because I ware an artificial limb," (Kurzman, 2001: p382).*

This conception of disability allows us to bring the body and/or mind back into the analysis of the relationship between disability and art. While the Social Model and Stigma both, to an extent separate the experience of exclusion and discrimination from the body, Crip theory offers a space where artists can discuss how their disability impacts their art (positively or negatively) but that inclusion of the body does not devalue the art, nor does it devalue the experience of living and creating art in a body/mind with disabilities.

Literature Review: Disability and Arts Education

Educational settings are a prime spot where the consequences of stigma arising from the good intentions of well-meaning policies plays out. Despite laws in place to include people with disabilities in educational settings, (Patterson, 2012: Rothstein 2014;), students with disabilities consistently remain isolated from their peers (Allen, 2010; Coleman et. al. 2015; Copeland, et. al 2004; Egilson & Traustadottir, 2009; Shah & Priestly 2010; Sullivan & Bal, 2013). People with disabilities are typically assumed to be less competent regardless of the task or the person's disability (Coleman & Cramer, 2015; Egilson & Traustadottr, 2009; Goffman 1963; Orr & Goodman 2010; Sullivan & Bal 2013) and often lack the proper supports and accommodations, leaving them vulnerable to being tracked into segregated spaces, despite research showing that "Mixed classes offer disabled students higher academic, social skills and potential for personal achievement" (Lenakakis & Koltsida, 2017: 253). This separation ultimately results in both social and material inequalities for people with disabilities.

Bowles and Gintis (1976) posit that schools do not educate children for the sake of knowledge but rather, to prepare students to be workers in the capitalist economy. They coined the term "correspondence principle" to describe the processes through which inequalities in schools are directly connected to inequalities in the labor structure. Through this lens, schools have no need to include students with disabilities if they will not eventually be employed. As it applies to art programs, some researchers have observed that well-meaning paraeducators may do the majority of art projects for students with disabilities, rather than allowing the student to make decisions and take control of their project (Coleman & Cramer, 2015; Coleman et. al. 2015; Young, 2008; Zederayko & Ward, 1999). The assumption is that if a student with disabilities cannot do the assignment without assistive technology, they will not have any need for the artistic skills anyway. This continues despite the fact that multiple studies have shown benefits to students with disabilities taking an active role in art projects.

Yet, many would argue that the model put forth by Bowles and Gintis (1976) is too fixed and unchanging, (Giroux, 2001; Apple, 1980). Students with disabilities have not been passive or accepting of the low expectations that the schools set for them. "Resistance theories" account for agency and change that occurs within the education system. "What is significant about [resistance theory] work is that pointing to the gaps and tensions that exist in social sites such as schools, it successfully undermines theories of reproduction that support a 'constant fit' between the school and the workplace," (Giroux, 2001: p. 100).

While this segregation has social and material consequences for artists with disabilities, multiple studies have demonstrated that connecting with others and developing a positive disability identity has a positive impact on well-being, as well as health consequences (Beresford, 2000; Bogart 2014; Bogart, 2015; Lester & Tritter, 2005; Nario-Redmond, Noel, & Fern, 2013; Shaw, 2015; Williams 2008). Thus, arts-based programs for people with disabilities can foster an environment to create a positive disability identity as well as placing a heavy emphasis on perfecting a skilled craft with the goal of producing professional, career artists (Cooley & Fox 2014; Fox 2015; Lenakakis & Koltsida, 2017; Scribner 2000; Solvang, 2012).

Despite evidence that participation in the arts is beneficial for people with disabilities, arts programs in schools are often inaccessible or discriminatory towards people many people with disabilities. Sometimes, people with disabilities seek out access to arts in outside of the school system, though, this takes considerable time, money and resources. In their study of a theater group that included people with and without disabilities, Lenakakis and Koltsida (2017) found that actors with disabilities flourished both as actors and in improving social interaction skills generally. They found that participating in the group increased feelings of belonging, empowerment, and an increased confidence in expressing and assessing emotions.

Even with these benefits, such programs are rarely offered through the scholastic setting. As Lenakakis (2004) discussed, special education teachers rarely have a background in the arts specifically. Since arts programs are often inaccessible or discriminatory towards people with disabilities, this structure segregates people with disabilities away from the arts, particularly for vulnerable populations experiencing disproportionality in special education who would likely lack resources to seek out private arts-based programs (Lenakakis, 2004; Sullivan & Bal 2013).

Conclusion

In short, my dissertation explores the organizational and personal narratives, surrounding two different disability-centered art spaces. The differences in the two populations served by the organizations will give me a snapshot of the meaning art plays to people with disabilities across the life course. In looking at multiple layers of the narratives surrounding the organization and the people involved in it, I will also be able to examine any tensions between organizational narratives, and the experiences, and/or goals of the individuals involved. This dissertations contributes to our understanding of disability and art, beyond these organizations, in that through their identities as artists with disabilities participants in these programs may produce art that resonates with other people with disabilities who are not associated with these organizations.

References

Allen, J., (2010). The sociology of disability and the struggle for inclusive education. *British Journal of Sociology of Education 31*(5) 603-619.

Allen, J., (2014). Inclusive education and the arts. *Cambridge Journal of Education, 44*(4) 511-523.

Andrews, J.E., Carnine, D.W., Couthinho, M.J., Edgar, E.B., Forness, S.R., Fuchs, L., Jordan, D., Kauffman, J.M., Patton, J.M., Paul, J., Rosell, J., Rueda, R., Schiller, E., Skrtic, T., & Wong, J., (2000). Bridging the special education divide. *Remedial and Special Education, 21*(5) 258-260.

Apple, M.W. (1980). The other side of the hidden curriculum: Correspondence theories and the labor process. *The Journal of Education, 162*(1) 47-66.

Arts4All Florida (2018) http://www.vsafl.org/ Accessed October 8, 2018.

Baglieri, S., J.W., Valle, D.J. Connor, & D.J., Gallagher, (2011). Disability studies in education: The need for plurality of perspectives on disability. *Remedial and Special Education, 32*(4) 267-278.

Beresford, P., (2000). What have madness and psychiatric system survivors got to do with disability studies? *Disability and Society*, *15*(1) 167-172.

Bilderbeck, A.C., Saunders, K.E.A., Price, J., & Goodwin, G.M., (2014). Psychiatric assessment of mood instability: A qualitative study of patient experience. *The British Journal of Psychiatry*, *204*(3) 234-239.

Bingham, S. C. & Green, S. E. (2016). *Seriously funny: Disability and the paradoxical power of humor.* (Bingham, S. & Green, S.). Boulder (CO): Lynne Rienner Publishers.

Black, D.W., Pfohl, B., Blum, N., McCormick, B., Allen, J., North C.S., Phillips, K.A., Robins, C., Siever, L., Silk, K.R., Williams, J.B.W. & Zimmerman, M., (2011). Attitudes towards borderline personality disorder: A survey of 706 mental health clinicians. *CNS Spectrums, 16* 67-74.

Blum, L. (2015). *Raising generation Rx: Mothering kids with disabilities in an age of inequality*. New York, NY: New York University Press.

Bogart, K.R. (2014). The role of disability self-concept in adaptation to congenital or acquired disability. *Rehabilitation Psychology*, *59*(1) 107-115.

Bogart, K.R., (2015). Disability identity predicts lower anxiety and depression in multiple sclerosis. *Rehabilitation Psychology*, *60*(1) 105-109.

Bowles, S., & Gintis, H., (1976). *Schooling in capitalist America: educational reform and the contradictions of economic life,* Chicago IL: Haymarket Books.

Brigham, N., Morocco, C.C., Clay, K., Zigmond, N., (2006). What makes a high school a good high school for students with disabilities. *Learning Disabilities Research & Practice, 21*(3) 184-190.

Cahill, S.E., & R. Eggleston, (1994). Managing emotions in public: The case of wheelchair users. *Social Psychology Quarterly, 57*(4) (1994) 300-312.

Cahill, S.E., &R. Eggleston, (1995). Reconsidering the stigma of physical disabilities: Wheelchair use and public kindness. *The Sociological Quarterly,* 36(4) 681-698.

Cardinal, R., (1972). *Outsider art*, New York, N.Y., Praeger.

Castagno, A.E., (2014). *Educated in whiteness: Good intentions and diversity in schools*, Minneapolis, MN: University of Minnesota Press.

Chan, D., Sireling, L., (2010). "I want to be bipolar'…A new phenomenon. *The Psychiatrist, 34* 103-105.

Chandler, E. (2017). Reflections on cripping the arts in Canada. *Art Journal*, *76*(3/4) 56-59.

Charles, J. L.K., & K. J. Bentley, (2014). Stigma as an organizing framework for understanding the early history of community mental health and psychiatric social work. *Social Work in Mental Health*, *14*(2) 149-173.

Coleman, M.B., & Cramer, E.S., (2015). Creating meaningful art experiences with assistive technology for students with physical, visual, severe, and multiple disabilities. *Art Education*, *68*(2) 6-13.

Coleman, M.B., Cramer, E.S., Park, Y., & Bell, S.M., (2015). Art educators' use of adaptations, assistive technology, and special education supports for students with physical, visual, severe, and multiple disabilities. *Journal of Developmental and Physical Disabilities 27*(5) p.637-660.

Cooley, J., & Fox, A.M., (2014). Disability art, aesthetics, and access: Creating exhibitions in a liberal arts setting. *Disability Studies Quarterly, 34*(1).

Copeland, S.R., Hughes, C., Carter, E.W., Guth, C., Presley, J.A., Williams, C.R., & Fowler, S.E. (2004). Increasing access to general education: Perspectives of participants in a high school support program. *Remedial and Special Education*, *25* 342-352.

Coriale, L., L. Grant, & J. Robertson, (2012). Exploring the educational experience of a social work student with a disability: A narrative. *Social Work Education, 31*(4) 422-434.

Cramer, E.S., Coleman, M.B., Park, Y., Bell, S.M., & Cole, J., (2015). Art educators' knowledge, attitudes, and experiences working with students who have physical, sensory, severe, or multiple disabilities. *Studies in Art Education*, (in Press).

Dunn, J., (2004). The politics of empathy: Social movements and victim repertoires. *Sociological Focus, 37*(3) 235-250.

Egilson, S. T., & R. Traustadottir, (2009). Assistance to Pupils with Physical Disabilities in Regular Schools: Promoting Inclusion or Creating Dependency? *European Journal of Special Needs Education, 24*(1): 21-36.

Foucault, M., (1988). *Madness and Civilization: A History of Insanity in the Age of Reason,* (Vintage Books, ed.) New York, NY: Random House (Original Work Published 1965).

Fox, A., (2015). Invigorating disability aesthetics through art and performance: A report from the bodies of work festival of disability arts and culture 2013. *Journal of Literary & Cultural Disability Studies 9*(3) 349-355.

Fraser, M., (2013). Cripping it up. *Journal of Visual Art Practice, 12*(3) 245-248.

Giroux, H.A. (2001). Reproduction, resistance, & accommodation in the schooling process. *Theory & Resistance in Education: A Pedagogy for the Opposition,* pp.(98-111) Massachusetts: Bergin & Garvey Publishers Inc.

Goffman, Erving (1963). *Stigma: Notes on management of spoiled identity.* New York: Simon and Schuster.

Green, S.E., (2007). Components of perceived stigma and perception of well-being among university students with and without disability experience. *Health Sociology Review 16*(3-4) 328-340.

Green, S.E., (2015). Staying true to their stories: Interviews with parents of children with disabilities. In Berger, R. & Lorenz, L. (Eds.). *Disability and Qualitative Inquiry: Methods for Rethinking an Ableist World.* Surrey (UK): Ashgate.

Green, S.E. (2017). Managing the emotions of reading Goffman: Erving Goffman and Spencer Cahill looking at disability," in S.E. Green & S.N. Barnartt (Eds.) *Sociology Looking At Disability: What Did We Know and When Did We Know It?* pp.(39-56) United Kingdom, Emerald Group Publishing Limited.

Green, S. E. & Bingham, S. C. (2017). I Could have so Easily been Excluded: Exploring Narratives of Inclusion and Exclusion in the Lives of Professional Performers with Disabilities. In Scorgie, K., & Sobsie, R. (Eds.). *Working with Families for Inclusive Education: Navigating Identity, Opportunity and Belonging, International Perspectives on Inclusive Education, Volume 10.* Pp 11-29. Bingley (UK): Emerald Group Publishing Limited.

Green, S. E., Darling, R. B., and Wilbers, L. (2017). Struggles and joys: A review of research on the social experience of parenting disabled children. in S.E. Green & S.N. Barnartt (Eds.) *Sociology Looking At Disability: What Did We Know and When Did We Know It?* pp.(39-56) United Kingdom, Emerald Group Publishing Limited.

Haraway, D.J., (1985). The manifesto for cyborgs: Science, technology and socialist feminism in the 1980s. *Socialist Review*, no. *80* 65-108.

Jung K.E., (2003). Chronic illness and academic accommodation: Meeting disabled students' "unique needs" and preserving the institutional order of the university. *Journal of Sociology and Social Welfare 30*(1) 91-112.

Kafer, A., (2013). *Feminist Queer Crip*, Indiana University Press.

Kurzman, S.L., (2001). Presence and prosthesis: A response to Nelson and Wright," *Cultural Anthropology*, *16*(3) 374-387.

Lenakakis, A., (2008). Theatre/drama pedagogy and special education, in Children and Adolescents with Psychosocial and Learning Disorders, Intervention Strategies, Ed. Elias Kourkoutas & Jean-Pierre Chartier, 455-470 Athens: Topos (in Greek).

Lenakakis, A., & Koltsida, M. (2017). Disabled and non-disabled actors working in partnership for a theatrical performance: A research on theatrical partnerships as enablers of social and behavioral skills for persons with disabilities. *Research in Drama Education: The Journal of Applied Theatre and Performance*, *22*(2) 251-269.

Lester, H., & Tritter, J.Q., (2005). Listen to my madness: Understanding the experiences of people with serious mental illness. *Sociology of Health and Illness*, *27*(5): 649-699.

Link, B.G. & J. C. Phelan, (2001) "Conceptualizing stigma," *Annual Review of Sociology*, *27*, 363-385.

Loseke, D.R., (2007). The study of identity as cultural institutional, organizational, and personal narratives: Theoretical and empirical integrations. *The Sociological Quarterly*, *48* 661-688.

Loseke, D.R. (2019). *Narrative productions of meaning: Exploring the work of stories in social life.* New York: Lexington Books.

Loseke, D.R. and Green, S.E. (2020). Introduction: Exploring narrative as a social science framework on disability and disabled people. In *New Narratives of Disability: Constructions, Clashes, and Controversies* (Sara E. Green and Donileen R. Loseke, Eds). *Research in Social Science and Disability, Volume 11,* Pp. 1-8. Bingley (UK): Emerald Group Publishing Limited.

Loesl, S., (2012). The adaptive art specialist: An integral part of a student's access to art. in *The Intersection of Arts Education and Special Education: Exemplary programs and approaches* (p.47-68) Washington DC: International Organization on Arts and Disability.

Lund E.M., Andrews, E.E., & Holt, J.M., (2014). How we treat our own: The experiences and characteristics of psychology trainees with disabilities. *Rehabilitation Psychology 59*(4) 367-375.

Maconi, M. L., Green, S. E., & Bingham, S. C. (2019). It's not all about coursework: Narratives of inclusion and exclusion among university students receiving disability accommodations. In *Promoting Social Inclusion: Co-creating Environments that Foster Equity and Belonging* (Kate Scorgie and Chris Forlin, Eds) *International Perspectives on Inclusive Education, Volume 13,* Pp. 181-194. Bingley (UK): Emerald Group Publishing Limited.

Manago, B., Davis, J.L. Goar, C., (2017). Discourse in action: Parents' use of medical and social models to resist disability stigma. *Social Sciences & Medicine, 184* 169-177.

Nario-Redmond, M.R., J.G. Noel, & E. Fern, (2013). Redefining disability, re-imagining the self: Disability identification predicts self-esteem and strategic responses to stigma. *Self & Identity, 12*(5) 468-488.

Oakes, J. (1982). Classroom social relationships: Exploring the Bowles and Gintis hypothesis. *Sociology of Education,* 55(4): 197-212.

Oakes, J.A. (2005). *Keeping track: How schools structure inequality,* Chapters 10 & 12, "The Search for Equity" and "Democracy's Canaries."

Oliver, M., & Barnes, C.,(2012). *The new politics of disablement*, New York, NY: Palgrave Macmillian.

Orr, A.C., & Goodman, N., (2010). People like me don't go to college:" The legacy of learning disability. *Journal of Ethnographic & Qualitative Research*, Vol 4 p. 213-225.

Parsons, T. (1951). *The social system,* Chicago: Free Press.

Parsons, T., (1964). *Social structure and personality*, Glencoe: Free Press.

Patterson, L., (2012). Points of access: Rehabilitation centers, summer camps, and student life in the making of disability activism, 1960-1973. *Journal of Social History* 46(2) 473-499.

Rothstein, L., (2014). Forty years of disability policy in legal education and the legal profession: What has it changed and what are the new issues? *American University Journal of Gender, Social Policy & the Law, 22*(3) 519-650.

Scribner, P. (2000). *Putting creativity to work: Careers in the arts for people with disabilities/ VSA Arts*, Baltimore, M.D., Social Security Administration's Office of Employment Support Programs.

Shah, S., & M. Priestly, (2010). Home and away: The changing impact of educational policies on disabled children's experiences of family and friendship. *Research Papers in Education, 25*(2) 155-175.

Shakespeare, T., (2014). *Disability rights and wrongs revisited*" 2nd Ed. Cornwall, Great Britain: Routeledge.

Shaw, C., (2015). "We have no need to lock ourselves away": Space, marginality, and negotiations of Deaf identity in late Soviet Moscow. *Slavic Review*, *74*(1) p57-78.

Solvang, Per Koren, (2012). Research paper: From identity politics to dismodernism? Changes in the social meaning of disability art. *European Journal of Disability Research*, *6*(3) 178-187.

Sullivan, A. L., & Bal, A., (2013). Disproportionality in special education: Effects of individual and school variables on disability risk. *Council for Exceptional Children*, *79*(4) 475-494.

Venville, A., A. Street, & E. Fossey, (2014). Student perspectives on disclosure of mental illness in post-compulsory education: Displacing doxa," *Disability & Society, 29*(5) 792-80.

Welch, M.J., (2017). Back to the future: Irving K. Zola's contributions to the sociology of disability. in S.E. Green & S.N. Barnartt (Eds.) *Sociology Looking At Disability: What Did We Know and When Did We Know It*? pp.(97-142) United Kingdom, Emerald Group Publishing Limited.

Werblow, J., A. Urick, and L. Duesbery. (2013). On the wrong track: How tracking is associated with dropping out of high school. *Equity & Excellence in Education*, *46*(2): 270-284.

Wexler, A.J., & Derby, J., (2015). Arts in institutions: The emergence of (disabled) outsiders. *Studies in Art Education*, *56*, 127-141.

Wilbers, L.E., (2015). "She has a pain problem, not a pill problem": Chronic pain management, stigma, and the family-An autoethnography. *Humanity and Society,* 39(1) p86-111.

Wilson, J.D., (2017). Reimagining disability and inclusive education through universal design for learning. *Disability Studies Quarterly, 37*(2).

Young, G.C., (2008). Autonomy of artistic expression for adult learners with disabilities. *International Journal of Art & Design Education, 27*, 116-123.

Zederayko, M.W., & Ward, K., (1999). What to do when students can’t hold a pencil. *Art Education*, *52*(4) 18-22.

Zola, I.K., (1993). Self, identity, and the naming question: Reflections on the language of disability. *Social Science and Medicine, 36*, 167-173.

Chapter 2: More than Therapy: Conformity and Resistance in an Organizational Narrative of Disability and the Performing Arts[1]

Introduction

Narratives of disability have traditionally been ones of personal tragedy (Coriale, Grant, & Robertson, 2012; Jung 2003; Oliver & Barnes 2012; Shah & Priestly, 2010; Shakespeare 2014). Yet, as this chapter will explore, there are multiple competing narratives told throughout all levels of social life (Loseke, 2007). These narratives are not fixed, but instead, are fluid and ever-changing. Different narratives are deployed at different times for different purposes. In this chapter, I explore the ways in which *Blue Butterfly Productions* navigates the tricky territory of constructing organizational narratives that empower and value people with disabilities while, at the same time, appeal to potential clients and donors who are more familiar with, and possibly subscribe to, the most widely known cultural narratives of disability as personal tragedy.

Cultural Narratives of Disability

Cultural narratives of disability are socially circulating, widely told formula stories (Berger 1997). Typically, formula stories include the character types of heroes, victims, and villains; plots are familiar and predictable.

Three kinds of cultural narratives of disability are the most common in the current era. Within the context of western capitalism, the most predominant is the "biomedical" narrative that

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frames disability as a personal, tragic, biomedical problem. This understanding focuses exclusively on what a disabled person cannot do (Coriale, Grant, & Robertson, 2012; Jung 2003; Oliver & Barnes 2012; Shah & Priestly, 2010; Shakespeare 2014). While this image supports offering services for people with disabilities, victimhood and passivity are not evaluated as desirable in a culture that values independence and agency (Best, 1997; Dunn 2004; Kimball, Moore, Vaccaro, Troiao, & Newman 2016; Loseke, 2007).

A second type of disability narrative is the “super crip” narrative, a character centered story telling of how a person overcame disability, often by heroic means. While this narrative seems to contradict the biomedical narrative that features disabled people as victims, it continues to reflect the idea that disability is an individual tragedy to be “overcome” by heroic individual efforts. By dramatizing how personal effort can overcome disability, the supercrip narrative also can serve to negate the need for services as well as objectify people with disabilities who are put on display as “motivation” for others to be heroic in overcoming difficulties (Cahill & Eggleston 1994; Calderón-Almendros & Calderón-Almendros, 2016; Dunn, 2004; Green 2015; Loseke, 2007; Rousso, 2013; Shaw, 2015).

The biomedical narrative of disability imagines that a deficit exists within the individual and is something to ‘fix, cure, accommodate, or endure” (Andrews, et. al. 2000, 259. Also, see Baglieri, Valle, Connor, & Gallagher, 2011), and the “supercrip” narrative draws attention to how individuals overcome their disabilities. In stark contrast, the third narrative, the social narrative, draws attention away from people who have disabilities and toward problems created by the organization of the social world. The plot of the social narrative of disability is how the built environment and social policies create the problems of disability. This narrative also directs attention to the social causes as well as the social and personal consequences of “stigma”

(Goffman 1963), constellations of beliefs about the deficiencies of disabled people that lead to prejudices, discriminations, and exclusions. For example, in a mixed-disability-status theater group, directors expressed concern about including people with disabilities when actors with disabilities forgot lines or became distracted-even though this happened to all of the actors, with or without disabilities (Lenakakis & Koltsida, 2017). While able-body/minded actors were assumed to just be “new” or “learning,” actors with disabilities were considered to be a liability to the quality of the production when they made similar mistakes. (Goffman, 1963; Link & Phelan, 2001).

These three common narratives of disability, the biomedical, the supercrip, and the social model, reflect analytic, rather than practical, differences. That is, theoretical dichotomies between the biomedical and the social narratives (Oliver & Barnes, 2012) fail to resonate with the lived experiences of many families with disabled members (Blum, 2015; Green, Darling, & Wilbers, 2017). Rather, personal narratives told by people with disabilities and their families often draw from multiple understandings of disability. This makes sense because people with disabilities do not live in a cultural vacuum. Particularly those who develop disability later in life may subscribe to some aspects of the cultural narrative of disability as biomedical tragedy. Furthermore, people with disabilities also interact with able body/minded people who often see the world through the biomedical narrative. Thus, relying on biomedical understandings of disability may be used to communicate more efficiently with others. For example, Manago, Davis, and Goar (2017) found in their interviews, that parents of children with disabilities used both the social model *and* the biomedical models to advocate for their children. Thus, a more nuanced approach is needed to address the sometimes contradictory experience of disability that many people live. Finally, yet critically, organizations involving disabled people can draw upon more than one cultural narrative. I turn now to the organizational narrative of *Blue Butterfly Productions*.

Organizational Narratives of Disability

Organizations whose clients are disabled are located within an environment containing several cultural narratives about disability and disabled people. Organizational actors may adopt or challenge these cultural narratives, depending on the goals of the organization. On one hand, the biomedical narrative of disability imagining the organization as heroically helping the pitiful victims of disability might be associated with receiving funding and public support from those viewing disability as a tragedy. Similarly, this narrative might be useful because it makes workers heroic and therefore offers "moral wages" to underpaid employees (Hochschild 1983; Kolb, 2011). However, such stories may be off-putting to potential clients who resist the cultural narrative that imagines their selves as deficient, their lives as inferior. Furthermore, for investors to view the organization favorably and worth funding, there must be some path to change and/or betterment; otherwise, what purpose is the organization serving?

Thus, organizations with disabled clients must construct a narrative that depicts the organization as heroic without doing so by sacrificing the agency, hope, or self-respect of clients. This may involve borrowing from both the tragic and the inspirational narratives of disability, to tell a story in which the organization provides a pathway for their client to become "inspirational." Still, other organizations may reject the widely circulated cultural narratives outright, instead, offering a counter-narratives for those who are dissatisfied with the cultural narratives to rally behind, as seen in many non-governmental social movement organizations (Fox, 2015; Oliver & Barnes, 2012; Patterson 2012; Solvang, 2012;).

It is important to remember that organizations, like culture and individuals, are not static, unchanging entities. Organizations may deploy different narratives in different circumstances for different purposes. Much of the existing research on counter narratives focuses on personal narratives or narratives of social movement organizations. Personal narratives give agency to the individuals telling their own story. People tell stories to make sense of the world and these stories can reify or subvert the cultural narrative. Adopting and creating personal narratives can be a means of advocacy in and of itself. Kimball et al. (2016) discussed the ways in which university students with disabilities viewed self-advocacy and storytelling as a form of collective action. Many students saw educating others about their experience as a way to raise awareness about what people with disabilities need. This form of storytelling as a type of advocacy was empowering to students in a way that allowed them to control the narrative, avoid victimhood, avoid objectification, as active agents, and still claim need for services.

Green (2015: 102) found in her interviews with parents of people with disabilities, "services are acquired by telling the right story in the right way." While her project focused on personal narratives, the same can be said of organizational narratives. Organizational narratives are created to evaluate who they help and how they help them. Furthermore, organizational narratives must identify a need they are serving in order to compete for funding and continue to exist. Like other organizations, disability-centered arts programs tell stories that are designed to resonate with various audiences and serve particular purposes for the organization. These stories are also embedded in understandings of what disability-centered art is and should be.

Competing Understandings of Disability-Centered Art

Solvang (2012:183) outlines three types of art that mainstream audiences might think of when they hear "disability art": "Art Therapy," "Outsider Art," and "Disability Aesthetic."

Art Therapy

Art therapy is commonly recognized throughout mainstream culture. However, many artists with disabilities actively resist this category. While art can indeed be “therapeutic” in a sense, Solvang (2012:183) articulates the distinction, stating that in art therapy, “the artist is a patient and the instructor is a therapist.” While art therapy is helpful to some people, this narrow understanding of the role art can play in the life of a person with disabilities devalues the skill and agency involved in being an artist with disabilities. Furthermore, it reinforces the narrative of people with disabilities as victims with an inferior quality of life rather than as full human beings with lives worth living.

Outsider Art

Outsider art can refer to any art created by someone of a marginalized group that lacks formal art training. While this is not specific to disability, there is an identifiable market for art produced by people with disabilities. Some of this began with what was initially referred to as “Institutional Art,” which was created by people living in Sanitoriums (Wexler, & Derby, 2015). Initially, art created by people who were institutionalized was used by medical professionals as further “proof” that the patient was not able to live outside of the asylum, particularly if the art did not conform to modernist ideas. However, some clinicians and professionals began to see the art as “raw” and more creative, due to the lack of formal art training or adherence to modernist values. It is important to note, though, that while this perspective shift may seem positive, it was still rooted in ableist assumptions that people living in institutions were less than human; this creativity was seen as stemming from their inability to grasp formal art concepts (Wexler & Derby 2015: p.128-129).

Still, this led to the eventual creation of the House of Artists in Austria in the middle of the twentieth century:

> House of Artists has been separate from the general psychiatric ward with its rigid schedule, focusing not on ‘preparing patients to re-enter society […] but rather offering patients a new social identity,” […] Residents have been treated first and foremost as artists, not as mental patients, and the merits of their artwork have been emphasized while their mental illnesses have been regarded as private matters (Wexler & Derby 2015, p.131).

Following the deinstitutionalization movement, some outpatient facilities in the United States used aspects of this model. Some artists who became known through these processes include Johann Hauser, Judith Scott, and Larry Bissonnette. Since the term “institutional art” no longer fit, Roger Cardinal (1972) coined it as “Outside Art.”.

Disability Aesthetic

Many formal venues for art produced by people with disabilities reject the label of “outsider art” due to the controversial nature of the term as a result of its exploitative history, and the implication that an “outsider” artist does not have any formal art training, when some artists with disabilities do have such training (Chandler 2017; Solvang, 2012). Many artists with disabilities see Disability Art as a social movement, although, there is not a universal consensus on whether the goal is to merge into mainstream arts or to keep disability arts as a separate and subversive category (Fox, 2015; Fraser, 2013; Solvang, 2012). Furthermore, there is dissent as to whether “disability art” refers to any art made by artists with disabilities or only art centered on the politics or experience of disability (Fox, 2015; Solvang, 2012). Even with these controversies, or perhaps because of them, art and art spaces centered around disability continue to attract attention and exist as a space for people with disabilities to identify and express themselves. According to Taylor (2005:767), “[D]isability Arts offer the solidarity of a collective or essentialist disability identity with the function of art seen clearly as a political instrument of social change."

Research Methods

Research Site

Blue Butterfly Productions is a local grassroots theater organization that includes a program called Theatre eXceptional which focuses exclusively on providing art spaces for people with disabilities. The program includes formal acting classes taught by professionally trained actors as well as opportunities to perform in mixed ability productions alongside professional actors without disabilities. The clients are primarily adults with intellectual disabilities although all disabilities are welcome. While this project explored the Blue Butterfly website as a whole, their most popular and commonly mentioned program was Theatre eXceptional.

Data Collection & Analysis

I began searching the organizational website for stories. While I include some information about the organization's mission statement and values, I mainly focused on stories to find out who the characters are in the story of the organization.

From there, I conducted Loseke's (2007) narrative analysis to look at how the organization and artists with disabilities constructed their stories. This type of analysis looks at story construction and the use of stories in making sense of information and conveying meaning (Loseke, 2007; Loseke 2012; Saldaña 2016). I started with establishing story context: Stories and testimonies on the website are explicitly chosen. It seems logical to assume the website serves many functions including public relations, and fundraising. Second, a close reading of the website shows how it is organized around implicit ideas about the role disability plays in the lives of individuals and moral evaluations about the organization and the people who participate, and/or donate money to the organization. Third, I categorized explicit descriptions of major characters and sought to identify (1) the villain, (2) the victim, (3) and the hero. I compared these to the cultural narrative of disability which identifies the villain as the disability itself, the victim as people with these disabilities, and the heroes as the organizations that help people with disabilities. This is a simple and familiar formula story that easily explains the organization's reason for existence. What I found was that challenging all three of these characters and replacing them with other characters involved an active commitment to not only naming different heroes, villains, and victims, but also explaining to those visiting the website why it is important for the organization to continue to exist, even if it is not the hero of its own story.

The final step is unpacking symbolic codes, which involves answering the following questions:

> *"What knowledge about the world does this statement assume? What would I need to believe about the world for this statement to be believable and important? What specific values are being reflected/transmitted?" (Loseke 2012:262).*

This will involve moral assumptions about disability and the role it plays in the lives of the clients of *Blue Butterfly Productions*.

Findings

Blue Butterfly Productions evokes a number of conceptual frames in their organizational narrative that are consistent with its emphasis on problems of stigma as a product of interactions and attitudes rather than as a result of disability itself. For example, materials on the website repeatedly articulate a commitment to affirming people with disabilities and their identities as competent artists rather than as people in need of help. Its home page explicitly upholds a commitment to fighting stigma and misconceptions about disability and providing a space for *artists* to learn and perfect their craft. This priority is echoed in the short biographies of the staff and board members of Blue Butterfly Production, many of whom highlighted their professional experience with participating in and teaching professional theater.

Myths, Misconceptions, & Stigma: Villains in the Quest for Accessible Art.

One distinction that stands out in the narratives on the Blue Butterfly website is that disability is not framed as the villain. Drawing heavily from understandings of stigma and the social model narrative, Blue Butterfly identifies a clear villain: negative attitudes about people with disabilities. This is identified in the very first page of the website.

> *Theatre eXceptional, an extension of Blue Butterfly Productions, produces two plays every year raising awareness* ***and eliminating the stigma so often placed on disability & mental illness.*** *Theatre eXceptional aspires to create innovative theatre and performance art with, for, and about people with disabilities* ***with the goal of addressing and eliminating the misconceptions and social stigmas*** *so often placed upon these communities that inhibit their full acceptance into our society,* (emphasis added) (http://www.bluebutterflyproductions.org/theatre-exceptional).

This framing does specific things for the organization in terms of attracting clients, donors, and declaring a need for the organization to exist. It offers a narrative that differs from the wider, cultural narrative of disability as tragedy, and also differs itself from many other similar organizations. This helps the organization stand out and grab the attention both of donors who already hold constructive views about people with disabilities, as well as those who are more familiar with the biomedical narrative yet, not entirely supportive of the accompanying notions of the inferiority of disabled people encouraged by this narrative. The narrative affirming disability as a positive identity that is excluded due to stigmatizing attitudes rather than lack of artistic ability may also be more appealing to artists with disabilities and their families, who may then choose to participate in the programs offered through Blue Butterfly and Theater eXceptional.

With this, there is also an implied potential for larger, socio-cultural change. Offering art spaces that can garner an outside audience and produce art that is on par with or exceeds other art groups that are not specifically reserved for people with disabilities, can work to change the cultural narrative, or at the very least, offer a competing narrative on a wider scale. A glimmer of hope for a societal change poises the organization for being stable and having long-term, improving success. The website frames this possibility for change by juxtaposing the emphasis on stigma and misconceptions as a villain, with emphasis of the quality of art performed by people with disabilities, suggesting that this program can refute these villains

> ***Society often excludes people with disabilities from playing a visible role in our communities,*** *so TheatreX works to empower artists with disabilities to collaborate and create art that will show off their profound talent and potential.* (http://www.bluebutterflyproductions.org/about-blue-butterfly-productions)

What is even more interesting is who is *not* the villain. Under the "About Us" tab on the website, the page states that the organization's vision is, "to expand boundaries and dispel myths through the performing arts" (http://www.bluebutterflyproductions.org/about-blue-butterfly-productions). The website thus, presents an obvious rejection of the cultural narrative of disability as a tragedy. "Myths" and "misconceptions," are the villains in this story. However, the narrative presented on the website does not vilify the people who believe these myths or discriminate against people with disabilities, (intentionally or unintentionally). This is illustrated in the quotes above through language that personifies "myths," "stigma," and "misconceptions," with no mention of the people who hold them. For example, from the first passage on the homepage, Blue Butterfly states that its goal is, "addressing and eliminating *the misconceptions and social stigmas* so often placed upon these communities" (emphasis added) (http://www.bluebutterflyproductions.org/theatre-exceptional). Yet, there is no discussion of *who* is placing stigma on such communities, as though it were an outside force. The closest the website gets to discussion people who may discriminate against those with disabilities are references to "society," but even this is nebulous enough to avoid placing any direct blame or guilt onto potential donors or clients.

This is important as it still allows donors to identify with the organization, which is evaluated as "moral" while distancing themselves from any villainous role. For this to be effective, the donors must believe that (1) people with disabilities are moral and deserving of an art space, (2) the organization offering this opportunity is moral, and therefore, (3) donors, volunteers, and anyone in a role that supports the organization is also moral and helping in some way.

Placing the blame on the myths and stigma also serves to avoid alienating people who may currently hold such beliefs or held them in the past. Furthermore, it redirects attention to the structure, rather than individuals, thus, providing a potential for more widespread changes which reinforces the widespread need for such organizations to exist. In a sense, people without disabilities are considered in need of help, in terms of unlearning myths, as the clients with disabilities themselves.

Who Was Victimized?

A central character in this organization's story is the victim.   The organization removes the association of victimhood from people with disabilities, with mixed results. Still, as Loseke (2007) and Dunn (2004) illustrate, victimhood, while absolved of blame, is still a devalued category. Thus, the organizational narrative must strive to identify a victim, (as what is a villain without a victim?) yet, still avoid estranging any potential clients or investors.

Similar to the steps taken to shift the villain identity away from individual people and onto concepts, the victim identity can also be shifted onto less tangible, yet still valid, ideas. One of the primary victims, listed on the front page in the main description, is art itself, which is deprived of the creativity and talents people with disabilities can bring to the table.

> *When we exclude artists with disabilities from playing a visible role in our industry, we as an art form miss out on an opportunity to collaborate and create with an entire generation of artists with profound talent and potential,* (http://www.bluebutterflyproductions.org/about-blue-butterfly-productions).

However, in order to continue to exist as an organization, there must be a population to whom services can be offered. Just as the villain is portrayed to be misconceptions and stigma, those misconceptions are about people. Is it possible to assert a need to serve a population without casting them as victims to some degree? The answer is… it's complicated.

> *In addition, these very artists are denied not only their right to express themselves through the performing arts, but also a venue in which to practice and perfect their craft. Through this collaboration, we hope to not only enrich the work we produce but also the experience of all who participate.* (http://www.bluebutterflyproductions.org/about-blue-butterfly-productions).

There is a lot to unpack in these two sentences. Embedded in this is also the belief that self-expression is important and a right. Thus, denying this right would be immoral. This quote begins with describing a way in which people are wronged by the villain of the story. In this sense, there is an identifiable victim. However, as Dunn (2004) illustrated in her work on battered women, victim identities can be shed in order to acquire more favorable ones. In this quote, people with disabilities have agency in that they are framed as capable of doing art and perfecting a craft. This deviates from the "art therapy" narrative in which the art is to "heal" a patient. Instead, in emphasizing that art produced by people with disabilities is a craft, they are labeled as "artists" rather than as "patients." While these shifts can run the risk of losing the explicit link between people and the need for services, it is possible for people who are wronged in some way to gain an identity, more similar to that of a hero, in being a "warrior," of fighter against the villain that wronged them.

And the Best Supporting Actress Goes To… : Working With Heroes Towards a Common Goal.

Given that the victim identity can be shifted, I will explore how Blue Butterfly does this. As suggested in the previous section, people with disabilities are, to an extent, portrayed as being victimized by the villain, which is stigma. However, labeling people with disabilities as victims risks devaluing the identities of people in ways that reinforce the cultural narratives that the organization seeks to challenge. Still, if people with disabilities are not victims in need of saving, the organization must justify the reason that it is needed.

Blue Butterfly does this, not by labeling itself as the hero but instead, casting itself in a supporting, but necessary role. In its Our Values section, Blue Butterfly emphasizes offering support and empowering actors and actresses with disabilities, as opposed to narratives of "saving" or "fixing" people.

> *Blue Butterfly Productions Endeavors to be Inclusive and Diverse; Maintain* ***Quality*** *and Sustainability; Embrace Risk and* ***Provide Support****; Encourage Boundary Expansion; Model Dignity, Respect, and Integrity; Be Provocative and* ***Empowering;*** *Provide Education and Enlightenment; Promote Acceptance and Accessibility; Demonstrate Fiscal Responsibility (Emphasis added) (http://www.bluebutterflyproductions.org/about-blue-butterfly-productions).*

The page for Theater eXceptional highlights a similar mission.

> *TheatreX works to* ***empower artists*** *with disabilities to collaborate and create art that will show off their profound talent and potential. Through this collaboration, we hope to not only enrich the work we produce but also the experience of all who participate. (Emphasis added) (http://www.bluebutterflyproductions.org/theatre-exceptional).*

Again, while subtle, referring to clients as "artists with disabilities" reinforces the idea that people with disabilities are capable artists who are agentic, not passive. In order to reinforce the narrative that rejects victimhood for people with disabilities, the initial description in the first page emphasizes the role that people with disabilities play within the organization, thus, taking on, at least in part, any claim to the hero character the organization may gain to those exploring the organization narrative.

> *Theatre eXceptional aspires to create innovative theatre and performance art with, for, and about people with disabilities* (http://www.bluebutterflyproductions.org/theatre-exceptional).

Including people with disabilities as an integral part of designing and providing services for people with disabilities muddles the taken for granted, implicit victim-savior relationship that is common in organizational narratives for non-profits. This story shares the hero identity with clients with disabilities, with the common goal of dispelling misconceptions about disability.

Discussion

Cultural narratives that describe disability as a tragic, personal problem are so pervasive that it is hard for individuals and organizations alike to escape repeating them. While Blue Butterfly Productions is not the only organization that seeks to challenge stigmatizing narratives about people with disabilities, it is an excellent case study. This is in large part to the ways in which it draws on conceptual frameworks that reject the notion of disability as tragedy, explicitly in their description and mission statement, calling out stigma specifically.

Blue Butterfly's approach to challenging traditional narratives of disability draw on both the Social Model of Disability and Goffmanian understandings of stigma. Rather than attributing the underrepresentation of people with disabilities to individual impairments, it is inaccessible art training and negative attitudes that impede art access for people with disabilities. Aspiring artists with disabilities are disabled by the lack of accessibility and negative attitudes from gatekeepers in other art programs. Thus, Blue Butterfly's mission is not to change their clients in any way but rather, to make their program one in which their clients can flourish.

While this use of social model rhetoric is helpful in reframing art programs and potential artists with disabilities, Blue Butterfly does not completely divorce the experience of disability from the body/minds of their clients. The narratives on their website focus most heavily on the interactions that lead people to devalue and stigmatize artists with disabilities. The goal of the program, in addition to making theater programs accessible for people with disabilities, is "eliminating misconceptions and social stigmas," thus, highlighting the need to change interactions in which some body/minds are devalued compared to others as the primary focus of the organization.

Of course, stating that stigma is the problem is not enough to frame a narrative as outright rejecting the cultural narrative of disability. Goffman (1963) himself held incredibly problematic, ableist views that are apparent in his groundbreaking work, *Stigma.* Goffman consistently refers to himself and the reader as "we normals," which not only highlights his privileged status but also draws the assumption that no one of a stigmatized status could possibly be reading his academic book. Furthermore, he purports that people with stigmatized identities will "torture" themselves to mimic those who are not stigmatized (Goffman, 1963). Goffman's assumption appears to be that people with stigmatized statuses, in this case, disability. The assumption of that is that people with stigmatized statuses desire to not have that status, rather than desiring to change the stigmatizing attitudes of others (Green 2017).

Furthermore, while it is easy to transfer villainhood from stigma, a product of the interaction, to people involved in the stigmatizing, doing such can distance people who potentially can offer donations and funding, as well as people who may hold some misinformed views about disability but are willing to learn from the organization. Therefore, Blue Butterfly and organizations like it must be very careful to keep concepts as the villains of the organizational story, rather than people.

Since recasting the villain is not enough to de-stigmatize disability and remove the association with victimhood, more must be done to further challenge the cultural narrative of disability. To do this, the organization must remove the stigma of victimhood from disability and people with disabilities. This can be done in two ways, (1) identifying another victim and (2) recasting people with disabilities as heroes within the organization. However, the organization must be careful not to write away the need for its existence. Thus, it must also include itself as an integral part of the hero as well.

While constructing such narratives take time, effort, and attention to detail, positive organizational narratives about disability have the potential to reach a wider audience than personal narratives alone and offer spaces for people with disabilities to construct positive identities of themselves as both artists and people with disabilities.

Conclusion

Blue Butterfly is a case study that offers a prototype for other organizations wanting to construct disability-positive narratives that actively resist and challenge the overarching cultural narratives forming disability as tragedy. It is important to remember that organizations do not exist in a vacuum and thus, challenging the cultural narratives of disability is an active, ongoing process.

As with all research, there are limitations to this study. Most noticeably, this is a case study of a single organization. Yet with the information provided about this organization in mind, future research may explore other websites to see if these themes reach across organizations and their narratives. I was surprised by the lack of stories about specific artists or testimonies about their own experience participating in Theater eXceptional. In-depth interviews with artists, employees, or board members of Blue Butterfly, may offer a better, more holistic understanding into the organization and/or the lives and identities of artists with disabilities. Each of these pieces will offer a deeper understanding of the role narratives play in understanding society and the self.

It is my goal to explore this organization in more depth during future projects. The program is relatively young, having been founded in 2015, giving it potential to continue constructing counternarratives about disability on the organizational level, as well as potential to interact with and influence other, similar organizations through the stories it tells. I find it fitting, that the organization's name is Blue Butterfly, I think of the organization as the cocoon, preparing a space for their clients to grow and take flight.

References

Andrews, J.E., Carnine, D.W., Couthinho, M.J., Edgar, E.B., Forness, S.R., Fuchs, L., Jordan, D., Kauffman, J.M., Patton, J.M., Paul, J., Rosell, J., Rueda, R., Schiller, E., Skrtic, T., & Wong, J., (2000). Bridging the special education divide, *Remedial and Special Education 21* (5) 258-260.

Baglieri, S., J.W., Valle, D.J. Connor, & D.J., Gallagher, (2011). Disability studies in education: The need for plurality of perspectives on disability. *Remedial and Special Education, 32*(4), 267-278.

Berger, A. A., (1997). *Narratives in popular culture, media, and everyday life*. Thousand Oaks, CA: Sage.

Best, J., (1997). Victimization and the victim industry. *Society, 34*, 9-17.

Blum, L. (2015). *Raising generation Rx: Mothering kids with disabilities in an age of inequality*. New York, NY: New York University Press.

Cahill, S.E., & R. Eggleston, (1994). Managing emotions in public: The case of wheelchair users. *Social Psychology Quarterly, 57*(4), 300-312.

Calderón-Almendros, I., & Calderón-Almendros, R., (2016). 'I open the coffin and here I am': disability as oppression and education as liberation in the construction of personal identity. *Disability & Society*, *31*(1), 100-115.

Cardinal, R. (1972) *Outsider art.* New York, NY Praeger

Chandler, E. (2017). Reflections on cripping the arts in Canada. *Art Journal*, *76*(3/4),56-59.

Coriale, L., L. Grant, & J. Robertson, (2012). Exploring the educational experience of a social work student with a disability: A narrative. *Social Work Education, 31*(4), 422-434.

Dunn, J., (2004). The politics of empathy: Social movements and victim repertoires. *Sociological Focus*, *37*(3),235-250.

Fox, A., (2015). Invigorating disability aesthetics through art and performance: A report from the bodies of work festival of disability arts and culture 2013. *Journal of Literary & Cultural Disability Studies 9*(3) 349-355.

Fraser, M., (2013). Cripping it up. *Journal of Visual Art Practice*, *12*(3) 245-248.

Goffman, E. (1963). *Stigma: Notes on management of spoiled identity.* New York: Simon and Schuster.

Green, S.E., (2015). Staying true to their stories: Interviews with parents of children with disabilities. In Berger, R. & Lorenz, L. (Eds.). *Disability and Qualitative Inquiry: Methods for Rethinking an Ableist World.* pp. (57-73) Surrey (UK): Ashgate.

Green, S.E. (2017). Managing the emotions of reading Goffman: Erving Goffman and Spencer Cahill looking at disability. In S.E. Green & S.N. Barnartt (Eds.) *Sociology Looking At Disability: What Did We Know and When Did We Know It?* pp.(39-56) United Kingdom, Emerald Group Publishing Limited.

Green, S. E., Darling, R. B., and Wilbers, L. (2017). Struggles and joys: A review of research on the social experience of parenting disabled children. In S.E. Green & S.N. Barnartt (Eds.) *Sociology Looking At Disability: What Did We Know and When Did We Know It?* pp.(39-56) United Kingdom, Emerald Group Publishing Limited.

Hochschild, A.R., (1983). *The managed heart: Commercialization of human feelings,* Berkley: University of California Press.

Jung K.E., (2003). Chronic illness and academic accommodation: Meeting disabled students' unique needs and preserving the institutional order of the university. *Journal of Sociology and Social Welfare, 30*(1), 91-112.

Kimball, E.W., Moore, A., Vaccaro, A., Troiano, P.F., & Newman, B.M., (2016). College students with disabilities redefine activism: Self-advocacy, storytelling, and collective action. *Journal of Diversity in Higher Education, 9*(3), 245-260.

Kolb, K., (2011). Sympathy work: Identity and emotion management among victim advocates and counselors. *Qualitative Sociology*, *34*(1), 101-119.

Lenakakis, A., & Koltsida, M., (2017). Disabled and non-disabled actors working in partnership for a theatrical performance: A research on theatrical partnerships as enablers of social and behavioral skills for persons with disabilities. *Research in Drama Education: The Journal of Applied Theatre and Performance*, *22*(2), 251-269.

Link, B.G. & J. C. Phelan, (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363-385.

Loseke, D.R., (2007). The study of identity as cultural institutional, organizational, and personal narratives: Theoretical and empirical integrations. *The Sociological Quarterly*, *48*, 661-688.

Loseke, Donileen R. (2012). The empirical analysis of formula stories. In J. A. Holstein & J. F. Gubrium (Eds) *Varieties of Narrative Analysis* pp. 251-71. Los Angeles, CA: Sage Publications.

Manago, B., Davis, J.L. Goar, C., (2017). Discourse in action: Parents' use of medical and social models to resist disability stigma. *Social Sciences & Medicine*, *184*, 169-177.

Oliver, M., & Barnes, C., (2012). *The new politics of disablement*, New York, NY: Palgrave Macmillian.

Patterson, L., (2012). Points of access: Rehabilitation centers, summer camps, and student life in the making of disability activism, 1960-1973. *Journal of Social History, 46*(2), 473-499.

Rousso, H., (2013). *Don't call me inspirational: A disabled feminist talks back*, Philadelphia, P.A., Temple University Press.

Saldaña, J., (2016) *The Coding Manual for Qualitative Researchers*, 3rd Ed. Los Angeles, CA: SAGE publications.

Shah, S., & Priestly, M., (2010). Home and away: the changing impact of educational policies on disabled children's experiences of family and friendship. *Research Papers in Education, 25*(2), 155-175.

Shakespeare, T., (2014). *Disability rights and wrongs revisited*, 2nd Ed. Cornwall, Great Britain: Routledge.

Shaw, C., (2015). 'We have no need to lock ourselves away': Space, marginality, and negotiations of Deaf identity in late Soviet Moscow. *Slavic Review, 74*(1), 57-78.

Solvang, Per Koren, (2012). From identity politics to dismodernism? Changes in the social meaning of disability art. *European Journal of Disability Research*, *6*(3),178-187.

Taylor, M. (2005). Self-identity and the arts education of disabled young people. *Disability & Society*, *20*, 763-778.

Wexler, A.J., & Derby, J., (2015). Arts in institutions: The emergence of (disabled) outsiders. *Studies in Art Education*, *56*, 127-141.

Chapter 3: “I’ve Used My Wide Array of Skills to Create A Life for Myself”: Managing Narratives with Competing Goals in an Arts-based Disability Ally Organization[2]

Introduction

Disability scholarship has long documented the ways in which people with disabilities are excluded, devalued, and stigmatized in both institutional settings and everyday life (Allen, 2010, 2014; Calderón-Almendros & Calderón-Almendros, 2016; Coriale, Grant, & Robertson, 2012; Egilson & Traustadottir, 2009; Goffman, 1963; Lenakakis & Koltsida, 2017; Manago, Davis, & Goar, 2017; Oliver & Barnes; 2012; Shakespeare, 2014; Zederayko & Ward, 1999). Through social movements and academic research, organizations and policy makers have made some efforts to make spaces more accessible and inclusive (Patterson, 2012; Shah & Priestly, 2010; Shaw, 2015). In order to reach these goals of accessibility and inclusiveness, many individuals and organizations have sought to become allies to people with disabilities and disability-rights based social movements (Carey, Block, & Scotch, 2019; Evans, Assadi & Harriott, 2005; Ostrove, Kornfeld, & Ibrahim, 2019; Patterson 2012; Van der Klift & Kunc, 2019).

However, in many cases, “accessibility” and “inclusion” have become poorly defined, catchall terms that are used with little discussion on what specifically is meant and how this concept will be practically implemented. This is further complicated in that many organizations

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seeking to be allies by “helping” people with disabilities do so without necessarily consulting people with disabilities on what they find “helpful” (Cahill & Eggleston, 1994; Gill, 2001; Evans et. al. 2005; Carey et. al. 2019; Dunn, 2019; Ostrove et. al. 2019). As Carey et al., (2019) demonstrate, well-meaning organizations led by parents and/or professionals may push agendas that may not align with, or may even conflict with, the goals and needs of people with disabilities. Some allies, both individuals and organizations, may fail to recognize their privilege and cling to condescending narratives of helping people with disabilities, with the underlying assumption that people with disabilities cannot help themselves (Dunn, 2019). Ostrove, et al. (2019) assert that

> *“Disabled people have experienced a long history of exploitation as research participants, and knowledge about people with disabilities has often been used for ‘management and control’ rather than to achieve social justice,” (p.928).*

Thus, in studying organizations that frame themselves as allies, we must look at how people with disabilities perceive the role of allies and the impact, positive or negative, that this alliance has on people with disabilities.

This chapter will focus on an organization, Arts4All Florida, which seeks to be an ally by training teachers to make art classrooms more accessible to students with disabilities. They are unusual in that they do not conceptualize themselves as being a form of art therapy. Rather, they promote inclusion and active participation in the arts as a human right. In rejecting the art therapy label, they also challenge existing culture narratives and understandings of disability as a personal tragedy and instead, draw from aspects of the social model of disability (Oliver & Barnes 2012) and Goffman’s (1963) concept of stigma to illuminate barriers to participation, to challenge negative assumptions about people with disabilities. In this chapter, I use narrative analysis of material accessed through the *Arts4All* website to address two interrelated research questions: 1. How do ally organizations both draw on and resist cultural narratives f disability in order to garner public support?; and 2. How do personal narratives of disabled artists associated with ally organizations support and/or resist organizational and cultural narratives about the connection between disability and art?

Why Study Ally Organizations?

Good intentions are not enough for a person or organization to be an ally. Positive action for meaningful change is needed (Brown & Ostrove 2013; Carey et. al. 2019; Evans et. al. 2005; Forber-Pratt, Mueller & Andrews, 2019; Russell, 2011; Russell & Bohan, 2016). Russell and Bohan (2016) make a distinction between "first-order" and "second-order" changes as a result of allyship. First order changes were defined as "superficial changes that were compatible with existing power dynamics, with no substantive challenge to institutional structures," while second-order changes work to "alter structures and challenge hierarchies of power" (Russell and Bohan, 2016: p 342). In their study on LGBTQ+ "allyship" within a church, Russell and Bohan (2016) found that much of the alliance focused on token ideas of "acceptance" without ever challenging heteronormativity, thus allowing "allies" to feel that they were being helpful, good people without challenging any power structures or making changes in their own lives.

Forber-Pratt et al. (2019) outline ways in which medical/rehabilitative professionals can be allies to their patients with disabilities. Traditionally, rehabilitative practitioners interact with and think about their patients using a medical model lens. They are also often working with people with acquired disabilities who also have a tendency to use a medical model lens. Forber-Pratt et al. (2019) propose that rather than adhering to medical savior narratives of the relationship between medical professionals and people with disabilities, medical professionals should work to help clients develop a disability-identity. “Psychologists, along with other rehabilitation practitioners, have an inherent ethical obligation to function as allies, activists, and advocates as part of professional responsibility and identity,” (Forber-Pratt et. al. 2019: p.123).

However, Carey et. al. (2019) argue that not all of those attempting to be allies are truly helpful to people with disabilities. Organizations led by stakeholders who do not have disabilities themselves are sometimes at odds with, and even in opposition to, the goals of organizations led by people with disabilities. Those with more power and cultural capital may have lower expectations about the quality of life for people with disabilities and can exert their own interests more easily. Furthermore, in focusing solely on the intentions of allies, the perspective of the privileged is prefaced with little to no focus on what this allyship means for marginalized groups, or if marginalized groups even view the privileged group as allies at all (Carey et. al. 2019; Russell & Bohan, 2016). Russell and Bohan (2016) assert that

> *“…nontarget allies retain the power to define the problem and provide solutions that sustain their own position as knowledgeable and powerful agents of social change, even as members of the target group tend to be portrayed as victims lacking in personal agency and unable to define for themselves the direction that change should take,” (p. 346).*

In their study on organizations led by parents of children with disabilities and organizations led by people with disabilities, Carey et al. (2019) found that some organizations led by parents sometimes proposed goals of “cure,” which are at odds with more social model-oriented organizations led by people with disabilities. Perhaps most insidious, some organizations even sought to give parents more rights to usurp the rights of their children in adulthood, even to the point of institutionalization without their child’s consent if it’s what the parents thought was best (Carey et. al. 2019). Thus, while claiming to be an ally to people with disabilities, some of these organizations pushed for measures that would further oppress people with disabilities. In not including people with disabilities in the leadership process, well-intentioned “allies” are able to push their own agenda at the expense of those with whom they claim to be allies. Still, some organizations and activists have taken up the cause of facilitating the active participation of people with disabilities in previously exclusive spaces. The purpose of this chapter is to examine how one such organization constructs narratives in the context of the competing goals of disability empowerment and fundraising.

Why Study Organizational Narratives?

Donileen Loseke (2007) describes the ways in which the world is made up of stories. There are many different levels of narratives, each of which are “created for different purposes, do different types of work, and are evaluated by different criteria.” Narratives of disability have traditionally been ones of personal tragedy (Coriale et al., 2012; Jung 2003; Oliver & Barnes 2012; Shah & Priestly, 2010; Shakespeare 2014). Yet, as this paper will explore, there are multiple types of competing narratives told throughout all levels of social life (Loseke, 2007). These narratives are not fixed, but instead, are fluid and ever-changing. Moreover, different narratives will be deployed at different times for different purposes. Loseke (2007) identifies different levels of narratives, such as cultural narratives, institutional narratives, organizational narratives, and personal narratives. These narratives my overlap, contradict each other, or sometimes do both.

Cultural narratives refer to the collective representation or categories of people depicted through widely told cultural stories. Typically, there are characters, often heroes, victims, and villains who follow a familiar plot. Within the context of western capitalism, the predominant cultural narrative frames disability as a personal, tragic, biomedical problem. This understanding focuses exclusively on what tasks a person cannot do, which in turn defines what counts as disability (Coriale et al., 2012; Jung 2003; Oliver & Barnes 2012; Shah & Priestly, 2010; Shakespeare 2014). Pity and tragedy arising from this narrative give people that status of “victims” of the feared villain, disability. These devalued identities allow people with disabilities to obtain services. Often, these services, and their providers, are the “heroes” of this story. However, victimhood and passivity are not seen as desirable in a culture that values independence and agency (Best, 1997; Dunn 2004; Kimball, Moore, Vaccaro, Troiao, & Newman 2016; Loseke, 2007).

Competing narratives of disability such as the Social Model (Oliver & Barnes, 2012) and Crip Theories (Kafer, 2013) have offered more empowering ideas about disability as well as offering a collective disability identity. The Social Model has informed the organizational narrative for some disability-centered non-profit organizations that demand that people, particularly policy makers, examine the negative consequences of social and physical environments that restrict the ability of people with impairments to participate in their communities (Oliver & Barnes, 2012). This paradigm has influenced public policy and practices by focusing attention on accessibility of public spaces, education, employment, housing, and all areas of social life, including art programs. This disability rights narrative has begun to compete with the narrative of personal tragedy in widely circulating understandings of disability in the United Kingdom, the United States, and Europe. Social Model (Oliver & Barnes, 2012) and Crip Theories (Kafer, 2013) understandings of disability offer a newer, more nuanced narrative for people with disabilities and ally organizations alike, mainly in that these narratives may offer paths for people with disabilities and their allies to fill the “heroic” role without objectifying people with disabilities for the horror or inspiration of able-body/minded people.

Social Model and Crip understandings of disabilities challenge the traditional narrative where external forces in society “rescue” people with disabilities. People with disabilities are redognized as being capable or making high quality art. However art created by people with disabilities is not often depicted in mainstream venues either because art classes are not disability accessible and lack the adaptive tools for people with disabilities to learn and practice their craft (Taylor, 2005; Young, 2008; Zederayko & Ward) or when people with disabilities do create art, it is presented as a niche category separate from “real art” (Cooley & Fox 2014; Fox 2015; Solvang, 2012; Wexler & Derby, 2015). This I present in ally-art programs for people with disabilities, in that by not making art accessible for would-be artists with disabilities, society misses out on the visual and performance art that people with disabilities could offer the art world.

Organizations that view themselves as disability allies may choose to adopt or challenge cultural narratives of disability, depending on the goals of the organization and what it is trying to achieve at a particular point in time. Stories told for one purpose may inadvertently negate other organizational goals. For example, the narrative of a “heroic” organization, helping those in need by providing a path to change and/or betterment makes the organization look good, which can result in more funding and support. However, such stories may be off-putting to potential clients who resist the narrative of disability as an inferior way of being. To ensure that their message is not at odds with the people they serve, organizations may use personal narratives to emphasize their allyship and the congruence between the organization’s goals and the goals of their clients. As we will see in this chapter, organizations also make use of personal narratives to advance organizational goals.

Thus, organizations must construct and circulate narratives that depict themselves as heroes without completely stripping its clients of agency or hope. This may involve borrowing from both the tragic and the inspirational narratives of disability, in which the organization provides a pathway for their client to become “inspirational.” Still, other organizations may reject both cultural narratives outright, instead, offering a counter-narratives for those who are dissatisfied with the cultural narratives to rally behind, as seen in many non-governmental social movement organizations (Fox, 2015; Oliver & Barnes, 2012; Patterson 2012; Solvang, 2012). Ally organizations serving marginalized groups may achieve this through stressing similarities their clients have to hegemonic groups, rejecting definitions of the dominant group, or sometimes a combination of the two. Egner (2019b)

> *Explores the degree to which these organizations stress sameness and/or difference in relation to the dominant group in establishing collective identity and collective consequences, and how this emphasis informs their position in relation to and the use of queer/crip or hegemonic discourses (p.141)*

Some organizations that view themselves as allies encourage “normality” and assimilation tactics to gain more “political room.” However, these tactics may contradict the goals and outcomes that clients are seeking (Egner 2019b). Yet, when stressing sameness, some people with multiple marginalized identities may find their needs ignored or even rejected by the organizations that claim to help them, leading them to disidentify with the organization or the identity as a whole (Egner, 2019a). Organizations that strive to be allies must recognize the heterogeneousness of their target group, or risk failing the segments of the population the organization claims to serve. Thus, some ally organizations seek to “Crip” the boundaries of their organizations, by challenging existing concepts of “normal” and the binary logic of “disabled/not disabled” (Enger, 2019b; Kafer 2013). While this may complicate the process of “boundary work,” a process by which organizations articulate who they serve and implicitly, who they do not, such ally organizations may be more aware of their clients (Egner, 2019a; 2019b).

Ally organizations must also be explicit about who they are serving to avoid co-optation. Carey et al. (2019) examined the ways in which supposed ally organizations run by parents of people with disabilities sometimes had goals diametrically opposed to the goals of people with disabilities. This is further complicated in that some of these parents are well-intentioned in their goals. Thus, the voices of people with disabilities must be the center of ally organizations’ decisions and goals. This can be achieved by including people with disabilities in leadership positions within the organization. However, since that information was not available for this project, this chapter will instead focus on the ways that organizational narratives align with or contradict the narratives actually told by people with disabilities.

Organizations, like culture and individuals, are not static, unchanging entities. The narratives they tell may shift and evolve over time, in concert with or resistance to changing cultural narratives. The subject of this case study, *Arts4All Florida,* the organization is currently in the process of rebranding itself, including changing its name, after some changes in funding and affiliations. Organizations are responsive to both their clients and funding sources. Furthermore, organizations may deploy different narratives in different circumstances for different purposes. Sometimes, organizations may use testimonials and personal narratives to build the narrative they use for themselves.

This last point highlights the importance of personal narratives. Personal narratives can be a form of agency for individuals telling their own stories. People tell stories to make sense of the world and these stories can reify or subvert cultural narratives. Adopting and creating personal narratives can be a means of advocacy in and of itself. Kimball et al. (2016) discussed the ways in which university students with disabilities viewed self-advocacy and storytelling as a form of collective action. Many students saw educating others about their experience to raise awareness about what people with disabilities need. This form of storytelling as a type of advocacy was empowering to students in a way that allowed them to control the narrative, avoid victimhood, avoid objectification, and still claim need for services (Kimball et al. 2016).

Personal narratives told by people with disabilities and their families often draw from multiple understandings of disability (Darling 2013, Green, Darling & Wilbers 2017). While people with disabilities experience fulfilling lives, they do not live in a cultural vacuum. People with disabilities, particularly those who develop disability later in life, may subscribe to some aspects of the cultural narrative of biomedical tragedy (Darling 2013). Furthermore, people with disabilities are also interacting with people who believe this cultural narrative. Thus, relying on biomedical understandings of disability may be used to communicate more efficiently with others. For example, Manago et al. (2017) found in their interviews with parents of children with disabilities, that parents used both the Social Model *and* the Biomedical models in order to advocate for their children.

People with disabilities must also make sense of their lives and identities within institutional and organizational narrative identities. Organizational narratives are created to evaluate who they help and how they help them. While people can create personal narratives that are subversive to the cultural and organizational narratives, going against these narratives can lead people to be cut off or to lose services (Dunn 2004; Loseke 2007).

Why Study Art Programs?

Like other artists, artists with disabilities want to be recognized for their artistic talents (Cooley & Fox, 2014; Fox 2015; Lenakakis & Koltsida, 2017). However, when people with disabilities who engage in the arts do get recognition, they are often praised for having disabilities, rather than for the art they produce (Rousso, 2013). In this paradigm, art is assumed to be ‘therapeutic” for people with disabilities rather than as a craft requiring skill and dedication (Kafer, 2013; Lenakakis & Koltsida, 2017; Rousso, 2013; Solvang, 2012). Even people with disabilities who are actively pursuing the arts receive subtle messages that their bodies do not belong. Disabled bodies are not the subject of portraits and are rarely seen in the performing arts. In her interview with students pursuing college-level art degrees Taylor (2005) found that her participants “rarely encounter a disabled artists as a role model and none of the students I interviewed had been taught by a disabled teacher before they came to college,” (p.766).

Art can be a powerful way to resist dominant narratives about disability and to draw attention to inequities. Allen (2014) asserts that

> *… the arts have emerged as an important site of activism for inclusion, as a ‘force that draws people into participation,’ and a political vehicle for centering ‘normally silenced or disenfranchised voices,” (p. 518).*

For many participants, art may be a desired path toward income and possibly independence.

This brings up another seemingly contradictory issue. Since the organizations experience courtesy stigma (Goffman 1963), mainstream customers may refuse to even consider resulting products and performances as true art[3]. However, such organizations sometimes work together to sell and showcase art and/or performances created by people with disabilities, opening up a market for alternative sources of art and a specific place to buy and sell such pieces. Therefore, such organizations have practical implications for artists with disabilities in addition to social ones. In opening up these possibilities, organizations also offer up new avenues for creating more empowered personal and organizational narratives.

Art also falls into an interesting category when it comes to tracking and disability access in the educational system. Wexler and Derby (2015) point out that "the art room has often been the first regular classroom where disabled learners are placed; yet, the needs of disabled leaners have often gone unmet" (p129). Zederayko and Ward (1999) outline inclusion is not the mere presence of people with disabilities in a room. Unless active participation is possible, the space is still exclusionary. This is particularly salient in art classrooms. While this appears to be one of the more inclusive spaces in schools, in terms of who is invited to be in the classroom, some art classrooms lack the assistive technology needed to facilitate participation for students with disabilities. Furthermore, multiple studies show that while art teachers are interested in making their lessons accessible to students with disabilities, they lack the knowledge on how to bring this goal to fruition. Zederayko and Ward (1999) detail this process in describing a general art classroom with two student with disabilities. Since each of the students shared an aide, at least one of the students had to observe and not participate at any given time. Furthermore, well-meaning aides sometimes over-accommodate and do too much of the artwork for the student, meaning that neither student was truly engaged in the artistic process (Coleman & Cramer, 2015;

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[3] Courtesy stigma refers to stigma experienced by a person or organization due to its association with someone who has a stigmatized identity. People working with this organization would be what Goffman (1963) refers to as "the wise" meaning "persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual" (p.28)

Coleman, Cramer, Park, & Bell 2015; Young, 2008; Zederayko & Ward, 1999). Thus, while the art classroom, on the surface, appeared to be the most accessible classroom space, the presence of a person with disabilities in the classroom does not necessarily indicate that the classroom or the content are accessible. Taylor (2005) describes the ways in which assistive technology can become an extension of oneself in the creation of art. She attributes the underrepresentation of artists with disabilities to both negative attitudes about disability, and the lack of equipment provided in many classrooms to account for students' impairments. Taylor (2005) asserts that "enabling support/classroom assistance is critical in the potential that it has to create access to the arts for all students, regardless of their support requirements," (p.766).

Multiple studies, both in the United States and abroad have documented a gap between the knowledge held by art educators and the knowledge held by Special Education educators. Art educators overwhelmingly agree with the statement that students with disabilities should be included in art classrooms but lack confidence or knowledge on how to implement inclusion, via assistive technologies or otherwise. Similarly, Special Education instructors agree that art is beneficial for students with disabilities but lack confidence or knowledge about how to teach arts to their students (Coleman et al. 2015; Colman & Cramer, 2015; Coleman, Cramer, Park, & Bell, 2015; Lenakakis, & Koltsida, 2017; Loesl, 2012; Penketh, 2014; Taylor 2005; Zederayko & Ward, 1999). Bridging this knowledge gap could increase inclusiveness in art classrooms and programs, which is beneficial for students, regardless of their artistic aspirations (Coleman et al. 2015; Colman & Cramer, 2015; Coleman, Cramer, Park, & Bell, 2015; Lenakakis, & Koltsida, 2017; Loesl, 2012; Penketh, 2014; Taylor 2005; Wexler & Derby, 2015; Young, 2008; Zederayko & Ward, 1999). For this reason, bridging this gap is one of the stated goals of one of the organization that is the focus of this chapter.

Research Methods

Site Selection-Why Arts4All Florida?

Arts4All Florida, originally called Florida Arts for the Handicapped Program and formerly part of the Very Special Arts (VSA) program, was founded in 1981 by the Florida Department of Education and Floridan Department of State, Division of Cultural Affairs. Since then, the organization has undergone multiple name and policy changes, most recently changing its name to *Arts4All Florida* and undergoing major changes as far as affiliations and funding are concerned. One of the main services provided by *Arts4All Florida* is assigning trained "teaching artists" into K-12 schools and to juvenile correctional facilities, in order to create accessible art spaces. The *Arts4All Florida* website defines a teaching artist as

> *"a professional who has the experience and knowledge to teach their craft to students and adults with various disabilities in a school setting, Department of Juvenile Justice facility, or adult program," (http://arts4allflorida.org/).*

This includes, but is not limited to, having a working knowledge of assistive technologies, and teaching other art teachers and/or Special Education teachers who to implement these technologies to make the arts more accessible for people with disabilities. Assistive technology can be a key to increasing accessibility in art programs (Coleman et al. 2015; Colman & Cramer, 2015; Loesl, 2012; Penketh, 2014; Zederayko & Ward, 1999). However, more than half of the instructors in Coleman et al.'s (2015) study had rarely to never used assistive technologies, as many did not have training on what was available or how to use such technologies.

According to the Mission Statement on the homepage of their website, *Arts4All Florida* aims to "provide, support, and champion arts education and cultural experiences for, and by people with disabilities," (www.arts4allflorida.org/). Much of this is done through providing disability-accessible art programs in schools, community centers, and juvenile correctional facilities throughout the state of Florida. The organization also works to promote artists with disabilities and provide training to art educators on disability accessibility. This statewide organization must manage multiple, sometimes competing narratives in order to appeal to participants and their families, the educational facilities they wish to maintain ties with, along with donors and funding sources. This makes it an ideal site for addressing my research questions.

Why Websites?

Since the advent of the Internet, online spaces have increasingly become spaces for organizations to promote themselves *and* places for people of marginalized groups to converge and tell stores that had previously been silenced (Egner 2019a, 2019b; Hine 2000; Maloney, 2013). Hine (2000) coined the term “virtual ethnography” to describe the process of recognizing that online forums can create cultural meanings in the same ways that physical spaces can. “Virtual ethnography is useful in exploring the ways in which the Internet is and becomes socially meaningful, allowing researchers to examine the Internet as both cultural and artifact” (Egner 2019a, p. 131).

Websites can be updated and changed in real time as the organizations or groups update or change their position on an issue or as more information is added. This will be particularly of interest as the *Arts4All Florida* website includes name changes and changes in affiliations over the years. In her work on Social Movement Organizations, Egner (2019b) illustrates how organizations’ websites can communicate vast amounts of information that may not be easily available through traditional qualitative methods including how pictures and narratives are a type of boundary work, designating an in-group and therefore, an out-group, even among organizations that state that their goal is to be inclusive.

Another important feature that online spaces provide is the ability to connect people who are geographically far apart yet share understandings and lived experiences. This is particularly useful for people with disabilities who may prevented from interacting with other people with similar shared experiences due to inaccessible environments (Egner, 2019a). This may be the case for artists with disabilities who tell their stories in the registry, as some artists indicate that they engage in art and sell art online as an adaptation to not being able to fit in to a rigid time schedule or inaccessible physical spaces.

In the following sections, I will explore in more detail what narratives are communicated through the organization's website, the purposes these narratives serve, and the ways in which they resist or reify cultural understandings of people with disabilities. I will do this by examining the history of the organization, as described on the website, and testimonials from teachers, parents, and artists with disabilities.

Data Collection & Analysis

Upon going to the Arts4All website, I immediately began searching for stories[4]. I found most of these in the Annual Reports and in the Artist Registry to identify organizational narratives and personal narratives, respectively. These different levels of narratives accomplish different things for both the organizations and the people within them (Loseke, 2007, 2012). Organizational narratives are unique in that if the narrative is not told in a way that appeals to both clients and donors, the organization may cease to exist (Loseke, 2007). Thus, *Arts4All Florida* must offer up a narrative that resonates with various audiences to serve the purposes for the organization.

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[4] This study using personal stories posted online to the Arts4All Florida website was deemed exempt for research with human subjects by the International Review Board at the University of South Florida.

Organizational narratives create easily recognizable stories in which the organization itself is one of many characters. These stories must identify who the organization helps and how it helps them in an easy to understand way. For this type of narrative, the organization must be a major "character" who plays a role that is both necessary and evaluated as morally good. Without these components, potential donors may question the need for the organization to exist. The most obvious and easily recognizable role for organizations in their narratives is for the organization to fill a hero role, in which they save their clients from a perceived barrier or villain. However, such stories may be off-putting to potential clients who resist the cultural narrative that imagines their selves as deficient, their lives as inferior (Loseke, 2012). Thus, organizations like *Arts4All Florida* must construct a narrative that depicts the organization as heroic without sacrificing the dignity of their clients.

Personal narratives are stories that individual people tell about themselves. ON the surface, it may be easy to assume that these narratives are pure, without an agenda, or free of outside influence. Yet, it's still important to remember that neither individual people nor their personal narratives exist in a vacuum (Loseke, 2007). Individual people draw on cultural narratives, organizational narratives, and even other people's individual narratives when making sense of their own lives. In the Artist Registry, artists are free to offer up their own narrative with little to no censoring from *Arts4All Florida.* In that sense, the artists are offering up their own personal narratives. However, like organizational narratives, these stories still have a goal-to sell art-and include familiar characters such as themselves, *Arts4All Florida*, and even more abstract characters, such as art itself. Personal narratives help individual people present themselves in a way that makes sense to them, and often with the hope that the narrative will appeal to others. Individuals will often, though not always, portray themselves as being morally "good." Yet, often, in the act of storying themselves, people highlight things they *do* showing agency and intent. This is where the personal narratives of clients may clash with the organizational narratives of nonprofits and governmental organizations. Individual people may not want to be pitied; they may want to be their own hero. Yet, in being their own hero, there may not be an obvious need for the organization to exist (Loseke, 2007, 2012).

The annual reports provide an important part of the organizational narrative as this is the document sent out to sponsors and potential clients. These stories are crafted for the particular purpose of attracting donors and clients Even stories that appear to be personal narratives, such as those from employees about what they do for the organization, were picked based on the degree to which they support the organization's goals.

I also explored the personal narratives told in the Artist Registry, where artists with disabilities shared their own stories and showcased artwork to sell. Additionally, I watched any promotional videos provided on the website to analyze the stories told via video. I specifically selected stories where artists talked about how their disability is related to their art.[5] Unlike the stories told in the annual reports, stories told in the artist registry are from the artists themselves. Some artists told stories that aligned with those told in the annual reports, but others did not. Stories in the Artist Registry are organized by alphabetical order of he artists' name. They are not selected or organized by *Arts4All Florida* to highlight stories that make the organization look good.

I conducted narrative analysis to look at how the organization and artists with disabilities constructed their stories. To use narrative analysis, as outlined by Loseke (2007), one must first

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[5] There were many narratives on the Artists Registry that did not mention disability at all. Some artists simply wanted to talk about the art that they sold and this was just one of many platforms where they advertised their art. This, in itself, is an interesting finding. However, since this chapter is about narratives of disability and allyship, narratives that did not mention disability were a bit beyond the scope of this chapter.

determine the context of the narrative, including who wrote the narrative, for whom it was written, and for what purpose it was constructed. In the case of *Arts4All Florida*, spokespeople of the organization write narratives for a variety of reasons that center around attracting clients and funding, as is the case of many nonprofits. Artists may have similar goals, as many sell their work on the website through the Artist Registry. However, the degree to which artists include stories of their disability, if at all, may vary.

Following this, I did a close reading of the narratives to fully ascertain the plot and the content of each narrative. This separates narrative analysis from thematic analysis in that narratives must, to some extent, have a beginning, middle, and end with some degree of conflict, whether explicitly or implicitly included. From there, I determined who the characters in this tory were. In each story, I sought to identify the villain, the hero, and the role that art played in the story. These characters do not always have to be human but can instead by ideas, such as disability or art itself.

To fully analyze the narrative, one must also unpack symbolic codes embedded in the narratives. This includes, but is not limited to, ideas about what is moral/immoral, what is considered normal/abnormal, and what is considered desirable or bad. To do so, I considered the following questions posed by Loseke (2012):

> *What knowledge about the world does this statement assume/ What would I need to believe about the world for this statement to be believable and important? What specific values are being reflected/transmitted?* (p. 262).

Findings

To provide context for the discussion of the three themes that emerged in the narrative analysis, I first outline the mission and history of this ally organization. Following this, I use personal narratives from artists with disabilities on the artists registry and compare and contrast these stories with stories that make up the organizational narrative. For the purposes of this chapter, I include stories from staff members as part of the organizational narratives, as they are speaking as representatives of the organization. All the names of artists, clients, and staff members are pseudonyms.

Arts4All Florida: Mission, Vision, and Guiding Principles

An essential part of any organizational narrative is the official mission statement. The inviting and uncluttered *Arts4All Florida* homepage (http://arts4allflorida.org/) displays it's mission, along with a concise plan as to how it will carry out this mission. The statement includes the following:

> *The mission of Arts4All Florida is to provide, support, and champion arts education and cultural experiences for and by people with disabilities. Our vision is to create a world in which the arts are universally accessible. We do this by:*
>
> - *Conducting art education programs in schools, Department of Juvenile Justice facilities, and community centers*
> - *Promoting the accomplishments of artists with disabilities through our artist registry, exhibitions, and performances*
> - *Increasing access to the arts through professional development workshops*

By including a clear and concise description of its goals, the organization can then provide evidence of its effectiveness in carrying out these goals. The website offers proof that it has taken the actions outlined in the bullet points above: (1) pictures and testimonials from programs in schools (located in the Annual Reports under http://arts4allflorida.org/content/our-impact), (2) an artist registry where artists with disabilities can showcase their work and link to personal pages where they sell their art (http://arts4allflorida.org/artist-registry), and (3) a schedule of upcoming webinars about setting up accessible art classes (http://arts4allflorida.org/content/webinars). Through its mission statement, goals, and these three types of evidence, the organization begins to tell a story in which it serves as a morally worthy ally to disabled artists by countering forces of exclusion and promoting the talent and value of the creative endeavors of artists.

As we will see in the following sections, however, the story is more complex than the mission statement might at first suggest. My narrative analysis of personal and staff stories that are featured on, or can be accessed through, the website identified three types of stories with three different types of villains: (1) Stories in which disability is not a villain, but a source of artistic creativity; (2) Stories of overcoming disability, in which a biomedical notion of disability is the villain; and (3) Stories of adapting to disability, in which the villain is a more nuanced, social model understanding of disability as barriers and negative attitudes. Taken together, these stories reveal tensions between cultural, organizational, and personal ideas about the relationship between art and disability.

Personal Narratives: Disability as a Source of Creativity

A few artists featured on the website rejected the cultural code of disability as a villain entirely, instead, crediting some of their creativity and personal identity to their disability. This sentiment was not echoed in most of the promotional material put forward by the organization, perhaps because this narrative theme does not as clearly establish a need for the programs offered through *Arts4All Florida*. Still, such stories were found among the descriptions and stories told by artists with disabilities. Trey Littles, for example, credits his synesthesia for his unique use of color.

> *As a child, my autism prevented me from communicating through traditional means until my mother used her experience in art therapy to open my eyes to all the world has to offer. Today I'm confident in my artistic abilities and have grown into an adult who uses his synesthesia, autism, and emotions to create unique and expressive pieces…I communicate my feelings through my color choices utilizing my synesthesia which involves a link between my emotions and colors[…] I intend*

> *to make a difference in the world by being an artist.-Trey Littles (http://arts4allflorida.org/artist-registry)*

In this narrative, Littles acknowledges both positive and negative aspects of his experience with a disability. His disabilities are not treated as unequivocal “heroes,” in his narrative. He did talk about difficulties he experienced due to autism. However, his story highlights ways in which disability also helps him express himself though art.

Other artists cited their disability as a call to use art to connect to others with similar disabilities. While the story above discusses how visual and sensory perceptions influence visual arts, Sydney Glenn, who uses multiple mediums including “painting, sculpture, video, installation, performance and storytelling,” uses disability as a theme across her artistic mediums- a theme she came to through her own personal experience.

> *Deformity, adversity, and empowerment- these are the themes of my work. Having been born with seven fingers total, (five fingers on my left-hand and two fingers on my right-hand) as an artist, I have chosen to take this unique personal experience and transform it into a shared experience with my audiences. I have created four distinct characters that represent different developmental stages a person born with a physical defect goes through [...] Birth defects occur in all groups of people and the adversity of the disabled can truly touch us all, especially when the adversity is overcome and the deformed then become the empowered.- Sydney Glenn (http://arts4allflorida.org/artist-registry?page=2)*

I would like to stress that I am by no means suggesting that these artists do not experience any difficulties or barriers related to their disabilities. Rather, I am saying that life with a disability, as an artist, or anyone for that matter, is not an inferior, negative way of being. These narratives stuck out because they counter the narrative that disability can only cause negative experiences.

In having an identity that is culturally devalued, it is assumed that people with certain disabilities are not able to produce high quality art. People with disabilities are often assumed to be less capable than people without disabilities in all activities (Cahill & Eggleston, 1994;

Calderón-Almendros & Calderón-Almendros, 2016; Goffman 1963; Lenakakis & Koltsida, 2017; Solvang, 2012; Zederayko & Ward, 1999). When it comes to art, there are some exceptions, where people with disabilities are considered to be more artistic or creative (Foucault, 1965/1988, Chan & Sireling, 2010). However, this is for the most part associated with mental illness. While this may appear positive and empowering, even "positive" stereotypes can be harmful. It takes away from the process of identity-making in that it is cultural stories, rather than the person themselves, deciding *which* talents, crafts, or skills artists with disabilities should excel.

Arts4All Florida offers the space and resources for such empowered artists to create and sell their art. However, these narratives are not highlighted in the same ways as other, more traditional narratives about disability. On one hand, these stories can only be told by the artists with disabilities themselves. Supportive others, such as family members or art educators cannot say where an individual artist's inspiration and creativity come from, as this assessment belongs to the artist alone. However, there is also a practical purpose to not highlighting these narratives front and center, mainly in that it does not focus on any need for the organization.

Personal Narratives: Overcoming Disability

In contrast to narratives that highlight disability as a source of creativity, some artists portrayed disability as a barrier to overcome. This is not surprising since disability is often culturally coded as a tragedy (Jung, 2003; Loseke, 2007; Oliver & Barnes, 2012; Shah & Priestly, 2010) making this narrative readily available and easy to use. It also easily suits the needs of the organization and the teachers in the organization, as well as some of the artistis with disabilities. Disability itself is the villain of this story. It is portrayed as a barrier that prevents the person with a disability from communicating with others, experiencing the world, or participating in the arts. Despite the drawbacks of this narrative, some people with disabilities may view themselves as the heroes who overcome their circumstances. Some stories told by artist themselves also echoed similar narratives.

> *As an individual with Epilepsy and Aspergers syndrome - a form of autism, I often felt like I could not do anything, but because of my life and social experience, I have overcome many challenges. Today I am the International spokesperson for the Center for Autism and Related Disabilities at the [a large public university in the Southeastern United States] and was just elected to the constituency board…I also was with several organizations that provide services to individuals with disabilities including therapy such as occupational and physical along with music and art therapy. My plan for the future is to graduate from [my university] with a PHD in education, open her own school and work with children with disabilities. Monica Bakerson (http://arts4allflorida.org/artist-registry?page=3)*

Monica has a similar story of overcoming her disabilities and moving from the initial conflict (difficulty with social experiences and confidence) to becoming a spokesperson for CARD and other organizations as well as working on a postgraduate degree. Yet, while it vilifies her disability, Monica's agency is not entirely stripped away. Monica maintains her agency by making a separation between herself and her disability. Unsurprisingly, organizational narratives echo this sentiment, in that this type of narrative provides the most direct link between the organization and a necessary hero role. Such narratives do serve a purpose for helping organizations, illustrating both the need for such programs and the positive results it creates.

Personal Narratives: Adapting to Disability

In stories of adaptation, the person with a disability has more agency in their interactions with their surroundings. While disability is often still cast as the implicit villain, it also addresses other aspects of the inaccessible policies or environment as villains. In many of these stories, artists address the inflexible work hours and schedules as a barrier to full employment for people with disabilities, congruent with those described by Social Models of disability (Oliver &

Barnes, 2012). For many artists, art offered not only a source of fulfillment but also a career path for people whose disabilities require a more flexible schedule.

> *"I'm a certified professional photographer, visual artist and licensed clinical social worker living in Florida. I live with several chronic illnesses that prevent me from working your typical 9-5, so I've used my wide array of skills to create a life for myself that prioritizes self-care and allows me to be self-employed" - Ashley Peters (http://arts4allflorida.org/artist-registry)*

While Ashley still attributes some difficulties to her chronic illnesses, she changes her career options, rather than "overcoming" aspects of the disability itself. In addition to adapting to new work schedules and careers, some artists also discussed the available mediums for creating art. Technology has offered many opportunities to make both art spaces and art skills more accessible. Anthony Blake, an artist with limited mobility and use of his hands, discusses in his video, "Painting with One Finger," the use of technology to create art, which he displays and sells professionally.

> *I started in art because I love it! I have a passion for it. When I was younger, I would paint traditionally. I used the paintbrush and acrylics just like any other artist would and as my disease progressed, I began to lose the use of my hands and was forced to transfer into more of a digital medium. I as fortunate enough to develop and understand how to use the computer and the computer software to my advantages early on and that's kind of how it started….I paint with my left hand but more specifically, I only paint with one finger on my left hand. I really only have, you know, two or three inches range of motion, left to right, and up and down, and that's it, right there. And I'm able to use the mousepad to do the brush strokes … I always say, if J. Lo. Is gonna insure her butt for a million dollars, I should insure my hand for a million dollars, because it's definitely my million dollar finger.-Anthony Blake (http://arts4allflorida.org/artist-registry ; https://www.youtube.com/watch?time_continue=140&v=IbRwnnnIogc)*

While this seems like the stories about overcoming disability, Blake's story focuses on the use and availability of adaptive technology, with somewhat minimal focus on the impairment aspect of his disability. The two narratives are very similar and have overlapping, though not identical, implications and uses for *Arts4All Florida*. Adaptation stories place more onus on policies, tools, and the environment in terms of accessibility/inaccessibility. *Arts4All Florida* is an organization that can offer such tools, teach artists how to use adaptive technologies, and advocate for art spaces to be accessible.

Organizational Narratives: Overcoming Disability

Organizational Narratives and Personal Narratives meet at an interesting intersection via the4 testimonials from staff members of the organization that are chosen to be included in the annual reports. While these are narratives from people, they can overlap into the world of organizational narratives in that staff members are often speaking on behalf of the organization. In their stories as representatives of the organization, it is unsurprising that they highlight the ways that the organization helps its clients, often resulting in narratives of people overcoming their disability with the help of the organization. Either explicitly or implicitly, *Arts4All Florida* is framed as the hero.

In the 2017-2018 Annual Report, a document that is linked to under the "Impact Tab" (http://arts4allflorida.org/content/our-impact) the following story is told by an educator employed by an educator employed by the organization:

> *"Lisa is a non-verbal student and usually communicates through a Promethean board. Ever since she started the dance residency two semesters ago, Lisa now uses non-verbal language to communicate with classmates and teachers. Lisa has also increased the use of sounds and is able to follow directions without re-direction…Lisa had trouble sitting down on the floor and getting back up, but ever since we began our dance creative process, Lisa sits and gets back up without any assistance and quicker than when we started. Lisa is a pure example of how the arts creates transformations and assists in growth and increase of skills." (2017-2018 Annual Report)*

This short story has a clear beginning, conflict, resolution, and happy ending. In the beginning, Lisa has a problem, and the conflict is that she is unable to communicate with others, due to her disability, the barrier/villain. In this story, *Arts4All Florida* offers a dance program and through this dance program, the conflict is resolved as her behavior and communication have improved-*Arts4All Florida* has saved the day. It's a familiar and easy story to understand.

The story of Lisa, an image of an organization that is a worthy investment for grants and funding. Still, these narratives are not entirely money driven. I firmly believe that educators and participants do indeed find the programs to be beneficial to people with disabilities and derive joy from seeing students improve and gain new skills.

> *"I discovered one girl IS AN AMAZING talented, natural artist. She has had difficulty with verbal & written comprehension & expression. HER JOY of drawing, painting, creating, and sharing-further developed her individuality & processing skills in my class. STEP BY STEP directions help her significantly. She smiles in the world of color!! Learning in a multi-sensory environment is essential." -Site Evaluation Annual Report 2016-2017*

These narratives still have elements of *Arts4All Florida* as a hero that helps students to "overcome" their disabilities. Still, showing progress in students does offer an avenue for people with similar disabilities to identify programs that could, in fact, benefit themselves in some way.

Organizational Narratives: Adapting to Disability

Given the potential usefulness of the narrative that disability is a barrier to be4 overcome, it would not be surprising if this was the organizational narrative *Arts4All Florida* chose to center. However, many of the organization's narratives highlighted the ways that *Arts4All Florida* teaches people to adapt to sociocultural and economic expectations of society as opposed to teaching clients to adapt to their disabilities per se. While the narratives as told by spokespeople were highlighted in the annual reports, the website's impact tab is prefaced with the following narrative:

For 38 years, Arts4All Florida has provided programs that make it possible for people with disabilities to contribute to the social, cultural, and economic life of Florida. Our programs have demonstrated success in ***increasing artistic skills****, fostering creativity,* ***promoting social***

***skills, creating self-confidence, teaching marketable skills**, and **providing new ways of communication** for people with disabilities. (emphasis added) (http://arts4allflorida.org/about-and-impact.html).*

The successes touted by the organization revolve around teaching artistic skills as a craft, and marketable skills to help promote oneself economically. Neither of these are inherent to disability and, thus, it is not necessarily disability that is being overcome. Instead, artists are taught how to handle socially imposed barriers, such as lack of art training due to inaccessible art classes, and low confidence stemming from low expectations surrounding disability. *Arts4All Florida* trains artists, which can help them to find niches outside of a typical 8-hour a day, 40-hour workweek which may be inaccessible for some of these artists with disabilities. Additionally, annual reports, particularly more recent ones, also shifted the focus from overcoming disabilities to narratives more focused on access.

In an effort to help schools and other organizations provide accessible art instruction, Arts4All Florida coordinated an adapted art tool and material fund for classroom teachers, teaching artists, and cultural organizations. (http://arts4allflorida.org/assets/docs/2018-2019%20Annual%20Report%20Arts4All%20FLORIDA-r.pdf).

By drawing on social model understandings of disability, *Arts4All Florida* can be an ally to people with disabilities by helping them overcome inaccessible environments without objectifying people with disabilities as victims of their body/minds. It is also worth noting that more recent annual reports draw on stories of adaptation and social model understandings of disability more clearly than older reports, showing that the organization itself also adapts to be a better ally to its clients as more empowering narratives become available. This ability to shift from traditional narratives of overcoming disability, in which the organization is the clearly identified hero, to one in which the organization is more of a side kick or helper shows a commitment to empowering clients, shows a commitment to allyship and support for the flourishing narratives of adapting to disabling situations becomes a more positive narrative for artists with disabilities.

Discussion

This chapter explores the plurality of narratives about and within and an ally organization that supports arts education for people with disabilities. Narratives can be used to support or subvert understandings of disability. While much of the promotional materials subscribed to more traditional understandings of disability, in which the organization, to an extent, “saves” students with disabilities, *Arts4All Florida* has increasingly begun to put narratives of adaptation to inaccessible societies front and center as their organizational narrative, which better empowers artists with disabilities. While this chapter is somewhat critical towards the cultural narratives of disability, the stories told support the claim that many students who have taken programs though *Arts4All Florida* did experience benefits, whether artistically or otherwise. Telling such stories could reach families that may also benefit from such programs.

I was particularly interested in the variability amongst the stories of artists with disabilities. Some artists did not tell stories at all, instead, preferring to give a brief description of the type of art they do with a link to their website where they sell their art. This, to some extent echoes Gill’s (2001) findings that people with disabilities do not necessarily want to be praised for routine things they do in their lives simply because they have a disability. For some of these artists, their disability may be irrelevant to their art and the organization is an ally only insofar as it provides another forum for them to sell their artwork. Other artists told long stories about their experience with disability, how they initially go involved in creating art, and their hopes about creating art or pursuing other goals in the future. I focused on the latter, as this gave me more of a snapshot into the artist's identity and their understanding of their disability.

As discussed earlier, it is important to be weary of organizations that are led primarily by those who adopt an identity as ally, as opposed to people with disabilities themselves. *Arts4All Florida* had its beginnings being funded primarily by the government and run by people who may not have had disabilities themselves. However, *Arts4All Florida* has also undergone extensive changes. By providing spaces for people with disabilities to tell their own stories and sell their own work, the organization is attempting to shift toward an organization that highlights the voices of people with disabilities. It is important to note that there is no attempt to silence or hide voices whose narrative seems to contradict the larger overarching narrative of the organization.

Additionally, *Arts4All Florida* does take actions, rather than simply preaching mere acceptance. It actively devotes resources to making art classrooms more accessible and promoting artists with disabilities. *Arts4All Florida* also confronts token-style inclusion that only considered whether persons with disabilities are in the classroom, without assessing the degree to which they have the resources to actively participate and express themselves with art. This action component of *Arts4All Florida's* mission is perhaps the most important component of the organization's allyship.

Artists who told stories about overcoming disability are not wrong to conceptualize their experience in this way. Sharing such stories can be powerful and for some people, overcoming difficulties stemming from their disability still allows them to be the hero of their own story. My goal is not to critique those who experience disability in this lens. Instead, I seek to answer questions of "what?" and "how?" narratives make up our world to such an extent that we often do not think about how we narrate ourselves or how our narratives change from context to context. Identifying different types of narratives, even when the differences are subtle, as is the case for overcoming vs. adaptation narratives, can open different understandings of what disability is and how it is experienced.

Discussions of finding funding and sponsors may appear cold and rational on the surface. However, many of the programs offered through *Arts4All Florida*, seeking to make art classrooms more accessible for students with disabilities, could not exist without money. Thus, attracting donors is not only practical but arguably, moral, in making it possible for organiers to fulfill a calling.

Additionally, understanding the purposes that different narratives serve gives us a better understanding of the complexity of social reality and bridges gaps in our understanding. A purpose can be as simple as trying to bridge a gap in understanding. The organizers who chose which stories to highlight in their promotional material are no more calculating than I am in choosing narratives to serve the interest of writing this chapter. In short, the goals of this paper is to better understand conceptions of disability and how organizations that wish to be allies draw on these conceptions of disability and how organizations that wish to be allies draw on these conceptions of disability in ways that promote or contradict the narratives of their clients.

Conclusion

As with all research, there are limitations. Perhaps most noticeably, this is a case study of only one organization that offers art programs to people with disabilities. This was done to explore the full depth that this organization’s website had to offer. With this information, future research may explore other websites to see if these themes reach across organizations. Additionally, in future research, with artists with disabilities, it may be informative to also reach out to artists who did *not* include information about their disability in their artist registry. Artists who do not discuss their disability on the Artist Registry may have their own reasons for doing so and may have a different perspective s to the role or art or *Arts4All Florida* in their lives. As stated multiple times, the narratives on this website are very short snapshots, some being only a few sentences long. In-depth interviews with artists, employees, or board members of *Arts4All Florida*, may offer a better, more holistic understanding into the organization and/or the lives and identities of artists with disabilities. Each of these pieces will offer a deeper understanding of the role narratives play in shaping organizations and what it means for organizations to consider themselves as allies.

References

Allen, J., (2010). "The sociology of disability and the struggle for inclusive education," *British Journal of Sociology of Education 31*(5) 603-619.

Allen, J., (2014). Inclusive education and the arts. *Cambridge Journal of Education*, *44*(4) 511-523.

Arts4All Florida (2018). http://www.vsafl.org/ Accessed October 8, 2018.

Best, J., (1997). Victimization and the victim industry. *Society, 34*: 9-17.

Brown, K.T., & Ostrove, J.M., (2013). What does it mean to be an ally?: The perception of allies from the perspective of people of color. *Journal of Applied Social Psychology, 43* 2211-2222.

Cahill, S.E., & R. Eggleston, (1994). Managing emotions in public: The case of wheelchair users. *Social Psychology Quarterly, 57*(4) (1994) 300-312.

Calderón-Almendros, I., & Calderón-Almendros, R., (2016). "I open the coffin and here I am: disability as oppression and education as liberation in the construction of personal identity. *Disability & Society*, *31*(1) 100-115.

Carey, A.C., Block, P., & Scotch, R.K., (2019). Sometimes allies: Parent-led disability organizations and social movements. *Disability Studies Quarterly, 39*(1).

Chan, D., Sireling, L., (2010). "I want to be bipolar"…A new phenomenon. *The Psychiatrist*, *34* 103-105.

Coleman, M.B., & Cramer, E.S., (2015). Creating meaningful art experiences with assistive technology for students with physical, visual, severe, and multiple disabilities. *Art Education*, 68(2) 6-13.

Coleman, M.B., Cramer, E.S., Park, Y., & Bell, S.M., (2015). Art educators' use of adaptations, assistive technology, and special education supports for students with physical, visual, severe, and multiple disabilities. *Journal of Developmental and Physical Disabilities* 27(5) p.637-660.

Cooley, J., & Fox, A.M., (2014). Disability art, aesthetics, and access: Creating exhibitions in a liberal arts setting. *Disability Studies Quarterly*, 34(1).

Coriale, L., L. Grant, & J. Robertson, (2012). Exploring the educational experience of a social work student with a disability: A narrative. *Social Work Education* 31(4) 422-434.

Cramer, E.S., Coleman, M.B., Park, Y., Bell, S.M., & Cole, J., (2015). Art educators' knowledge, attitudes, and experiences working with students who have physical, sensory, severe, or multiple disabilities," *Studies in Art Education*, (in Press).

Darling, R.B. (2012). Disability and identity: Negotiating self in a changing society. Boulder, CO and London: Lynne Rienner Publishers.

Dunn, J., (2004). The politics of empathy: Social movements and victim repertoires. *Sociological Focus*, 37(3) 235-250.

Egilson, S. T., and Traustadottir, R., (2009). Assistance to pupils with physical disabilities in regular schools: promoting inclusion or creating dependency? *European Journal of Special Needs Education* 24(1): 21-36.

Egner, J.E. (2019a). The disability rights community was never mine: Neuroqueer disidentification? *Gender & Society, 33*(1) 123-147.

Egner, J.E. (2019b). Hegemonic or queer?: A comparative analysis of five LGBTQIA/disability intersectional social movement organizations. *Humanity and Society, 43*(2), 140-178.

Evans, N.J., Assadi, J.L., & Harriott, T.K., (2005). Encouraging the development of disability allies, in R.D. Reason, E.M. Broido, T. Davis, & N.J. Evans, (Eds.) *Developing social justice allies: New directions for student services,* (pp.67-79) San Francisco, CA: Jossey-Bass.

Forber-Pratt, A.J., Mueller, C.O., & Andrews, E.E., (2019) Disability identity and allyship in rehabilitation psychology: Sit, stand, sign and show up. *Rehabilitation Psychology,* 64(2) 119-129.

Foucault, M., (1988) *Madness and Civilization: A History of Insanity in the Age of Reason,* (Vintage Books, ed.) New York, NY: Random House (Original Work Published 1965).

Fox, A., (2015) “Invigorating disability aesthetics through art and performance: a report from the Bodies of Work Festival of Disability Arts and Culture 2013” *Journal of Literary & Cultural Disability Studies* 9(3) 349-355.

Gill, C.J., (2001) Divided understandings: The social experience of disability, In G.L. Albrecht, K.D., Seelman, & M. Bury, (Eds) *Handbook of disability studies,* (pp.351-372) Thousand Oaks, CA: Sage.

Goffman, Erving (1963). *Stigma: Notes on management of spoiled identity.* New York: Simon and Schuster.

Green, S. E., Darling, R. B., and Wilbers, L. (2017). “Struggles and joys: A review of research on the social experience of parenting disabled children” in S.E. Green & S.N. Barnartt (Eds.) *Sociology Looking At Disability: What Did We Know and When Did We Know It?* pp.(39-56) United Kingdom, Emerald Group Publishing Limited.

Hine, C. (2000) *Virtual ethnography,* London: SAGE Publications.

Jung K.E., (2003). Chronic illness and academic accommodation: Meeting disabled students’ “unique needs” and preserving the institutional order of the university. *Journal of Sociology and Social Welfare 30*(1) 91-112.

Kafer, A., (2013) *Feminist queer crip*, Indiana University Press.

Kimball, E.W., Moore, A., Vaccaro, A., Troiano, P.F., & Newman, B.M., (2016) College students with disabilities redefine activism: Self-advocacy, storytelling, and collective action. *Journal of Diversity in Higher Education,* 9(3) 245-260.

Lenakakis, A., & Koltsida, M., (2017) “Disabled and non-disabled actors working in partnership for a theatrical performance: a research on theatrical partnerships as enablers of social and behavioral skills for persons with disabilities, Research in Drama Education: The Journal of Applied Theatre and Performance, 22(2) 251-269.

Loesl, S., (2012) “The Adaptive art specialist: An integral part of a student’s access to art,” IN *The intersection of arts education and Special Education: Exemplary programs and approaches* (p.47-68) Washington DC: International Organization on Arts and Disability.

Loseke, D.R., (2007). “The Study of Identity as Cultural Institutional, Organizational, and Personal Narratives: Theoretical and Empirical Integrations,” *The Sociological Quarterly,* 48 661-688.

Loseke, D.R. (2012). The empirical analysis of formula stories. In J. Holstein & J. Gubrium (Eds.), *Varieties of narrative analysis* (pp.251-271) Los Angeles, CA: SAGE Publications.

Maloney, P., (2013). Online networks and emotional energy. *Information, Communication & Society, 16*(1), 105-124.

Manago, B., Davis, J.L. Goar, C., (2017). Discourse in action: Parents' use of medical and social models to resist disability stigma. *Social Sciences & Medicine* 184 169-177.

Oliver, M., & Barnes, C., (2012). *The new politics of disablement*, New York, NY: Palgrave Macmillian.

Ostrove, J.M., Kornfeld, M., & Ibrahim, M., (2019). Actors against ableism? Qualities of nondisabled allies from the perspective of people with physical disabilities. *Journal of Social Issues*, 75(3) 924-942.

Patterson, L., (2012). Points of access: rehabilitation centers, summer camps, and student life in the making of disability activism, 1960-1973. *Journal of Social History* 46(2) 473-499.

Penketh, C., (2014). Putting disability studies to work in art education. *International Journal of Art & Design Education*, 33, 291-300.

Rousso, H., (2013). *Don't Call Me Inspirational: A Disabled Feminist Talk Back,* Philadelphia, P.A., Temple University Press.

Russell, G.M., (2011). Motives of heterosexual allies in collective action for equality. *Journal of Social Issues*, 67 358-375.

Russell, G.M., & Bohan, J.S., (2016). Institutional allyship for LGBT equality: Underlying processes and potentials for change," *Journal of Social Issues*, 72(2) 335-354.

Shah, S., & Priestly, M., (2010). Home and away: The changing impact of educational policies on disabled children's experiences of family and friendship. *Research Papers in Education* 25(2) 155-175.

Shakespeare, T., (2014). *Disability rights and wrongs revisited*. 2nd Ed. Cornwall, Great Britain: Routeledge.

Shaw, C., (2015) We have no need to lock ourselves away': Space, marginality, and negotiations of Deaf identity in Late Soviet Moscow. *Slavic Review*, 74(1) p57-78.

Solvang, Per Koren, (2012). Research Paper: From identity politics to dismodernism? Changes in the social meaning of disability art. *European Journal of Disability Research*, 6(3) 178-187.

Taylor, M. (2005). Self-identity and the Arts Education of Disabled Young People," Disability & Society, 20 763-778.

Wexler, A.J., & Derby, J., (2015.) Arts in institutions: The emergence of (disabled) outsiders. Studies in Art Education, 56, 127-141.

Young, G.C., (2008). Autonomy of artistic expression for adult learners with disabilities. *International Journal of Art & Design Education*, 27, 116-123.

Zederayko, M.W., & Ward, K., (1999). “What to do when students can’t hold a pencil,” *Art Education*, 52(4) 18-22.

Chapter 4: “When you get into this world, you’re constantly connected to things”: How parents of people with disabilities create and reproduce social and cultural capital through disability-based arts programs

Introduction

Art spaces can be important sites of inclusion and exclusion. Unfortunately, people with disabilities are regularly excluded from art spaces except those defined as “therapeutic,” and have reported significant barriers to establishing careers in the arts (Green & Bingham, 2017). This denies people with disabilities the opportunity to produce their own art and continues the cycle of low expectations for the contributions from people with disabilities.

Yet, people with disabilities and their families can and do resist low expectations and negative attitudes through creating disability-centered spaces with high expectations and where their work is recognized as high quality (Hall, 2013; Maconi, 2020; Simplican Leader, Kosciulek, & Leahy, 2015). Parents of people with disabilities use their own social and cultural capital to create and/or locate communities in which their children can flourish (Green, Barnhill, Green, Hawken, Humphrey, and Sanderson, 2011). In these spaces, people with disabilities and their families create social capital through connecting with each other and identifying other networks and disability-centered activities (Bourdieu, 1986; Goulding, 2012; White & Mackenzie, 2015). Furthermore, within these networks, people with disabilities and their families may seek out spaces that bestow higher levels of cultural capital, such as art spaces (Bourdieu, 1986; Goulding, 2012; Hall, 2013). This paper seeks to address the questions: (1)How do parents of participants in disability-based arts programs that promote inclusion view the work of the organization and its role in their children’s lives? And (2) What facilitators and/or barriers do parents of program participants perceive in relation to the opportunities their children have had to participate in the arts at various points in the family life course?

Literature Review

This review builds a case that parents of people with disabilities may draw on their own social and cultural capital to combat stigma and low expectations for the success of their children, and that disability-centered art spaces can be an important arena in which to explore how this process occurs. In the sub-sections that follow, I provide a brief overview of literatures on social and cultural capital, disability-based stigma and the problem of low expectations, and disability-centered spaces as a potential antidote to stigma and low expectations. In each section, I make specific connections to the participation of people with disabilities in the arts.

Social and Cultural Capital

"Social capital is comprised of networks of people and relationships that contribute to the garnering of capital in its other forms" (Trainor, 2008: p. 151). Social capital is important, particularly for people with disabilities, for multiple reasons. Social capital increases the sense of subjective well-being and their sense of belonging (Hall, 2013; White & Mackenzie, 2015); it also increases one's access to resources, through social networks. This is particularly important among people with disabilities, as this is a group who statistically, has less economic capital or political power than those without disabilities (Goulding, 2012; Hall, 2013; Trainor, 2010).

In her work on children receiving accommodations for their disabilities in the school system, Clark (2018) highlights the importance of social capital in acquiring resources. While money is certainly a major factor in resource allocation, some families with money did not know where to begin to seek services, while other parents, who were more well-connected socially to other parents of children with disabilities, were able to get informed advice and services.

In addition to social capital, cultural capital also enhances chances for success. Trainor (2008) describes cultural capital as, “cultural goods that contribute to the reification of status and power on the basis of accumulated capital that is highly valued in the larger society” (p.151). Participation and consumption of the arts generally increases one’s cultural capital (Goulding, 2012). Art as a skilled craft takes time and resources to master, bestowing onto it a degree of social status that not everyone is able to access. Thus, this paper will examine how participation in the arts is reciprocally related to resisting low expectations through the use of social and cultural capital that is further cultivated through participation in the arts. Parents of people with disabilities who are participating in art programs, in many cases, are using their own cultural, social, and economic capital to develop capital for the benefit of their children with disabilities. As Trainor (2010: pp. 36) points out, “[e]conomic capital mediates parents’ access to cultural and social capital, in turn, mediating their approaches to collaboration” which can enhance the potential for success of their children with disabilities.

The Problem of Stigma and Low Expectations

For people with disabilities and their families, stigma can be a barrier to creating and maintaining cultural capital. Stigma is the process by which some identities are devalued and deemed to be inferior to others, and thus, is a product of social interactions rather than disability itself (Goffman, 1963). People across various types of disabilities experience stigma as their bodies and/or minds are often evaluated by others, particularly those with power, as being different in an inherently negative way, which Goffman would refer to as a “spoiled identity.” When someone has a spoiled identity, all of their actions are interpreted by others through the lens of that label (Goffman, 1963; Link & Phelan, 2001). Thus, when people with disabilities are labeled as “less than,” the activities they participate in and the products of their hard work are also assumed to be “less than” or inferior, before even being evaluated.

In addition to individuals with disabilities, family members also experience what Goffman (1963) calls “courtesy stigma,” by which they are stigmatized due to their close association to someone who is stigmatized. This can place family members in a liminal state, where they feel like they belong neither among those with disabilities nor among those without disabilities (Green, 2017). Organizations that cater to people with disabilities also experience courtesy stigmas (Goffman, 1963; Maconi 2020). In the context of art-based organizations, mainstream consumers may refuse to even consider buying art or watching performances produced by people with disabilities, under the assumption that the resulting product is inferior simply because it is produced by people with disabilities.

When people are stigmatized, others often hold low expectations in regards to what they are able to accomplish. The low expectations others have for the success and potential of people with disabilities is well documented (Calderón-Almendros, I., & Calderón-Almendros 2016; Cramer, Coleman, Park, Bell, & Cole 2015; Lenakakis & Koltsida, 2017; Loesl, 2012; Van der Klift & Kunc, 2019). This is due, in part, to the medical model of disability, which depicts disability as an inherent tragedy and people with disabilities as in need of being cured or fixed (Oliver & Barnes, 2012). The Medical Model is so taken for granted, it did not have a name until the Social Model, a challenge to the status quo, was created (Egner, 2017).

The medical model of disability has also contributed to a focus on the therapeutic benefit of art for people with disabilities - to the exclusion of a focus on the artistic contributions of trained artists with disabilities. It is well documented that art has the capacity to increase one’s sense of well-being, help with self-expression, and even help reclaim political voice for people with disabilities (Allen, 2014; Coleman & Cramer, 2015; Cooley & Fox, 2014; Fox, 2015; Hall, 2013; Solvang, 2012; Young 2008). However, the stigma and low expectations associated with the medical model of disability can lead to the assumption that art can *only* be therapeutic for people with disabilities, rather than being a skilled craft in which talent must be honed through dedication, training, and practice (Lenakakis & Koltsida, 2017; Kafer 2013; Rousso, 2013; Solvang, 2013). This assumption is implicit in the "outsider art" phenomena. Near the beginning of the twentieth century, some sanatoriums began to include venues for patients to create art and some of that art was sold, by the institutions, for profit (Wexler & Derby 2015). Originally referred to as "institutional art," this practice gave rise to artists, such as Johann Hauser, Judith Scott, and Larry Bissonnette, who were praised for their unusual art styles. These and other "outsider artists" were essentialized as "naturally" more creative than the general public (Chan & Sireling, 2010; Wexler & Derby, 2015). It is important to note that while many people are fascinated by Outsider Art, it does not carry the same level of cultural capital as art produced by those with formal art training (Goulding 2012; Hall, 2013).

The view that artists with disabilities can produce without training because artistic talent is an essential part of their disability, may also be reflected in the contradictory relationship between disability and art education in schools. Wexler and Derby (2015) point out, for example, that "the art room has often been the first regular classroom where disabled learners are placed; yet, the needs of disabled learners have often gone unmet." Despite the multiple adaptive tools available, many art classes and programs are not aware of how to implement these changes to make art education inclusive (Coleman & Cramer, 2015; Coleman, Cramer, Park & Bell, 2105; Cramer et.al. 2015; Loesl, 2012; Zederayko & Ward, 1999).

Low expectations associated with disability are so widely accepted that lack of participation, or lack of success, experienced by people with disabilities in the arts is likely to be attributed to disability rather than to unaccommodating settings or lack of needed tools (Oliver & Barnes, 2012; Zederayko & Ward 1999). When people with disabilities do succeed in mainstream art settings, they may be viewed as naturally talented because of their disability; praised as an exception to the rule rather than proof that trained artists with disabilities can produce high quality art (Calderón-Almendros & Calderón-Almendros, 2016); or praised for producing art although they are disabled, rather than for the art they produce (Rousso 2013).

Furthermore, art work and artistic performances by people with disabilities may be judged by higher standards than those applied to their non-disabled counterparts. For example, in a mixed-disability theater group, Lenakakis & Koltsida (2017) found that when actors with disabilities forgot their lines during rehearsals, some people took it as a sign that the actors would not be able to perform at a high level of quality, even though actors without disabilities also sometimes forgot their lines during rehearsals.

In summary, for people with stigmatized identities, like disability, public expectations and reactions are complex and contradictory. Simple mistakes or lack of success tend to be attributed to disability rather than the environment or difficulty of the task itself. Conversely, when people with disabilities are successful in mainstream settings, they are often assumed to be the exception to the rule or their success is seen as a fluke or an essential characteristic of the disability rather than the result of hard work and training (Calderón-Almendros & Calderón-Almendros, 2016). Both lenses reinforce the low expectations of people with disabilities and focus attention on the disability rather than on artistic achievement (Rousso, 2013). It is not surprising that people with disabilities who regularly are not recognized for their achievements and talents on their own merit in mainstream settings, regardless of how well they do, seek out spaces where disability is seen as neither remarkable nor a barrier to success.

Disability-Centered Art Spaces as a Potential Antidote to Stigma and Low Expectations

Due to the seemingly ubiquitous experience of low expectations for people with disabilities in mainstream settings, people with disabilities and their families may actively seek out disability-centered spaces. While inclusion is often the stated goal of disability-centered organizations, mainstream settings can be hostile, and the mere presence of a person with disabilities is not enough to make the space “inclusive” (Hall, 2009; Van der Klift & Kunc, 2019; Zederayko & Ward 1999). Through disability-centered activities, people with disabilities make connections with each other. These connections can increase the social capital of the group’s members (Bourdieu, 1986; Goulding, 2012; Trainor, 2008). Van der Klift and Kunc (2019) outline some key differences between oppressive segregated groups, and positive identity-centered emancipatory groups. For groups centered around marginalized communities to be emancipatory, participation in the groups must be voluntary, groups must express acceptance and respect, and quite importantly, expectations for what their members can achieve must be high.

Many artists with disabilities challenge the low expectations and stigmatized views of others and seek to be recognized for their artistic talents (Lenakakis & Koltsida, 2017; Fox, 2015; Cooley & Fox, 2014). Due to exclusion and/or lack of support in mainstream art settings, disability-centered art settings have emerged as an important site for both inclusion and resistance of ableist attitudes (Cooley & Fox, 2014; Fox, 2015; Hall, 2013; Ineland, 2016; Maconi, 2020). These disability-centered art spaces are, therefore, more than recreational facilities; they are spaces that actively challenge cultural assumptions of what people with disabilities can or cannot achieve. Participation and success in these spaces are the expectations, rather than the exception. As Allen (2014:518) asserts, “the arts have emerged as an important site of activism for inclusion, as a ‘force that draws people into participation,’ and a political vehicle for centering ‘normally silenced or disenfranchised voices.”

Due to assumptions surrounding Outsider Art, many organizations that teach art as a craft for people with disabilities actively reject the “Outsider Art” label (Chandler 2017; Hall, 2013; Solvang, 2012). As more nuanced theories and definitions of disability have emerged, art programs for people with disabilities have also increasingly begun to shift away from a therapy-only model and towards a narrative of access to the arts as a human right (Hall, 2013; Ineland, 2016; Maconi 2020). While this shift has been widely praised by disability rights activists, it has led to some ambiguity and heterogeneous expectations, particularly when working with a wide age group. “A major obstacle for achieving the goal of social inclusion for people with intellectual and developmental disabilities is that the concept of social inclusion remains unclear” (Simplican et. al., 2015: p. 19).

Simplican and colleagues (2015) break social inclusion for people with disabilities into two major categories: interpersonal relationships and community engagement. Inclusive art programs have the capacity to meet both these needs for social inclusion. Inclusive art spaces bring people with disabilities together into a non-judgmental space where they can connect to others who have a shared history of marginalization (Hall, 2013; Ostrove, Kornfeld, & Ibrahim, 2019; Shaw 2015). As Calderón-Almendros & Calderón-Almendros (2016) detail, when Rafael Calderón-Almendros, who has Down Syndrome, was recognized for his musical talent, in a space where he was the only person with disabilities, he did not feel included but instead, felt objectified, as if he were a prop for the organization to showcase rather than a true member of any group. Furthermore, a connection to other people who have disabilities enhances one's sense of well-being (White & Mackenzie, 2015).

Many inclusive art programs that reject the art therapy label express the goal that some of their participants will be able to present their art to the wider community that these programs exist in (Hall, 2013; Maconi, 2020). Hall (2013) describes this process as "gifting" artistic products and performances to the general public. Through "gifting," the power dynamic between people with disabilities and people without disabilities is challenged, as it is people with disabilities who have the power and bestowing something onto people without disabilities, rather than passively accepting therapy or instruction from able-body/minded professionals. "Creative arts are understood to be a mediator between positions of social exclusion and of inclusion for marginalized people and places, building self-confidence and strengthening social networks," (Hall, 2013: p.244).

In this study, I use the stories parents tell about their children's experiences with the arts and art education to explore the ways in which parental social and cultural capital is both used and reproduced as parents attempt to mediate the exclusion of disability by creating inclusive social networks in which their children can thrive.

Research Methods

This study is part of a larger research project on art programs for people with disabilities. It is my research philosophy that I must be compassionate and appreciative of what my research participants give me. I strive to produce engaged research that will ultimately give back to the groups and communities that I have studied. As part of the larger project, I spent fifteen months as a volunteer in an inclusive theater company that provides training and performance opportunities for people with disabilities. Students and actors with disabilities learn from and perform with theater professionals without disabilities. Before the pandemic, the group held both introductory and advanced acting classes, produced at least two student showcases each year, and held at least two professional performances in local theaters annually. In March of 2020, in response to the Covid-19 pandemic, the theater group moved all of its classes and student showcases to an online setting and the classes remained online for the rest of 2020. During my volunteer work with this group, I assisted with acting classes and behind the scenes work on the student showcases and professional stage productions. I worked alongside theater staff, students, community volunteers, and parents of participants in building theater sets, helping with costumes, and working backstage with people with disabilities. I also attended meetings of the organization's board of directors and participated in social events with staff, students, and their families. I stayed involved as a volunteer up until classes moved online due to the Covid-19 pandemic. After that, I still remained connected to those involved and attended online performances, though, I was no longer needed as a volunteer to help set up or break down the sets and space, due to the online environment.

Data Collection

Data for this study are drawn from interviews conducted as part of a research project on the experiences of parents of children and adults with disabilities. The principal investigator of that project is Sara Green and I served as part of the research team and conducted interviews for the project. As part of that larger data collection effort, participants for this study were recruited through the theater group in which I volunteered, in accordance with the protocol that was reviewed and approved by the University of South Florida Institutional Review Board (IRB Study # 105141. The project received exempt status because all interview data was de-identified during the transcription process. Despite the exempt status, informed consent was obtained from each parent after the purpose and scope of the interview and project were explained and their questions were answered.

The theater group sent out a recruitment e-mail in which the study was described. The email included my contact information and asked parents to contact me if they were interested in being interviewed. The recruitment strategy resulted in interviews with ten parents (seven mothers and three fathers) of eight children and adults with disabilities. Eight of the parents had at least one child or adult who was enrolled in classes and/or had participated in performances with the inclusive theater group. The other two parents were the mother and father of a younger child who heard about the study through other interviewees and asked to participate.

Interviews were conducted between the fall of 2019 and spring of 2021. Interviews with two of the ten parents occurred after the start of the pandemic. Four of the eight parents who were initially interviewed before the pandemic were re-interviewed after the start of the pandemic. In most cases, parents interviewed before the pandemic chose to be interviewed at home, but three mothers and one father chose a local coffee shop or restaurant instead. After the pandemic, interviews were conducted by phone or on teams.

The interviews took the form of in-depth conversations in which parents were asked to reflect on experiences across the span of their children's lives. The interviews lasted between one half hour and over two hours – with most lasting over an hour. I draw my interview style from Glesne, who encourages researchers to remember that interviews are an interactive process and to "Try thinking of your role as that of a collaborator whose conversational actions facilitate others in the telling of their stories," (Glesne, 2016: 113).

The interviews were semi-structured and used an interview guide, but allowed participants to direct the course of the interview and highlight what they believed is most important about their experiences as parents of children with disabilities. The interview guide began with very open-ended questions such as, “Can you tell me a little about yourself and your family” and “Can you tell me about “____ [child with a disability].” It then focused on experiences with family, community, service providers, and educational and recreational programs at various points of the child’s life. Because I was particularly interested in disability and the arts, I probes were added to the interview guide to solicit information about the family’s engagement with the arts in general and with the inclusive theater company in particular.

Description of Participants

The interview protocol did not specifically ask for demographic information on parents or children. However, most parents included at least some demographic information in their descriptions of themselves, their families, and their children with disabilities. Among parents who reported their own age, ages ranged from 31 to 62. Past and current occupations of interviewees and spouses that were mentioned include: accountant, business owner, doctor, firefighter, nurse, operations manager, and teacher. Several of the mothers reported that they had quit jobs and/or college in order to care for their children with disabilities and described themselves as “stay at home moms.” Others, however, continued working and some completed degrees or started new careers after the birth of their children. Several interviewees had worked for disability-centered organizations and/or in health care or special education settings. Eight of the ten parents were the birth parents of the child with a disability, one was a step parent, and one was an adoptive parent. At the time of the initial interview, eight interviewees reported being married, one was widowed, and one was single.

The ages of children with disabilities that were reported ranged from 9 to 39. Two were under 21. All others were adults. Four of the eight children that were the focus of the interviews were described as daughters and four were described as sons. Five of the eight children had been diagnosed with Down syndrome, one had been diagnosed with cerebral palsy, one had been diagnosed with William’s syndrome and one had an intellectual disability. All of the adult children were described as having significant and continuing needs for support due to their disability, and all ten parents had a child with disabilities still living in their home at the time of the interview. Seven of the eight children had participated in the inclusive theater group as students and performers. Only the 9 year old child had not.

Data Analysis

The transcripts for each of the ten participants averaged over 18,000 words (including follow-up interviews), resulting in a total of over 180,000 words available for analysis.

I conducted my analysis of these transcripts in several stages. First, I worked on “getting to know the stories” (Green, 2015: 109). I read and re-read the transcripts to understand the messages each interviewee wanted to get across. This strategy is consistent with an emancipatory approach in which the researcher seeks to be true to the goals participants bring to the project. Proponents of emancipatory research argue that the experiences and perspectives of people with disabilities are silenced when research is performed “on” or “about” rather than “with” them. People with disabilities have called for research that actively addresses the issues they face and that has potential to improve lives (Oliver and Barnes, 2012). Green (2015) points out that the act of telling stories that are marginalized can be a type of activism.

Second, I used thematic analysis to look for patterns in the stories my participants shared with me. While the participants spanned age ranges, and had family members with different types of disabilities, the use of social and cultural capital was a broad theme that ran through the interviews. The parents included in the interviews described jobs, family connections, and social participation that provided them with substantial access to social and cultural capital.

My third step was to dig deeper into the theme of parental use of social and cultural capital to explore why and how parents make use of their own capital in attempting to meet the needs of their children. I identified three sub-themes within this broad theme: 1. *Parental Reaction to Low Expectations for People with Disabilities; 2. Deploying Social and Cultural Capital to Identify Activities with High Expectations for People with Disabilities; and 3. The Value of High Expectations in Artistic Settings for People with Disabilities*. The findings section is organized around these three topics.

Findings

Parents actively sought out activities and spaces with high expectations for their children with disabilities to counteract the low expectations they were often met with in society. Families were met with low expectations for their children as early as infancy, with doctors immediately focusing on what their children supposedly *won't* be able to accomplish in their conversations with parents about what to expect with their child's diagnosis. From there, teachers, friends, and even family members continually communicated low expectations for children with disabilities. While these were not always malicious, these expectations can negatively impact children with disabilities and their families. Because of this, parents often used their social and cultural capital to seek out spaces in which their children will experience high expectations. Once families were able to find one disability-centered space, they often connected with other parents to identify and sometimes, even create disability-centered spaces with high expectations for their participants. Using this social capital often further built social capital, as it opened other networks to further identify other disability-positive spaces. Additionally, these spaces with high expectations allowed their children with disabilities to build cultural capital, by participating in training to accomplish highly valued skills. These spaces are important for people with disabilities in terms of building social and cultural capital, which is traditionally denied to them. This study will outline this process and its importance, both to people with disabilities and their families.

Parental Reaction to Low Expectations for People with Disabilities

Parents regularly told stories about doctors and family members expressing low expectations for their children with disabilities. Often times, medical professionals treated the birth of a child with a disability as a tragedy and, when notifying parents of their child's disability, focused exclusively on what they believed the child would never accomplish:

> *Every time Jeremy has accomplished something, I want to send [the doctor] a video because when he delivered the diagnosis after the testing he came back, he went through every possible thing [Jeremy will] never do. [Jeremy] was like a week old, and [the doctor was] telling me basically what level of math he will achieve, what level of reading he will achieve, or won't achieve for that matter... That was the worst part of it. It's hard enough getting [the diagnosis]… You can't tell anybody what their one-week old baby will or won't do. -Janice*

Parents actively tried to resist this narrative of tragedy. They resented the fact that others were making assumptions about the possible life achievements of infants. Furthermore, some of the families I spoke with, had children who, sing, dance, and perform with their theater group, despite predictions from doctors that they would never be able to speak or perform simple tasks. On the rare occasion when one of the parents, Kristin, did later receive an apology from the doctor years later, her response was, "I don't really want you to apologize, I just want you to see that when babies are two years old, you can't predict."

Because of this, parents consistently tried to draw attention to what their children *could* achieve, despite negative forecasts from doctors.

> *The hardest thing was going to evaluation meetings… They would be like, "Ok, so, she doesn't do this, now she should be doing this, and so she's not doing that yet." … Every meeting, they're pointing out her delays and deficiencies. … I went into one of these*

> *meetings and I sat down, and I said, "Before we get started, I'm going to list for you the things Savannah does do. She has this many sign language words, she has this many verbal words, she is doing this, she is doing this…that's where I want to start today, is with what Savannah is doing." It was the hardest thing and it carries with you … Like, do you not see? Look at this wonderful person! Do you not see what she does?-Faith*

Low expectations were not limited to medical settings. Many parents found that these low expectations were echoed by teachers and school administrators. Often times, this was not malicious. Well-meaning teachers sometimes overaccommodated students with disabilities rather than allowing them to learn at their own pace or with supports.

> *He was in gen ed 1st grade with an assistant, and he passed everything, all of the 1st grade requirements for gen ed, and then we kept him back another year, to work on his independence, because they were coddling him, because he was in a class with all typical kids and he was cute. So, that was hard, to try to explain to them, that it's time, that he's fully capable and that's not fair to him. That's not fair to us that you do this. He's fully able. So we had to kind of put our foot down with them. -Janice*

Difficulties with low expectations in mainstream schools was so common, that five of the seven families I spoke with discussed actively seeking out private schools specifically for people with disabilities. At the same time, parents who wanted to keep their children in the mainstream school had to actively fight pressure to place them in a segregated school or special education classes.

Yet, when given the space to flourish, people with disabilities regularly met or even exceeded the expectations that were set for them. Parents themselves often found themselves impressed by what their children were able to accomplish when given a chance. Claire, one of the founders of the theater group, raised her son to be "ferociously independent" and encouraged him to be successful in all of his pursuits, such as in becoming a successful DJ and participating in sports. Yet even she was surprised when in high school, with no prior theater experience, he auditioned and made it into the high school production of *Oklahoma.* This later led to him being able to land roles in other mainstream productions, including shows affiliated with a local college, after they contacted him to see if he would be interested in participating.

> *My goal was always for him to be ferociously independent... He's incredibly proud to be a man with Down Syndrome, and to have accomplished the things that he's accomplished, and throughout his life, he would ask me, like, when he wanted to be a DJ, "Do Down Syndrome people be party DJs?" I said, "I don't know. Want to be the first one?" and he said, "Yes, I do," and he was. We would go to see his sister in Shakespeare plays, at the St. Pete Shakespeare Company, and he asked Allison, "Do Down Syndrome people be in Shakespeare?" and Allison goes, "I don't know. Wanna be the first one?" So he was cast as the soothsayer in Julius Caesar, and the casting was wonderful, because they played up the fact that he was a citizen of Rome, with a disability, that no one took seriously… And I was thrilled that they took the fact that this was a person with an obvious disability, and incorporated that into the show. So it feels like with him, any time he's asked if he can do something, we've said, "Let's try it and see." I've never said, "No." -Claire*

Though people with disabilities can and do meet their goals and succeed (in art and other endeavors) everyday, it is daunting when one is always having to overcome assumptions of inadequacy and doubt. Many parents in the study had children who were interested in art at a young age yet, did not participate or get training until later in life due to being rejected or excluded from mainstream programs on the basis of their disability. Furthermore, even some of the art spaces that *do* cater to people with disabilities still offer low expectations, where art is treated as a time-passer rather than a skill that can be learned. Claire reported constantly having to correct others who assume their theater program mostly caters to "high-functioning" actors with disabilities, an accusation that comes from both the public and even other disability-centered theater programs.

> *[The directors of another disability-centered theater company] met with Allison and I about possibly merging with us. And one of the things that she said that was very telling, was she said, "The population we work with is much lower-functioning than your population." And Allison and I both said at the same time, "No. Actually, they're not. We have some pretty low-functioning folks that have really severe disabilities, but we work with them and we create an environment where they're successful and the expectations are higher."-Claire*

In summary, every parent interviewed had stories about medical and educational professionals communicating low expectations for their child with disabilities. These negative assessments were made, usually within the first year of the child's life, sometimes only a few weeks after the birth. It's also worth noting that these low expectations were not necessarily malicious. In school settings, many parents perceived that teachers or aides may have been trying to be kind by over accommodating students and not holding them accountable. Yet, even well-intended actions communicated low expectations and were upsetting to parents, who realized the impact it could have on their children.

While I focused in this section on low expectations set by professionals, family members and friends also communicated low expectations for the children of the participants that I interviewed. Sometimes, well-intended family members did not enforce the same house rules for children with disabilities when growing up, while babysitting, compared to their able-body/minded siblings, or critiquing parents for being "too hard on" their child with disabilities. Thus, parents felt surrounded by others who held low expectations for the ability of their children to succeed.

The Importance of Supports

This isn't to say that people with disabilities don't need supports. On the contrary, setting high expectations without providing the necessary supports and accommodations can be just as harmful and belittling. The problem with many settings, however, is that many schools and activities approached disability with a dichotomous lens that either the person with disabilities can succeed on their own without supports or they are not suited for the space at all. Many parents expressed frustrations with incidents where their children were excluded if they could not meet specific high expectations on their own.

Isabelle, for example, felt exasperated when teachers refused to challenge her son due to his inability to pass the state standardized test. Her son was not able to pass the test on his own and therefore, teachers, even well-meaning ones, did not place a value on challenging and educating him due to not meeting this high expectation. Isabelle acknowledged that it was unlikely that her son would do well on the standardized test but nevertheless, was upset that educators were unwilling to help him progress academically, even if at a different rate than other students. The fact that teachers ignored the educational needs of students who did not pass the test ultimately led her to pull her son out of public school in favor of a disability-specific private school.

> *His teachers loved him, the kids loved him, but I just felt like they loved him because he was cute, and everybody wanted to help him and like, coddle him and just be very like, nurturing with him, and that's not what we needed. It was a struggle to get them to lift their expectations a bit. I have very high expectations of him. I have expectations for his behavior and expectations for his learning and expectations for his mobility. I just felt like we weren't on the same page as far as my expectations and their expectations for him. I felt like they knew he had intellectual disability, so they weren't going to push him very much. They weren't going to expect much from him and that's not what I wanted. Not only that but when I pushed my expectations of him,* ***they said, "Well then he's going to have to test well,"*** *and I'm like, "Well, that's not the issue here." I don't,* ***he's obviously not going to pass your state standardized test,*** *like, very clearly, like, I'm going to tell you that right now, if he's here until 5th grade, he's never going to pass one test, at all, and that's totally fine. I said,* ***"But there has to be another way to measure his learning other than standardized testing."*** *If he's independently himself learning,* ***even if he's not at grade level, then that's a huge accomplishment for him****, and I think that was the biggest part. So I made that choice, we made that choice to switch him over to the [disability-specific school], even though there was less kids and less chance of social interaction. He just needed-, they're more therapy-based, and independent learning-based, so he's getting like one-on-one independent learning time, and a lot of movement and therapy at school as well, on top of us doing independent therapies after school as well. So like, he's going from therapy to learning to therapy, and then we're going home and just trying to relax as a family. So there's definitely a lot of investment that we're putting into the school, into therapies and the time that we're spending doing all of those things. – Isabelle*

Isabelle’s son went on to thrive in the private school, where he had more individualized attention and was educated in conjunction with therapies and supports related to his disability. He was not incapable of learning, but just needed different supports and a more individualized timeline for grasping concepts, very much in line with Kafer’s (2013) concept of Crip Time. Kristin experienced similar pressures when the school threatened to take her son’s aide away in an attempt to pressure her to move her son into the Special Education classroom or a disability-specific school. Her son had been meeting expectations and was able to be successful in the mainstream classroom, with the extra supports provided by the aide yet, the school treated this as an unfair advantage and had the position that if her son was to be in the mainstream classroom, it was only appropriate for him to be there if he were able to succeed there without supports.

> *At one point, I think it was in elementary, they told me they were taking his one-on-one [aide] away… and I said, “So, what are you going to do when you have to call me to tell me he choked to death at the lunch table? Or what are you going to do when a stranger walks-…somebody forces him off campus because they have the chocolate that he wants?” … I did have to kind of fight for some of the stuff but yeah, it worked.-Kristin*

Just as low expectations can be harmful, setting expectations too high, especially without appropriate accommodations, can be just as harmful. There is a fundamental difference here between equality and equity. Unfortunately, many organizations, particularly schools, seemed to be operating under the assumption of equality- that everyone must be treated the same, rather than equity-that those who need help should be offered supports to help them achieve their goals. “The problem here is that when sameness and fairness are collapsed into the same thing, it is impossible to enact differential approaches (because that would be unfair) even if that is what is needed to ultimately achieve equality,” (Castagno 2014: p.313). As seen in Isabelle’s story, there is also the question as to whether everyone needs the same goals. She indicated that even with accommodations, her son likely wouldn’t be successful on the same tests that his peers were taking. Yet, she argued that there is still an importance to challenge and educate her son, even if the goal is simply for him to continue learning and a focus on self-improvement and progression.

These issues offer an important layer of complexity in terms of disability and inclusion. Very strict academic theoretical frameworks, such as the social model presume that full inclusion is the goal and that ideally, all students with disabilities should be in the mainstream classroom and mainstream activities (Oliver & Barnes, 2012). However, many parents turned to separate disability-centered settings to find spaces that offer both high expectations and the supports to meet those expectations. Furthermore, high expectations do not need to be the same expectations for everyone across the board. Many times, parents valued high expectations in terms of their children doing their best and constantly improving, but that does not necessarily mean that they have to meet every benchmark or meet those benchmarks at the same time as their non-disabled peers. The main takeaway in terms of expectations is that high expectations are beneficial to everyone, but that expectations can be more focused on being one's best self and offering reasonable supports should be the norm, rather than conceptualized as "special treatment."

Deploying Social and Cultural Capital to Identify Activities with High Expectations for People with Disabilities

After experiencing low expectations from both doctors and family members and/or high expectations in the absence of appropriate supports, some parents sought out disability-centered spaces through schools and recreational activities. These spaces allow people with disabilities, and their families, to connect with others who have similar experiences. Every person I interviewed spoke at length about the multiple activities in which their children participated. In seeking out disability-centered spaces, such as schools for people with disabilities, parents talked to other parents of people with disabilities, to identify other disability-centered spaces and activities that their children might enjoy.

> *When you get into this world, you're constantly connected to things and you hear things, just like Theater. My friend, her son has autism, and the boys were actually in kindergarten together with that amazing teacher, so she and I have been best friends ever since then. -Janice*

It is important to note that the people I was able to contact through this theater program are not in any way representative of all people with disabilities. On the contrary, these parents had access to financial, social, and cultural capital that others lack. Private schools and participation in extra-curricular activities is costly - in terms of both parental time and money. The particular theater program through which participants were recruited does offer some scholarships and payment plans. Many of the parents, though, first heard about it through their already established social networks.

> *[Savannah] used to swim on a Special Olympics team and she probably did that 7 or 8 years. ... Brian [family member of the founders of the theater program] was on that team, so, they were just friends and the moms kind of get to know each other… At the end of the year swim banquet, Allison [one of the founders] held these little sticks of paper, you know, like an inch high and 6 inches long saying, "We're starting a theater group. -Faith*

It's also interesting to note that just as participants learned about this theater program through their social networks, the founders of the program used their own social capital to reach out to people participating in the same activities as their family member with disabilities. Gabrielle, a board member, discussed how one of her daughters was involved in the very first production, which at that time had only 4 members with disabilities.

> *I'm friends with Claire, who started [the theater program] and Brian, her son. Brian and Carrie were on a bowling league together. In The Boys Next Door, there were regular actors playing the parts of handicapped individuals, and they decided that, for one of the dance themes, they wanted a few, that were handicapped to be in that scene, so, there were four from our bowling group that they asked to come and do it so Carrie was asked to, and then, it just evolved. I got involved and helped and we did a lot. -Gabrielle*

Moreover, these social connections were highly valued by participants with disabilities. , According to parents, these social connections may have even been more important than the art itself for some participants. Brian's parents, for example, said he highly prioritized his friendships and social connections made through the wide variety of artistic and recreational activities in which he participated. These friendships not only built social capital but also led participants to value the space even more, as participants looked forward to the social opportunity to see friends. Brian's dad said, for example,

> *I would suggest it's the social, community bonding element of it [is Brian's favorite thing about the theater program]. The performances of course are just over the top for everybody, but it's that time together, it's that commitment to a schedule, it's that routine, that engaging together with people, I think that's what is most important to him. He will not miss a day. He will not. He keeps the calendar, he keeps Claire and I on schedule. And I think it is, I think it's the sense of community that they all get and share, and even when you have such a diverse combination of disabilities, you have artists with autism, you have artists with Down Syndrome, and all kinds of other conditions and, I think what happens is all that kind of goes away when they're all together, and they're just this community of actors working on a play. And I think that's what he loves the most.* -Clyde

Thus, according to parents, social capital plays a role in helping people with disabilities and their families find disability-positive spaces and these spaces reproduce social and cultural capital for both people with disabilities and their families. It was interesting to find that the activities parents found for their children were not necessarily related to each other in terms of what types of activities were offered. Many people who met in athletic groups for people with disabilities later joined artistic groups for people with disabilities and vice versa. Regardless of the nature of the activities, opportunities for social interaction and network building were highly valued by parents. This was made particularly clear during the pandemic. All of the parents who were interviewed after the pandemic began expressed that the lack of in-person interaction had a negative impact on their child's enjoyment of the activities in which they were involved. Kristin, for example, notes that her son "*…didn't really like Theater on Zoom, because there was not interaction. It was just memorizing lines and reciting… He was very disappointed.*"

While parents lamented the loss of personal interaction, they also credited the remote activities with keeping their children socially engaged – though in a less than ideal way.

> *I must largely credit the substitutions that they've done and the replacements that they've done in keeping [Savannah] above ground, above sea level emotionally… Right now, she's on Zoom. She's in a program through this university called Lift Your Heart, but I think about eight of them have parents similar to me where, they're also having their child participate from home… So she's not fully lacking contact with the outside world.-Faith*

Thus, even during the pandemic, the reproduction of social capital through program participation was a key element in the stories parents told.

Traditionally, people with disabilities are presumed to possess low levels of social and cultural capital. However, disability-centered spaces (both artistic and non-artistic) are important spaces for creating and using social and cultural capital. Parents tapped into their own resources, often created through disability-centered spaces, to find - and in some cases, even create - more disability-centered spaces that allow people with disabilities to create social and cultural capital. Parents often befriended other parents of children at these disability-centered schools or activities and then further recommend other spaces that they have found to be affirming for their own children. The social capital built up in these instances is valued for more than just the resources it provides. While these networks increased access to resources for those involved, many parents reported that their children, and in many cases, themselves, made life-long friends through these activities. These friendships are highly valued and were sometimes participants' favorite aspects of their time partaking in these activities. Still, it is important to examine that these networks also provide. In addition to providing disability affirming spaces with high expectations, these spaces also provide resources that build cultural capital through mastering artistic finesse, athletic strategy, or other valued skills related to the activities they choose.

The Value of High Expectations in Artistic Settings for People with Disabilities

Parents sought out a variety of disability-centered spaces that communicated high expectations for people with disabilities. This section will explore how art-spaces in particular can cultivate cultural capital and high expectations. Participating in creating and consuming art is associated with higher levels of cultural capital (Chan & Goldthorpe, 2007; Goulding, 2012). While art organizations are subject to courtesy stigma through their association with people with disabilities (Goffman, 1963), they also can challenge this stigma, specifically in rejecting the "art therapy" label and framing themselves as teaching a skilled craft (Maconi, 2020; Maconi 2021).

> *If any other student practices at home more than Savannah, I want to meet them because I don't think there is one. She is such a serious student, she studies her lines, she practices her music, all the time and so that brings her joy. It's serious to her.* ***It's a craft to her…*** *She's dedicated, she's devoted, she loves it. -Faith*

While most of the parents spoke about their children's love of performing, they also spoke of their children's commitment to theater as a craft. Particularly, many students were willing to go to multiple rehearsals for months leading up to their main performance, exhibiting dedication to creating a high-quality performance.

> *[There are] LOTS of rehearsals, but he was fine with that. I think he likes the process. I think he likes going and he never ever doesn't want to go. He's always, "Yes!" .... I think it's the process and then the rehearsals and the socialization that he likes too. -Jeremy*

Participation in the arts was not limited to this particular theater group. Many participants had children who were involved in choirs, dance clubs, and the visual arts as well. Jackie, a woman with Down Syndrome, creates paintings through a disability-centered art program that are available for sale in a gallery on the premises. Jackie has sold multiple paintings, earning her economic capital in addition to the cultural capital gained through honing her painting as a skilled craft.

> *[Jackie] was working at the painting center and [a woman] asked which ones she made, and she made one of a marina… The woman paid $600.00 for the painting…. She bought it for $600.00, she took it to North Carolina, put it in her home there, she has a home here and there… she said it was the focal point of every time somebody comes in. -Lily*

In these art spaces, both performance and visual, people with disabilities were given high expectations from the people around them and succeeded in producing high-quality work, on top of the social capital made through relationships with other participants and their families. In a sense, participating in the arts is both a creator of, and a result of cultural capital.

Access to disability-centered art programs increases access to cultural capital in two ways. Firstly, studying art as a craft, rather than therapy, holds a certain degree of status, both in the art itself and in the financial investment families make when enrolling their family members with disabilities in these programs. Secondly, participating in such programs also widens one's social network, further linking families to other programs and resources.

Discussion

It is widely agreed that inclusion for people with disabilities is the goal but Simplican and colleagues (2015) point out, there is not a single, clear, agreed upon definition for what inclusion is and how inclusion should be implemented. With low expectations being expressed by professionals and sometimes, well-intended others, parents prioritize finding spaces the communicate high expectations for their children. Often, these spaces are disability-centered spaces, ideally designed for and by people with disabilities.

Low expectations did not necessarily come from a place of hatefulness or malice. Often times, low expectations came from a place of good intentions, such as teacher or family members overaccommodating children with disabilities, in a misguided attempt to not put too much pressure on children with disabilities. Yet, good intentions is not enough to erase the impact it may have on the life of the person with disabilities. Since having good intentions does not mean expectations are high, having a space with a clientele or target audience of people with disabilities does not automatically make the space disability-affirming. High expectations are a necessary prerequisite for truly supporting people with disabilities.

Therefore, families seeking out places with high expectations for their family members with disabilities cannot rely on simply choosing any space labeled “for people with disabilities.” In this case, social capital can be incredibly helpful in that parents who are newly seeking out such spaces can use their networks to get advice on what spaces are or are not disability-affirming. It is through this social capital that parents can find programs (artistic or otherwise) that will hold their children to high standards and help them to build social capital.

These spaces are more important than ever in adulthood. Some parents talked about the gap in services and available disability-centered spaces for young adults with disabilities. This is one arena where the power of social capital played an important role. Some of the children whose parents I interviewed had been enrolled in a disability-specific school at some point and parents found out about the theater group I worked with, or other activities, from families they met through their children’s schools. Parents continued to broaden their social capital as they met other families through the activities that they found.

The power and importance of social capital among people with disabilities cannot be overstated. Social capital connected people with disabilities to friends, which is important on an interpersonal level, but it also connected people to activities for gaining cultural capital and sometimes, even paid employment. The role social capital plays in the lives of people with disabilities is still understudied and should be examined more. However, it’s also important to note that in this particular study, the people involved in the theater group and similar activities for the most part, come from families who are able to pay to participate in multiple programs and who are able to provide or arrange transportation. Future research should explore the social networks of people with disabilities who are not able to rely on family members with high levels of cultural capital for assistance in finding and funding participation in disability-centered programs. We may also benefit from studying more publicly funded art programs for people with disabilities. Are the pathways of moving between disability-centered activities similar amongst groups of friends who have disabilities or are there key differences?

This study illuminates the ways that art programs can offer high expectations and avoid reductionist narratives of art as therapeutic and/or “outsider art.” Furthermore, it highlights how art programs (as well as other organizations) can provide a platform for people with disabilities to build social and cultural capital. Just as inclusion is more than simply having marginalized people in the room, social capital is not as simple as simply making friends and knowing others with disabilities. Rather, it involves connecting to, and sometimes creating, resources and using one’s interpersonal connections as a resource.

In terms of identifying and creating disability-affirming spaces, the ability to build social and cultural capital is important as it relates to empowerment. People with disabilities and their families are not the passive recipients of services but rather, active agents with the ability to choose the spaces that meet their needs and even create new spaces. This active component of choice differentiates true inclusion from token inclusion in that people with disabilities. High expectations also show that the participants in these programs are valued as competent human beings rather than as recipients of charity of help. For these reasons, providing spaces where people with disabilities are met with high expectations and opportunities to connect with others can be an antidote, in a way, to the lifelong experiences of low expectations and stigma. Since stigma arises from interactions, rather than from disability itself, providing disability-centered spaces with high expectations de-stigmatizes people with disabilities, since in these interactions, people with disabilities are valued and presumed to be competent.

As social scientists, we also must remember that our work and our participants' lives do not exist in a bubble. As everyone was impacted by the Covid-19 pandemic, people with disabilities and their families had to make major alterations to their daily life. For some participants, difficult choices had to be made regarding which therapies and medical appointments to continue going to, if they could not be done online. Given the circumstances, most of the people who agreed to a follow-up interview expressed some degree of relief that certain activities, such as the theater group, had transitioned to online so that they did not have to make the decision as to whether or not to quit, due to safety reasons. It was a bittersweet thankfulness, as every person reported that their children were happier with the program when it was in-person yet, remaining in the program, had it not transitioned to an online setting, would not have been a safe option.

While some participants mentioned feelings of ambivalence regarding the ability to practice artistic crafts in the online settings, *all* of the participants discussed at length the extent to which their children mourned the loss of being able to see their friends in-person. The very social connections that had brought them to the art spaces to begin with had also moved online as well. Participants did say that their children used phones and the Internet to stay in contact with friends. Similar to the sentiments about their activities moving online, they were both sad that some aspects of the relationships were not as strong in a virtual setting yet, given the circumstances, were thankful that there was an alternative to being disconnected entirely.

Returning to the idea of social and cultural capital, there is an assumption among many groups that online classes is an option. Yet, there are large segments of the population who may not have access to certain technologies reliable Internet connections. While parents *did* discuss difficulties that their children had with participating in classes online, this was mostly related to lack of knowledge about how online platforms worked rather than lack of access to the technology itself.

Given the complicated feelings surrounding participating online, research in the upcoming months should pay attention to how attitudes and behaviors surrounding participation in recreational activities may change for people with disabilities as more people get vaccinated and in-person activities resume. Will these activities resume to being completely in-person or will hybrid or online options become more popular?

Our research and our experiences have shown us that social connections to other people play a vital role in our lives, our happiness, and our opportunities. People with disabilities are able to connect to others and use these connections to resist negative attitudes and expectations, through developing spaces where their talent and hard work is fully recognized and appreciated. True inclusion can only be achieved once mainstream spaces see what people with disabilities can achieve in settings with high expectations.

References

Allen, J., (2014). Inclusive education and the arts. *Cambridge Journal of Education*, 44(4) 511-523.

Bourdieu, P., (1986). The forms of capital. In J.G. Richardson (Ed.) *Handbook of theory and research for sociology of education* (pp. 241-258). New York: Greenwood.

Calderón-Almendros, I., & Calderón-Almendros, R. (2016). ‘I open the coffin and here I am’: Disability as oppression and education as liberation in the construction of personal identity. *Disability & Society, 31*(1) 100-115.

Castagno, A.E., (2014). *Educated in whiteness: Good intentions and diversity in schools*, Minneapolis, MN: University of Minnesota Press.

Chan, D., Sireling, L. (2010). I want to be bipolar…A new phenomenon. *The Psychiatrist, 34* 103-105.

Chandler, E. (2017). Reflections on cripping the arts in Canada. *Art Journal*, 76(3/4) 56-59.

Clark, L.B., (2018). Beyond bias: Cultural capital in anti-discrimination law. *Harvard Civil Rights-Civil Liberties Law Review*, 53(2) 381-444.

Coleman, M.B., & Cramer, E.S. (2015). Creating meaningful art experiences with assistive technology for students with physical, visual, severe, and multiple disabilities. *Art Education*, *68*(2) 6-13.

Coleman, M.B., Cramer, E.S., Park, Y., & Bell, S.M. (2015). Art educators' use of adaptations, assistive technology, and special education supports for students with physical, visual, severe, and multiple disabilities. *Journal of Developmental and Physical Disabilities, 27*(5) 637-660.

Cooley, J., & Fox, A.M. (2014). Disability art, aesthetics, and access: Creating exhibitions in a liberal arts setting. *Disability Studies Quarterly*, *34*(1).

Cramer, E.S., Coleman, M.B., Park, Y., Bell, S.M., & Cole, J. (2015). Art educators' knowledge, attitudes, and experiences working with students who have physical, sensory, severe, or multiple disabilities. *Studies in Art Education*. (in Press).

Egner, J, (2017). "A messy trajectory: From medical sociology to crip theory," in S.E. Green & S.N. Barnartt (Eds.) *Sociology Looking At Disability: What Did We Know and When Did We Know It?* pp.(159-192) United Kingdom, Emerald Group Publishing Limited.

Fox, A. (2015). Invigorating disability aesthetics through art and performance: A report from the bodies of work festival of disability arts and culture 2013. *Journal of Literary & Cultural Disability Studies, 9*(3) 349-355.

Glesne, C., (2016). *Becoming Qualitative Researchers: An Introduction,* 5th Edition Boston: Pearson.

Goffman, E. (1963). *Stigma: Notes on management of spoiled identity.* New York: Simon and Schuster.

Goulding, A., (2012). How can contemporary art contribute towards the development of social and cultural capital for people aged 64 and older. The Gerontologist, *53*(6) 1009-1019.

Green, S.E., (2015). Staying true to their stories: Interviews with parents of children with disabilities. In Berger, R. & Lorenz, L. (Eds.). *Disability and Qualitative Inquiry: Methods for Rethinking an Ableist World.* Surrey (UK): Ashgate.

Green, S.E. (2017). Managing the emotions of reading Goffman: Erving Goffman and Spencer Cahill looking at disability. in S.E. Green & S.N. Barnartt (Eds.) *Sociology Looking At Disability: What Did We Know and When Did We Know It?* pp.(39-56) United Kingdom, Emerald Group Publishing Limited.

Green, S. E. & Bingham, S. C. (2017). I could have so easily been excluded: Exploring narratives of inclusion and exclusion in the lives of professional performers with disabilities. In Scorgie, K. & Sobsie, R. (Eds.) *Working with Families for Inclusive Education: Navigating Identity, Opportunity and Belonging, International Perspectives on Inclusive Education, Volume 10.* Pp 11-29. Bingley (UK): Emerald Group Publishing Limited.

Green, S. E., Barnhill, J., Green, S., Hawkin, D. T., Humphrey, S. and Sanderson, S. (2011). "Creating a village to raise a child: Constructing community in families of children with disabilities. In Carey, A. C. & Scotch, R. K. Disability and Community, Research in Social Science and Disability, Volume 6, Pp 113-133. Bingley (UK): Emerald Group Publishing Limited.

Hall, E., (2013). Making and gifting belonging: Creative arts and people with learning disabilities, *Environment and Planning*, *45*(2) 244-262.

Hall, S.A., (2009). The social inclusion of people with disabilities: A qualitative meta-analysis. *Journal of Ethnographic Qualitative Research*, *3* 162-173.

Ineland, J., (2016). "Hybrid structures and cultural diversity in welfare services for people with intellectual disabilities. The case of inclusive education and disability arts in Sweden." *European Journal of Disability Research 10* 289-300.

Kafer, A., (2013). *Feminist queer crip*, Indiana University Press.

Lenakakis, A., & Koltsida, M. (2017). Disabled and non-disabled actors working in partnership for a theatrical performance: A research on theatrical partnerships as enablers of social and behavioral skills for persons with disabilities. *Research in Drama Education: The Journal of Applied Theatre and Performance, 22*(2) 251-269.

Link, B.G. & J. C. Phelan, (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*, 363-385.

Loesl, S. (2012). The adaptive art specialist: An integral part of a student's access to art. in *The intersection of arts education and Special Education: Exemplary programs and approaches*. pp 47-68. Washington DC: International Organization on Arts and Disability

Maconi, M.L., (2019 online, 2020 in print). "More than therapy: Conformity and resistance in an organizational narrative of disability and the performing arts." Pp.123-136. In Sara E. Green & Donileen R. Loseke (Eds.)*, New Narratives of Disability: Constructions, Clashes, and Controversies. Research in Social Science and Disability, Volume 11.* Bingley (UK): Emerald Group Publishing Limited.

Oliver, M., & Barnes, C. (2012). *The new politics of disablement*. New York, NY: Palgrave Macmillian

Ostrove, J.M., Kornfeld, M., & Ibrahim, M. (2019). Actors against ableism? Qualities of nondisabled allies from the perspective of people with physical disabilities. *Journal of Social Issues, 75*(3) 924-942.

Rousso, H. (2013). *Don't call me inspirational: A disabled feminist talk back*. Philadelphia PA: Temple University Press.

Shaw, C. (2015). We have no need to lock ourselves away: Space, marginality, and negotiations of Deaf identity in Late Soviet Moscow. *Slavic Review*, *74*(1) 57-78.

Simplican, S.C., Leader, G., Kosciulek, J., Leahy, M., (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation," *Research in Developmental Disabilities, 38* 18-29.

Solvang, P. K., (2012). Research paper: From identity politics to dismodernism?: Changes in the social meaning of disability art. *European Journal of Disability Research*, *6*(3) 178-187.

Trainor, A.A., (2008). Using cultural and social capital to improve post-secondary outcomes and expand transitional models for youth with disabilities. *The Journal of Special Education, 42*(3) 148-162.

Trainor, A.A., (2010). Educators' expectations of parent participation: The role of cultural and social capital. *Multiple Voices for Ethnically Diverse Exceptional Learners, 12*(2) 33-50.

Van der Klift E. & Kunc, N. (2019). Segregation versus solidarity: Rethinking the uncritical commitment to inclusion. in K. Scorgie & C. Forlin (Eds.). *Promoting social inclusion: Co-creating environments that foster equity and belongin*g. pp 17-24. Bingley, UK: Emerald Publishing Limited.

Wexler, A.J., & Derby, J. (2015). Arts in institutions: The emergence of (disabled) outsiders. *Studies in Art Education, 56*, 127-141.

White, K., & Mackenzie, L., (2015). Strategies used by older women with intellectual disability to create and maintain their social networks: An exploratory qualitative study. British Journal of Occupational Therapy *78*(10) 630-639.

Young, G.C. (2008). Autonomy of artistic expression for adult learners with disabilities. *International Journal of Art & Design Education, 27*, 116-123.

Zederayko, M.W., & Ward, K. (1999). What to do when students can't hold a pencil. *Art Education*, *52*(4) 18-22.

Chapter 5: Discussion

The purpose of this project was to explore narrative constructions of participation in the arts among people with disabilities in two arts programs that have been specifically designed to enhance inclusion for people with disabilities: Blue Butterfly Production's Theatre eXceptional and Arts4All Florida. I began the study with three research questions, each of which has been addressed in a standalone chapter in this dissertation. This project and the research questions are as much about narratives as about disability or arts programs. Narratives provide a nuanced understanding of social worlds that allow one to examine the influence of culture and how storytellers, both people and organizations, conform to or resist that culture. "Narrative analysis also illuminates additional cultural features of movements that are underplayed or neglected in other approaches" (Davis, 2002: pp.27).

Narratives are one way that shared meanings are co-constructed and communicated (Bergstrand & Jasper, 2018; Davis, 2002; Loseke, 2007; Loseke, 2012). Narratives are powerful in that they are able to *do* things. For example, many social movements and activists groups use narratives to recruit others and communicate their meanings and values (Cabaniss, 2019; Davis, 2002). Davis (2002) points out that "Social movements are dominated by stories and storytelling, and narrative goes to the heart of the very cultural and ideational processes these scholars have been addressing, including frames, rhetoric, interpretations, public discourse, movement culture, and collective identity," (pp.4). Similar to the art programs discussed in this dissertation, social movements require the mobilization of people, funds, and other resources. Narratives are able to inspire groups of people to participate in and/or donate to organizations (Cabaniss, 2019; Davis, 2002; Dunn, 2005; Geiss, 2019).

Academic Narratives of Disability

Though much of the literature on cultural and organizational narratives focuses on social movements, non-profit organizations, or politics, academic models also provide narratives that can make it into the mainstream discourse. Just as people with disabilities are not a monolith, neither is academia. There are numerous theories about disability in various academic disciplines in the natural sciences, social sciences, and humanities. This dissertation focuses on three narratives in particular: Medical Model Narratives, Social Model Narratives, and Crip and Cyborg Narratives. All three have influenced public stories about disability in various ways,

Medical Model: Medical Model narratives focus on disability as a biomedical problem that the medical system should try to "fix." In this narrative, disability is a villain and the person with the disability is its victim. There are two ways that this narrative ends; either medical providers are able to cure the disability, thus making the providers the hero, or there is no hero and the disability is an ongoing tragedy. This narrative has dominated scholarly and public understandings of disability and still predominates in the health and natural sciences and in mainstream social sciences as well. Disability studies was established as an academic discipline to challenge the dominance of this narrative (Oliver & Barnes, 2012).

Social Model: Social Model narratives make a distinction between impairment, related to the diagnosis, and disability, by which people are disadvantaged by inaccessible environments and negative attitudes. In this narrative, the diagnosis/impairment is not the villain. Instead, the villain is inaccessibility. Depending on the context, the villain could be people who hold negative attitudes about disability or those who do not design accessible environments or policies. However, as discussed in Chapter 2, it is easier to persuade others if you don’t vilify them, as no one likes to think of themselves as the villain. Therefore, many organizations that use this narrative draw on the abstract concepts as villains rather than people as villains. In this narrative, people with disabilities may take on a survivor or warrior role, where they have been wronged by the villain, but rather than passively accepting this, they fight back and work as heroes to educate the public and influence policy to increase accessibility and change negative attitudes (Dunn, 2005). This narrative is often used by social movement organizations, in addition to academics and the goal is nearly always full inclusion and integration (Oliver & Barnes, 2012).

Crip and Cyborg Perspectives: Crip and Cyborg understandings of disability also prioritize increasing accessibility. However, this narrative does not make the distinction between the body and disability in the way that the Social Model does. Rather, Crip and Cyborg understandings challenge the idea of “normality” itself and reject the binary categories of disabled/not disabled. This understanding values universal design and maintains that having supports available could be helpful to everyone, with or without disabilities. At the same time though, this narrative recognizes that people with shared experiences of discrimination *and* disability may seek out disability-centered spaces rather than preferring mainstream inclusion at all times. Furthermore, disability is seen as a source of pride and an integral part of one’s identity. In this narrative, people may acknowledge some difficulties associated with their disability but disability is not the villain. Rather, the villain is binary thinking and the idea that there is a “normal” state of being which, ironically, no one can ever truly attain. This narrative also allows for the warrior/survivor character for people with disabilities. This narrative is also well-suited for organizations who wish to portray their role in relation to people with disabilities as a side kick rather than a hero.

Unlike the social model, providing disability-centered spaces is not a violation of the narrative's end goal, which is empowerment rather than inclusion, though these concepts overlap significantly (Kafer 2013).

Results reported in this dissertation suggest that life is much too complicated to fit neatly into one of these three narratives of disability. While Crip and Cyborg perspectives offer a view of disability that includes some elements of the other two, stories about lived experiences are likely to fall outside of even the more complex picture of disability these perspectives paint. In the next section, I summarize the findings of the three empirical chapters – drawing attention to the complexity of the stories told about disability and art by individuals and organizations.

Summary of the Findings

Chapter 2 addressed the question "How do disability-based arts organizations that promote inclusion frame their identities in publicly broadcast narratives?" through a narrative analysis of publicly available descriptions of Blue Butterfly Productions. In this chapter we see that organizations that serve people with disabilities must work hard to explain their importance and need to exist while at the same time, empowering and highlighting the abilities of their clients. There is an easy-to-adapt, cultural narrative that non-profit organizations in a sense are heroes that can "rescue" people with disabilities from their disability. Yet, this narrative is extremely objectifying and may be off-putting to potential clients. It also presumes that having a disability is an inherently negative experience with a low quality of life. Therefore, Blue Butterfly Productions, with their expressed commitment to empowering and valuing their clients frame stigma and misconceptions, rather than disability, as the villain. Furthermore, Blue Butterfly Productions also casts themselves as being more of a sidekick or support system, allowing their clients with disabilities to be their own heroes. This takes extra effort, in that it actively challenges the well-known cultural narrative of disability as tragedy. However, this extra effort proves to be worth it, in that it articulates the need for its own existence and funding while at the same time, celebrating their clients with disabilities and attracting participants interested in challenging traditional narratives to disability.

Chapter 3 addressed the question "How do adult artists who advertise their work on organizational websites of disability-based arts programs that promote inclusion describe themselves and their art?" by analyzing the descriptions artists post of themselves and their work on the Arts4All website, paying particular attention to the relationship between the goals of this ally organization and the stories artists tell about themselves its members. Findings suggest that disability is a varied experience and individuals may conform to or reject traditional cultural narratives about the relationship between disability and art. Some participants may even do both. Some artists subscribed to traditional cultural narratives of "overcoming" disability through arts. Artists who use this narrative are not wrong for doing so and may even find it empowering. However, other artists challenged that narrative, either by drawing on the Social Model of disability and telling stories of using art as an adaptation to an inaccessible society or even stating that their disability inspires their art and makes them an even better artist. As for the organization, whose platform these artists are using to sell their art, the organization used both stories of art helping people with disabilities to "overcome" some aspect of their disabilities *and* stories of people with disabilities using art to adapt to their surroundings. It's also worth noting that when looking through the reports over time, older reports and promotional materials included more stories of "overcoming" disability while newer, more recently published materials highlighted more stories of adaptation. This to some extent mirrors the shift in the organization's recent change in affiliation and indicates a move towards a more disability-positive organizational narrative.

In Chapter 4, I addressed two questions: 1. “How do parents of participants in disability-based arts programs that promote inclusion view the work of the organization and its role in their children’s lives?”; and 2. “What facilitators and/or barriers do parents of program participants perceive in relation to the opportunities their children have had to participate in the arts at various points in the family life course?” In answer to the first questions, findings suggest that disability-based art programs fulfill multiple role in their children's lives. In keeping with the other chapters of this dissertation, parents appreciated disability-based art programs that set high expectations for their children and provided appropriate supports to trained them as competent artists who are learning and perfecting their craft. This art program, along with other disability-centered activities they enrolled their family members in was a nice reprieve from the dual problem of low expectations and high expectations without appropriate supports that their children constantly encountered in everyday life.

This art program fulfilled other roles though, not mentioned in previous chapters. This art program, as well as other disability-based activities their children participated in, allowed families to build and use social and cultural capital. Many parents reported that once they found one disability-positive space, they quickly made friends with the parents and family members of the other participants in the program. This, in turn, allowed them to learn about other spaces that offered high expectations with appropriate supports for people with disabilities. Furthermore, the disability-based theater group arguably came to exist through these networks of social and cultural capital, in that the founders, one of whom was also a parent who participated in the study, were able to find some of their earliest members through disability-based sports teams and activities that their child participated in. Thus, not only did social capital through these programs help parents find spaces with high expectations for people with disabilities, but social capital also helped to create new spaces and resources for people with disabilities.

Of course, these programs do not exist in a cultural vacuum. There were many barriers to creating and finding these activities. Many parents did not have experience with disability prior to their children being born. Once their children were born, doctors, friends and family members often immediately treated the birth of a child with disabilities as a tragedy and emphasized all of the things their children would supposedly never accomplish. Parents had to actively fight these low expectations, that they continued to encounter through schools, and even some spaces that claimed to primarily serve people with disabilities. Additionally, because of these low expectations, it can be difficult to start new activities for people with disabilities and gain the funding and capital needed. Still, these parents did work hard and were able to encounter some facilitators as well, to finding disability-positive spaces. The social capital and relationships they made with other families with people with disabilities was an important facilitator in finding out about other resources and spaces with high expectations and the supports needed to meet them. It is worth noting that generally, many of these families also had access to some financial resources as well.

Broader Implications: Revisiting Narratives of Disability

In addition to answering three specific research questions, taken together, the chapters in this dissertation reveal the tension between medical and social narratives of disability in the public sphere. While scholars often categorize narratives into boxes, everyday experiences of people and organizations are likely to be messier and more complex. For example, there is sometimes a gap between organizational and personal narratives. Organizational narratives may obscure some of the real-life complexities of participation in the organization in order to better sell a familiar and less complex story to potential donors (Geiss, 2019). Even organizations, though, are as complex, dynamic, and fluid as the people who participate in them. Therefore, organizations also may draw on different narratives, at different times, for different purposes. These complexities became much more apparent in this project than I initially anticipated.

In this study, individuals and organizations often drew on multiple narratives at different, or sometimes at the same, time. This complexity is found in other studies that have tried to identify which narratives parents use to advocate for their children (Mango, Davis, & Goar, 2017). It was also interesting to find that parents and organizations drew on established narratives but used them for different purposes than the creators of some of these narratives intended. This was most evident in the ways that parents and organizations drew on Social Model understandings to explain why they chose or created segregated settings, rather than as a means to push for full inclusion. Furthermore, Medical Model narratives, while focused on the diagnosis, were not associating disability with tragedy or shame, nor was the diagnosis eclipsing all other aspects of the person. Instead, medical model narratives were sometimes used as a way to communicate needs for support, which can actually help attain the ends (i.e.-supports/accommodations) that the Social Model claims to seek.

Even the individual narratives themselves were difficult to categorize. For example, when employees or board members tell stories about their time with the organization, is this a personal narrative, or an organizational narrative? In truth, it is both of these at once, even when we have to make a decision and focus on one of these categories for the sake of analysis. Furthermore, "narratives of adaptation," as discussed in Chapter 3, could arguably be about adapting to inaccessible environments *and* adapting to one's disability itself. Thus, in addition to my findings from each chapter, such as how organizations can empower people with disabilities while still storying the need for themselves using narratives, the larger overarching theme through all of these is the complexity of narratives when enacted in everyday life. People, organizations, and culture, are too fluid to fit into neat, separate boxes.

The individual and organizational narratives in this project were more complicated than either the medical or social models of disability would predict. Clients these programs are heterogeneous and have different stories to tell Some fell in perfectly with the organizational narrative of training artists. Other participants and families did not necessarily conceptualize themselves as artists, or at least, not in the sense of being a master status, but still gained numerous benefits from art beyond therapeutic interventions. Further, citing therapeutic goals as a motivation for participating in art programs did not mean that participants didn't also value becoming competent artists. People were able to find art programs to be both fulfilling in terms of learning a skilled craft *and* therapeutic at the same time. Perhaps most interesting of all is that many of the parents interviewed for Chapter 4 drew from multiple narratives at the same time. In the following sections, I explore some specific themes related to complexity that cut across the findings of individual chapters.

Too High or Too Low: Managing Expectations for People with Disabilities

Many disability scholars have documented the problem of setting low expectations for people with disabilities. My findings in this project offer some important nuance to this issue. The problem is not low expectations alone but rather, the binary logic that people must either meet the standards set for able-bodied participants, in the exact same way as able-bodied participants without any help, or they do not belong in the space and will never be able to achieve anything in that realm. Many parents reported that their children *did* require extra supports or time to meet certain benchmarks that their non-disabled peers were meeting but that doesn’t mean they couldn’t meet them. When people with disabilities fail to meet expectations in certain settings, there needs to be thought as to what can be done to help the person meet expectations rather than taking this as a sign that they do not belong in the space.

In my time working with the inclusive theater group, I had the privilege of witnessing first-hand how instances when participants struggled with aspects of the show were able to become opportunities for support and creativity. For example, some participants had difficulties singing or reciting lines for reasons related to their disabilities. Very simple adjustments, such as the use of voice synthesizer or giving some students dance solos rather than singing solos, depending on their needs and/or interests, allowed students who may have been excluded in other venues to participate fully and excel at what they were good at and able to do. Approaching inclusion in this way is beneficial, not just for people with disabilities but for everyone. Having different abilities that fall along a range is human, despite the binary disabled/not disabled distinctions so often used in settings that include people with disabilities.

Inclusion vs. Disability-Centered Spaces

The creators of the Social Model as well as many disability-rights social movements and activist organizations envisioned an end goal of total inclusion and integration (Oliver & Barnes, 2012). These narratives were created to oppose disability-segregated spaces. However, Van der Klift and Kunc (2019) point out that “an uncritical commitment to ‘absolute’ inclusion may undermine the deeper goal of the emancipation of disabled people,” (pp.17). Furthermore, many parents and the disability-centered organizations drew on Social Model-type narratives and argument to explain why they *did* seek out disability-centered, segregated spaces.

Often times, disability-centered spaces prioritized offering supports and reasonable accommodation. Despite the legal mandate of inclusion, many settings, such as schools and activities, did not offer appropriate supports. As discussed throughout this dissertation, the mere presence of a person with disabilities in a room is not enough to say there is “inclusion” yet, too many organizations felt they had satisfied their legal obligation at this point. Furthermore, some parents even recounted stories in which schools threatened to remove accommodations and supports, arguing that it is “unfair” to the other students or that if they student cannot succeed without supports, they shouldn’t be in the mainstream classroom.

Therefore, when mainstream settings refused to offer reasonable accommodations, many families sought out spaces that *did* offer supports. Social Model narratives focus on how people are disabled by inaccessible spaces, lack of assistive technology or supports, and negative attitudes or stereotypes. The end goal of this academic narrative and social movements that have used this narrative is that since these are all things that can be changed, recognizing these instances of inaccessibility will lead to creating accessible spaces, offering support, and educating others to change attitudes. Yet, this end goal is not what happened in many people’s lived realities. Instead, this is where the Social Model and Crip/Cyborg narratives of disability diverge. Many parents pointed to the inaccessible spaces that lacked proper supports and were led by people with negative attitudes about disability to explain why they *left* such settings in favor of spaces that were more accessible and disability-affirming.

Van der Klift and Kunc (2019) outline what makes a space that appears segregated disability-affirming vs. oppressive. They argue that even spaces or policies created by well-intended people can be oppressive if it is created with low expectations and paternalistic benevolence rather than to celebrate people with disabilities as competent people who may need certain supports. Unfortunately, too many mainstream organizations are run by well-intentioned professionals who ultimately hold stigmatizing views and low expectations for people with disabilities.

Therefore, finding segregated, but disability-affirming spaces where they were able to connect to other people with disabilities and their families offered more opportunities and resources than remaining in mainstream settings. These were the settings where accessibility is prioritized and disability is celebrated. Furthermore, unlike many mainstream settings where the goal often seemed to be for everyone to meet the same (usually designed for able-body/minded) benchmarks, these disability-centered spaces celebrate the diversity in human variation and make tailored, individualized adjustments accordingly.

Disability-centered spaces also deviate from the Social Model in that they do not as strictly make a separation between bodily impairments and disability. While the distinction between impairment and inaccessible environments and negative attitudes can be a useful tool for social movements and policy in terms of drawing attention to how to increase accessibility, this strict separation does not reflect how many people with disabilities describe themselves or their experiences.

People’s bodies, minds, and diagnosis impacted how they moved through and experienced the world. For many, it did impact how they related to art and how they chose to participate in these programs. Many people were very proud of themselves and their identities and did not want to make any separation between their diagnosis and their sense of self. Participants and their families were proud of what they had accomplished, as people with disabilities. Some disabilities may have impacted how participants in the programs sing, move, dance, paint, or any other aspect of how they participated in art programs. Rather than seeking to perform every task as similarly as possible to way in which a presumably able-bodied artist would, disability-centered art programs created ways for participants to put their own unique stamp on their art, sometimes in ways that included their disability.

Disability was not something to be hidden, obscured or ignored but rather included, accommodated, and celebrated. With the inclusive theater group that I worked with, accommodations were often worked into the scenes if needed. Assistants or aides could be incorporated into scenes with actors or actresses who needed them. Performers with memory difficulties could be near the curtain or an assistant who could offer cues when needed. Performers could also use dance, pantomiming, or us a DynaVox if vocalizing or singing was difficult. There were many ways for disability pride to be incorporated into the art created in disability-centered art programs. For example, sign language was used to accompany one of the songs used by *all* of the inclusive theatre group. In the visual arts, both low tech and high tech options were used by artists, some of whom used videos to proudly show how they use the technologies and how their disability and the use of these technologies influences their art.

For some, these assistive technologies acted as an extension of the self. This furthers Kafer's (2013) concept of the Cyborg. When one artist, for example, lost some of his mobility, including his arms which he used for painting, he began using assistive technology that allows him to create digital art using one hand. His website, as registered with the Artist Registry, is called Single-Handed Studio, as this newer way of creating art is a part of him and his work. Assistive technology is not limited to technology per se but also guide dogs and human assistants. Furthermore, it highlights the embodied aspect of disability and that a separation between the body, diagnosis, and identity, does not reflect the lived experiences of people with disabilities, nor is that separation something we desire.

Art as Activism

Some artists with disabilities argue that disability-centered art is a form of activism and a type of social movement (Cooley & Fox, 2014; Fox, 2015; Fraser, 2013; Solvang, 2012). Solvang (2012) asserts that, “Art has gained an important position in the identity politics of the disability movement,” (pp.178). The disability-art world has multiple factions, with some competing goals. While some seek to eventually blend in to the mainstream entirely to the extent that the disability-status of the artist does not matter, others prefer disability-centered spaces (Fraser 2013; Solvang, 2012). There is even some disagreement regarding whether the term “disability art” should apply to any art made by artists with disabilities, or only art that has an activist goal or purpose (Cooley & Fox, 2014; Fox, 2015; Fraser, 2013; Solvang, 2012).

In keeping with our findings of disability arts being heterogeneous in terms of goals and needs, Solvang (2012) posed the question: “Do [disabled artists] see their art production as a contribution to disability awareness, or as an autonomous aesthetic practice?” (pp. 180) only to find a range of responses, some of which were diametrically opposed to each other, particularly when it came to the topic of whether or not integration into mainstream spaces was the goal. Fraser (2013), an artist with disabilities found segregated spaces to be more disability affirming, in part due to how many people he encountered in mainstream settings who believed that “most disabled artists were just considered to be doing their own therapy rather than it being seen as valid art” (pp.245). Still, even with the varied goals and needs, disability-centered art spaces remain as places for building a positive collective identity around disability (Solvang, 2012).

Given this close link between disability-art and activism, it is unsurprising that many of the organizational narratives that disability-centered art programs use significantly overlap with those of social movement organizations. “If what a story communicates about the world is to be accepted, it must affirm not negate the self-conceptions that audience members hold of themselves," (Davis, 2002; pp.18) though, this is increasingly difficult in a heterogeneous world. Still, Fraser (2013) who views his art as a form of activism has the goal that, "Although at least 60 per cent of those audiences were no doubt left thinking exactly the same about disability as they had done before watching it, I would hope that the other 40 per cent were in some way changed," (pp. 247).

Heroes vs. Sidekicks in Organizational Narratives

"Public narratives of human services are organizationally necessary in defining clients, communicating services provided, and generating public support," (Geiss, 2019: pp539). Art programs for people with disabilities are constantly using narratives for these purposes. It's important to remember that narratives aren't just created. Narratives are a type of interaction. Members of an organization create narratives to do different things and serve different purposes. Equally, if not more, important though is that narratives are interpreted by the people that these narratives reach. In an increasingly heterogeneous world, different members of the public may interpret the same narrative in different ways (Fisher 2003).

In their work on Character Theory, Bergstrand and Jasper (2018) referred an "essential triad" of narratives in that complete narratives typically require, a villain, victim, and hero. Without these three characters, the story is incomplete. Arguably, the "victim" is one of the most important characters as, without a supposed victim or harm, there is no "problem" at all (Bergstrand and Jasper 2018; Dunn, 2005; Geiss, 2019). Creating an image of a victim can be difficult though, in that victims must be, to some extent, too helpless to save themselves, hence the need for a hero, and this helplessness is typically negatively evaluated by society (Bergstrand and Jasper 2018; Dunn, 2005). In fact, Bergstrand and Jasper 2018 found powerlessness to be a stronger indicator of the victim category than “goodness” though, if victims are not “good,” the public may not categorize them as worthy of saving.

Even if evaluated as “good,” few people desire to be evaluated as “helpless.” Solvang (2012) even found that some artists with disabilities preferred villain characters over victims, such as “the Tiny Tim of Dickens,” because villains, such as Richard III, were at least “a strong person” (pp.182). Many clients may try to reclaim their agency yet, doing so, and or challenging existing narratives may lead others to categorize the person as being able to help themselves and therefore, there is no need for services, as they may not even be a “problem.” In her work on battered women, Dunn (2005) asserts that battered women often confounded advocates with the “heterogeneity and complexity, their lived reality may confound simplistic attempts to neatly ascertain their victim status” (pp16). This heterogeneity of clients and their narratives impacts organizations that work with people with disability as well. This put disability-centered art programs in a difficult position. If people with disabilities aren’t victims, is there even a problem for them to solve? For what reason does the organization exist?

The organizations in this dissertation were able to use narratives and identify a victim in the society that loses out on the art that artists with disability can create. Still, there are two more essential characters in the story. “Villains focus blame, provide a clear target for action, intensify negative emotions, and solidify group identities. A correctly cast victim-good, innocent, and in need of protection- can also motivate action and encourage recruitment to a cause; it can help to increase perceptions that a particular problem is an injustice worth combatting. Heroes form a rallying point, increase agreement among members and boost commitment to a cause,” (Bergstrand and Jasper 2018: pp 229). Obviously though, the organization cannot be the villain. The organization may seek to be a hero. Afterall, a hero is both positively evaluated and is considered to be powerful (Bergstrand and Jasper 2018). Yet, this begs the question as to where people with disabilities fit into this narrative.

Characters also have inherent moral designations, which can be good or bad (Bergstrand and Jasper 2018; Dunn, 2005; Geiss, 2019). Therefore, it is the organization's goal to find good/moral characters for both the organization and the clients. Bergstrand and Jasper (2018) also addressed the role of side kick, a role that was evaluated as both "good" and "powerful," albeit, a little less powerful than the hero. While it may then be tempting to story the organization as a hero and clients as sidekicks, narrating the clients as heroes is more empowering and attractive to clients and thus, will attract more clients and funding to the organization. Furthermore, if the victim is a society that has lost out on the art that could be created by artists with disabilities, it makes more narrative sense for the artists themselves to be the heroes. Still, having a sidekick does not take power away from the hero and allows both characters to be positively evaluated, thus making it the perfect role for the organization.

Given the courtesy stigma associated with art produced by people with disabilities, some artists with disabilities may carefully consider whether to disclose the fact that they have a disability or not. On one hand, disclosure may make some sites for promoting one's art, such as Arts4All Florida's artist registry, available. On the other hand, once the narrative is on the Internet, it is difficult to erase, meaning disclosure may cause some potential art buyers to reject the artist's work entirely due to the disclosure rather than their art. This decision may fall into a category Trinch (2007) refers to as "face threatening," by which the image or identity a person wants to protect their reputation or the public image that they have presented to others.

Dominant cultural and organizational narratives have also changed overtime as new information and theories are constructed and disseminated. In recent years, there ahs also been a shift in more pluralistic narratives. People are made up of multiple identities but sometimes, struggle when organizations or intuitions focus on one identity exclusively (Trinch, 2007). Similar to Dunn's (2005) finding that battered women drew from both victim and survivor identities, Chapter 3 of this dissertation showed that artists with disabilities, and the organizations that serve them, may also draw from multiple narratives of overcoming disability, adapting to disability, and even finding creativity and inspiration from one's disability.

The same can be said about the creation of disability-centered spaces and programs. The creation and maintenance of such programs is not a single event but rather, an ongoing process through which policies are constantly enacted, reevaluated, and changed as the programs' creators constantly interact with clients, employees, donors, and the public at large (Fisher, 2003).

"No matter how efficient a programme might be, if it fails to confront the basic value frames that shape our understandings of the problem, it is bound to be rejected" (Fisher, 2003: pp12).

Implications for Policy and Practice

This project offers potential blueprints for other art programs seeking to serve people with disabilities and can offer narratives that empower and don't objectify their clients with disabilities. Using narratives that support, rather than "rescue" people with disabilities benefits both the clients and the organizations. Clients do not want to be objectified and therefore, are drawn to organizations that empower them yet, the supporting role that these organizations can offer still justifies the organization's reason to exist and continue receiving funding.

While I strive to articulate the ways in which these art programs offer benefits beyond what is conceptualized as therapy, I would be remiss if I did not at least acknowledge some of the benefits that might, at the very least, overlap with therapeutic goals. Many families did talk about aspects, such as personal growth, confidence, and even improved communication skills that seemed to accompany participation in disability-centered arts. My goal is not to denigrate therapy, nor do I wish to ignore any therapeutic effects. Art therapy can undoubtedly be beneficial for people, with or without disabilities. However, when this is the only lens through which the relationship between art and people with disabilities is examined, we not only miss the range of benefits and relationships that art and disability can foster, but we also infantilize people with disabilities by limiting them to a lens of people in need of fixing, rather than as competent artists or consumers of art. Nevertheless, it is also important to avoid reductionist narratives about art and disability, where people with disabilities are artistic savants, in that this excludes people with disabilities who aren't instant savants, yet who may be able to master artistic skills with training and practice. The artistic savant narrative also runs the risk of erasing the need for art-training programs, since if the skill is in-born and from the disability alone, there is not need for training. Thus, recognizing people with disabilities as being not only able to create high-quality art, but also as capable of learning, practicing and perfecting a craft honors both the desires and capabilities of people with disabilities and the need and usefulness of art-based disability-centered organizations.

The findings also, in some ways, break down the dichotomy of art as therapeutic and/or for fun and art as a highbrow master identity as an artist, since I found that reasons for participating in these programs fell along a range of varying degrees of commitment to mastering the craft. Furthermore, participants often drew from multiple available narratives about the role that art and the art-based organizations played in their family members' lives. Many people who are dedicated to perfecting their craft also value the space as a place to have fun and connect with friends. Trying to force the space to be one or the other strips it of its nuance and misses the array of rich benefits that these art-spaces can offer.

Thus, even though I stress that this project is not about art therapy, that does not mean that these findings can't apply to therapeutic spaces. Recognizing how art and accommodations can be used to celebrate disability, not simply cope with certain aspects of it, can have a positive impact on art therapy patients and may be beneficial for therapists as well. Furthermore, if an art therapy patient excels at art, this interest could be further explored through other non-therapeutic disability-centered art programs. Art therapists could be familiar with such organizations in the area and suggest these to patients who might enjoy pursuing the arts outside of therapy. This can be a story both/and rather than an either/or situation.

Although this dissertation was focused on art programs, every interview conducted for Chapter 4 had some discussion of difficulties with the K-12 school system. While it is easy to criticize, it is important to remember that most teachers and administers likely had good intentions and simply lacked the training of how to more fully include students with disabilities. *Arts4All Florida* includes training for art teachers in their mission statement so that art teachers become more equipped to fully include students with disabilities. Some of this training could be beneficial for homeroom teachers as well, as many of the adjustments made are more about offering supports rather than being art-specific. For example, the same tools that make it easier for a student with disabilities to hold a marker to draw many also make it easier for the student to use a pencil to write. Art can be a way for people to express themselves and may therefore, help students who have difficulty communicating to express themselves non-verbally, even if the class in question is not an art class.

These findings may also apply to other disability-centered organizations beyond the arts. While more data would be needed to make this claim, it is worth noting that many interview participants indicated that their children also participated in adaptive sports and offered similar narratives about the role those sports played in their lives. While there are likely some differences, it is very possible that framing adaptive sports as the side kick/supporting character in the lives of athletes with disabilities can help to empower and support athletes who desire to train their way up to a skilled professional level.

This project enhances our understanding of disability and art, both within and beyond these organizations. Art can be a fulfilling hobby to people with disabilities, but both of these organizations offer the resources for people with disabilities to pursue an artist identity and career in the arts if they so choose. Moreover, these organizations offer other benefits as well, such as building social capital and increasing access to other disability-centered spaces. Therefore, while these programs sought to, and succeeded in, training people with disabilities to participate in art as a skilled craft, they also offered a range of other benefits that meet the heterogeneous needs of the population that they serve. The art programs in this study were able to do so by offering a space and training, rather than mandating a goal, to empower artists with disabilities to decide what art means to them, and supporting artists with disabilities to meet their own goals and to affirm their own identity and connection to art.

Even more importantly though, it is a mistake to examine what art can offer to people with disabilities without also exploring what people with disabilities can offer the art world. Many participants were very passionate about their craft, with some being heavily involved in multiple art-based programs for people with disabilities. At least one participant even sold some of her artwork for hundreds of dollars, showing that her work was high quality enough to be appreciated and valued by others. Furthermore, the inclusive theater group for people with disabilities put on full-length, professional productions that regularly sold out during its 4-day run time. People with disabilities were not passively accepting the perks of participating in art but were active artists who put hours and hours of dedicated work to produce high quality art and/or performances.

Limitations and Suggestions for Future Research

This study is not without limitations. Ultimately, this is a case study of two Florida-based disability-centered art programs. More research must be done to determine the extent to which my findings apply to disability-art programs in other regions. Furthermore, while many of the parents I interviewed had children who also participated in the visual arts, all but two of the parents I interviewed had children who were participating in a theatre group for people with disabilities, and these two parents were married to each other and shared a child. It could be useful to interview people with disabilities who participate in only the visual arts or in other performing art spaces, such as dance.

Furthermore, I interviewed parents of participants in a disability-centered theater program and relied on written autobiographies of disabled artists. While the parent interviews gave unique insights, including narratives about stigma and courtesy stigma experienced when their child was young, I was not able to interview actors' first-hand accounts of disabled artists for this project.

These limitations offer up multiple exciting paths for future research projects. First and foremost, it would be useful to see how other similar organizations in other states and regions narrate themselves, art, and their relationship to people with disabilities. This can help to understand how generalizability of these findings but it can also uncover regional differences in how art and disability are discussed.

Furthermore, many of the participants in these art groups were also involved in adaptive sports. This topic came up a lot, particularly in terms of exploring social capital. A project that starts recruitment with adaptive sports teams and focuses on the role that sports can play in the lives of people with disabilities could help us to better understand how families of people with disabilities create and use social capital in other disability-centered settings. The extent to which these findings are similar or differ from findings regarding social capital in the art world can offer further insight as to how people with disabilities and their families use social capital in general. This may spill over into other arenas as well, including schooling, employment, and other activities.

Future research should also explore the perspectives of other stakeholders including participants themselves, staff members and board members of the disability-centered organizations. I was able to get a glimpse into staff and board members, as some of the parents that I spoke with are on the board and one parent is one of the founders. However, it would be exciting to get an even more complete picture with other members as well as teachers, set designers, and the actors themselves.

Some of my interviews were conducted after the Covid-19 pandemic began. I had the unique opportunity to re-interview some participants who had already been interviewed in 2019. Although I have some preliminary findings about how the pandemic impacted the experience of participating in disability-centered art programs, I would love to opportunity to interview more people to create a more robust article on this topic. Some preliminary findings include the complicated tension between gratefulness that the program continued to meet in an online platform rather than stopping entirely, and lamentations that things “weren’t the same.” This makes sense when you consider that much of the social capital and camaraderie among participants and their parents was built in the seemingly inconsequential conversations that happen during pick-up and drop-off when participants could discuss non-theater related topics. Still, parents also expressed relief that the program did *not* continue to meet in person, due to the health concerns surrounding Covid-19. A few participants did drop out due to dissatisfaction with the online environment. This brings me to two specific research questions that have come out of the pandemic. (1) How did families cope with and adjust to changes in modes of participation in art programs during the pandemic? And (2) As things begin to re-open and meet in person again, what is the transition back to in-person classes like?

Additionally, I have recently accepted a job at Moffitt Cancer Center as a researcher. I have already been privileged to join onto some projects exploring the lived experience of going through cancer treatment, particularly for people of marginalized identities. However, as I get my footing there, I would love to pursue a project with Moffitt's art center. The center has an art program for people undergoing cancer treatment. Pursuing a project to assess what the art center means for cancer patients and the role that art plays in participants' lives would be a wonderful future project that I am interested in pursuing.

In summary, this dissertation points to the need for future research into the complex relationship between disability, art, and the organizations that serve disabled artists. Results suggest that people with disabilities engage with the arts for many complex reasons, and simplistic assumptions about those reasons can demean the talent and artistic contributions of disabled artists, and mask other benefits that participation in the arts. Just as art can take many unique forms, people with disabilities relate to art in a variety of ways and the stories they tell reflect this complexity. The use of multiple narratives by people and organizations points to a need for research to develop more complex understandings of disability, art, and the relationship between the two in order to create meaningful social change for disabled people and their families, and to enhance artistic experiences for the communities in which they live and create.

References

Bergstrand, Kelly and James M. Jasper. (2018). Villains, victims, and heroes in character theory and affect control theory. *Social Psychology Quarterly, 81*:228-247.

Cabaniss, Emily R. (2019). Shifting the power: Youth activist' narrative reframing of the immigrant rights movement. *Sociological Inquiry, 89*:482-507

Cooley, J., & Fox, A.M., (2014). Disability art, aesthetics, and access: Creating exhibitions in a liberal arts setting. *Disability Studies Quarterly, 34*(1)

Davis, Joseph E. (2002). Narrative and social movements: The power of stories. In *Stories of Change: Narrative and Social Movements*, edited by Joseph E. Davis, 3-30. Albany, NY: State University of New York Press.

Dunn, Jennifer L. (2005). "Victims' and 'survivors": Emerging vocabularies of motive for 'women who Stay. *Sociological Inquiry 75*:1-30.

Fisher, Frank. (2003). *Reframing public policy: Discursive politics and deliberative practices.* New York: Oxford University Press.

Fox, A., (2015) Invigorating disability aesthetics through art and performance: A report from the bodies of work festival of disability arts and culture 2013. *Journal of Literary & Cultural Disability Studies* 9(3) 349-355

Fraser, M., (2013) Cripping it up. *Journal of Visual Art Practice*, 12(3) 245-248

Geiss, C., (2019). Connecting practical doings to cultural meanings: Exploring the work of moral mediators in human service organizations. *Symbolic Interaction* 42:539-563.

Kafer, A., (2013) *Feminist Queer Crip*, Indiana University Press

Loseke, D.R., (2007). The study of identity as cultural institutional, organizational, and personal narratives: Theoretical and empirical integrations. *The Sociological Quarterly*, 48 661-688

Loseke, D.R. (2012). The empirical analysis of formula stories. In J. Holstein & J. Gubrium (Eds.), *Varieties of narrative analysis* (pp.251-271) Los Angeles, CA: SAGE Publications

Manago, B., Davis, J.L. Goar, C., (2017) Discourse in action: Parents' use of medical and social models to resist disability stigma. *Social Sciences & Medicine*, 184 169-177

Oliver, M., & Barnes, C., (2012) *The new politics of disablement*, New York, NY: Palgrave Macmillian

Solvang, Per Koren, (2012) Research paper: From identity politics to dismodernism? Changes in the social meaning of disability art. *European Journal of Disability Research*, 6(3) 178-187

Trinch, Shonna. 2007. “Deconstructing the ‘stakes’ in high stakes gatekeeping interviews: Battered women and narration. *Journal of Pragmatics* 39:1895-1918.

Van der Klift, E., & Kunc, N. (2019) Segregation versus solidarity: Rethinking the uncritical commitment to inclusion. In *Promoting Social Inclusion: Co-creating Environments that Foster Equity and Belonging* (Kate Scorgie and Chris Forlin, Eds) *International Perspectives on Inclusive Education, Volume 13,* pp. 17-24. Bingley (UK): Emerald Group Publishing Limited.

Appendix A: Permission to Use Published Materials

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Appendix B: IRB Letter of Exempt Status

My interview data collected for Chapter 4 was from a larger project on parenting people with disabilities, headed by Dr. Sara E. Green. The Institutional Review Board (IRB) approved the project for Exempt Status on 7/9/2019.

UNIVERSITY OF
SOUTH FLORIDA

RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-7091

7/9/2019

Sara Green, Ph.D.
Sociology
4202 E. Fowler Ave., CPR 107
Tampa, FL 33620

RE: **Expedited Study Determined Exempt at Continuing Review**
IRB#: CR9_105141
Title: Exploring the Social Experience of Fathers and Mothers of Children with Disabilities

Study Approval Period: 7/5/2019

Dear Dr. Green:

On 7/5/2019, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within including those outlined below. Please note that this protocol is now approved under the 2018 Common Rule (45 CFR 46) and is **now exempt**. Thus, **Continuing Review is no longer required** and your application will be closed per USF HRPP policy.

The IRB determined that your study qualified for exempt review based on criteria for exemption in the federal regulations as outlined by 45 CFR 46.104(d):

(2) Research that only includes interactions involving educational tests(cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:(i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 45 CFR 46.111(a)(7).

As the principal investigator for this study, it is your responsibility to ensure that this research is conducted as outlined in your application and consistent with the ethical principles outlined in the Belmont Report and with USF HRPP policies and procedures.

Please note, as per USF HRPP policy, once the exempt determination is made, the application is closed in ARC. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant an Amendment or new application.

We appreciate your dedication to the ethical conduct of human subjects research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

Kristen Salomon, Ph.D., Chairperson
USF Institutional Review Board

Appendix C: Interview Guide

The interviews will be semi-structured and parents will be allowed to take the lead in telling the stories of their experiences. The following is to be used as a general guide rather than as a set of structured questions. The probes should be utilized only if parents have difficulty thinking of something to say about a particular aspect of their experience.

Tell me about yourself

    Probes:
    age
    work/edication
    hobbies/recreational activities (**probe about experiences with arts and performance**)
    likes and dislikes

Tell me about __________ (name of the child with the disability)

    Probes:
    age
    work/school
    hobbies/recreational activities (**probe about experiences with arts and performance**)
    likes and dislikes
    name of the official diagnosis(ses)
    age at diagnosis

Is he/she able to care for his/her personal care needs independently?

    If not, what kind of assistance does he/she need?
    If yes, what other kinds of assistance does he/she need?
    At this time, who provides the majority of this assistance and how is it funded?

Can you tell me about any educational programs ________ has attended since high school?

What is his/her current living situation?

Can you tell me a bit about his/her friendships and social life?

So, how did he/she become involved with Theatre Exceptional?

How long has he/she been interested in acting?

What classes has taken at Theatre X and how did he/she choose?

What do YOU like best about Theatre X?

What does ______ like best about Theatre X?

Are there any aspects of the program or experience that YOU would like to see changed?
Are there any aspects of the program or experience that would like to see changed?

What were your original goals or reasons for enrolling in the program? Has this changed over time?

Can you tell me a bit about what this experience is doing for him/her?

How has your opinion about _______abilities and talents changed since he/she become involved?

Can you tell me a little about how Theatre X has affected his/her social life and friendships?

Is he/she involved with any other arts programs now? Can you tell me about those?

Has he/she been involved in the arts in the past? Can you tell me about that?

Does he/she enjoy the arts or performances as a spectator? Can you tell me about that?

Tell me about the rest of your family?

Probes:

- spouse
  - age
  - work
  - hobbies/recreational activities (**probe about experiences with arts and performance**)
  - likes and dislikes
  - how long have you been married
  - are both of you the biological parents of ____ (child with the disability)

- other children
  - number of other children
  - ages
  - work/school
  - hobbies/recreational activities **(probe about the arts and performance)**
  - likes and dislikes

- parents (child’s grandparents)
- your siblings (child’s aunts and uncles)

Before you became a parent, what did you think parenthood would be like?

How has your experience been different from what you expected?

How do you think parenting a child with a disability is different from parenting a child without a disability?

At this stage of your family's experience, what is the impact of your child's disability on your:

work life
relationship with your spouse
family life
physical and emotional health and well-being
social life (relationships with friends, neighbors, relatives, etc)
recreational activities
finances
sense of who you are and what you are able to do

Would you walk us through a typical day in **your** life now that _____ is a young adult?

We'd like for you to think back over the course of your child's life so that we can get an idea of how things have been at various stages of your experience as parents. We'll start with ______'s birth and initial diagnosis and then talk about his/her early childhood, teenage years and then his/her young adulthood.

Birth and Infancy

What was the time leading up to his/her birth like for you?
What was the actual birth experience like?
How soon did you suspect that there was something different about ________?
What was it like to receive the diagnoses?
How did strangers react to ______ when he/she was a baby and how did you respond?
What kind of medical, social or other professionals did you have to deal with after the diagnosis and what was that like?
At that time, what was the impact of your child's initial diagnosis on your:
  work life
  relationship with your spouse
  family life
  physical and emotional health and well-being
  social life (relationships with friends, neighbors, relatives, etc)
  recreational activities
  finances
  sense of who you are and what you are able to do
Would you walk us through a typical day in your life when ______ was a baby (before starting pre-school)

Did ______ display any interest or talent in the arts or performance before starting school?

What was the best thing about your life at this stage? What was the worst thing?

Childhood (pre-school through end of elementary school)

What was it like for you when _________ first went to school?

What kind of school/program did he/she attend? How did you feel about that?

Can you tell me about his/her friends and social life inside and outside of school?

How did strangers react to ______ when he/she was a young child and how did you respond?

What kind of medical, social or other professionals did you have to deal with at this time in _______'s life and what was this like for you?

Was you child involved in the arts at this time in his/her life? Can you tell me about that?

At this stage of your family's experience, what was the impact of your child's disability on your:

work life
relationship with your spouse and family members
family life
physical and emotional health and well-being
social life (relationships with friends, neighbors, relatives, etc)
recreational activities
finances
sense of who you are and what you are able to do

Would you walk us through a typical day in your life when was in elementary school?

What was the best thing about your life at this stage? What was the worst thing?

Youth (middle, high school, college years)

What was it like for you when _________ went to middle and high school?

What kind of school/program did he/she attend? How did you feel about that?

Can you tell me about his/her friends and social life inside and outside of school?

How did strangers react to ______ when he/she was a teenager and how did you respond?

What kind of medical, social or other professionals did you have to deal with at this time in _______'s life and what was this like for you?

Was you child involved in the arts at this time in his/her life? Can you tell me about that?

At this stage of your family's experience, what was the impact of your child's disability on your:

work life
relationship with your spouse and family members
family life
physical and emotional health and well-being
social life (relationships with friends, neighbors, relatives, etc)
recreational activities
finances

sense of who you are and what you are able to do
Would you walk us through a typical day in your life when was in middle and high school?
What was the best thing about your life at this stage? What was the worst thing?

Looking back over the years of your parenting experiences, what has been the biggest challenge of being ___________'s (name of child with disability) parent?

Looking back over the years of your parenting experiences, what has been the greatest reward of being ___________'s (name of child with disability) parent?

What worries you most about the future?
What advice to you have for new parents of children with disabilities?