

Arts-Based Appreciative Inquiry with Artists Labeled/with Intellectual and Developmental Disabilities

BY

SARA MILLER

B.S., University of Evansville, 2004

M.A., Southern Illinois University, 2006

DISSERTATION

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Defense Committee:

Carrie Sandahl, Chair and Advisor

Aly Patsavas

Lieke van Heumen

Joy Hammel, Occupational Therapy

Ann Fudge Schormans, McMaster University

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CONTRIBUTION OF AUTHORS

Sara Miller and Lieke van Heumen co-authored Chapter IV of this dissertation.

Conception of the project began while both researchers were transitioning in-person inclusive research to online formats due to COVID-19 restrictions on in-person research. Miller and van Heumen met periodically while submitting revisions to their projects to the UIC Institutional Review Board. Van Heumen, the more experienced researcher, encouraged Miller to carefully evaluate and reflect on ethical and methodological considerations of the transition. Together, Miller and van Heumen decided to develop a paper describing their experience moving their inclusive projects online. After determining that Miller would be first author, Miller took the lead and found a relevant call for proposals for the Journal of Enabling Technologies. The call asked for submissions that highlighted “The value and potential of enabling technologies for people with disabilities during COVID-19.” Miller contacted the journal guest editor to ensure that this paper was a good fit for the journal. The editor encouraged the submission.

Miller and van Heumen met to develop an outline for the paper. Specific sections of the paper were assigned to each researcher. Miller drafted a section of the introduction that reflected on the impact of the pandemic while van Heumen drafted a section of the introduction that described inclusive research principles. Each researcher described research aims and procedures of their individual case studies. Miller also drafted the conclusion/discussion section of the paper that reflected on lessons learned and future directions. Miller and van Heumen reviewed and edited each other’s contributions and then scheduled a series of meetings to review and finalize edits. Miller edited the references section per the journal’s requirements. Miller submitted the final draft of the paper with van Heumen’s supervision and corresponded with the editor until notification was received that the paper had been accepted to the journal. Miller and van Heumen

scheduled a series of meetings to respond to peer reviewers' comments, and Miller submitted the revised draft to the journal for review.

TABLE OF CONTENTS

<u>CHAPTER</u>	<u>PAGE</u>
I. INTRODUCTION.....	1
A. Introduction.....	1
B. Research Aims	2
C. Terms and Labels.....	3
D. COVID-19	8
E. Arts of Life.....	10
1. Mission and values	10
2. Funding.....	11
3. The studio spaces.....	12
F. Overview of Chapters	14
1. Chapter I: Introduction	14
2. Chapter II: Literature review	14
3. Chapter III: Methods	15
4. Chapter IV: Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: Technological adaptations	15
5. Chapter V: Arts-based appreciative inquiry with artists labeled/with intellectual and developmental disabilities: “So they know what we want in the future.”	16
6. Chapter VI: Artists labeled/with intellectual and developmental disabilities in studio practice: Stories of social connection and mutual support	16
7. Chapter VII: Discussion	17
II. LITERATURE REVIEW.....	18
A. Ableism and Intellectual and Developmental Disability	18
1. Causes and impact of ableism in the lives of people labeled/with intellectual and developmental disabilities.....	20
B. Collective Resistance: Self-Advocacy and Art.....	25
C. Community-Based Studios for Artists Labeled/with Intellectual and Developmental Disabilities	33
1. Art for employment, education, and recreation (normalization).....	37
2. Art for therapy	40
3. Art for social change	43
D. Conclusion	44
III. METHODS.....	47
A. Researcher Orientation	47
B. Research Aims	49
C. Disability Theory	50
D. Inclusive Research and Evaluation	52

TABLE OF CONTENTS (continued)

<u>CHAPTER</u>	<u>PAGE</u>
E.	Arts-based Appreciative Inquiry..... 55
1.	Background 58
2.	Recruitment and consent procedures..... 61
3.	Participant observation 63
4.	Appreciative inquiry individual interviews 65
5.	Appreciative inquiry focus groups 67
6.	Data analysis..... 72
7.	Dissemination of findings 76
8.	Data management and confidentiality 77
9.	Participant compensation 78
IV.	INCLUSIVE ONLINE RESEARCH WITH PEOPLE LABELED WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES DURING THE COVID- 19 PANDEMIC: TECHNOLOGICAL ADAPTATIONS..... 79
A.	Structured Abstract 79
B.	Inclusive Abstract 80
C.	Introduction..... 80
1.	The impact of the COVID-19 pandemic on people with intellectual and developmental disabilities 81
2.	Technology and online access for people with intellectual and developmental disabilities 81
3.	Inclusive research with people with Intellectual and developmental disabilities..... 82
D.	Case Study 1: Art-Based Participatory Program Evaluation with Artists with 84 Intellectual and Developmental Disabilities 84
1.	Background 84
2.	Research aim and procedures 85
3.	Recruitment and consent procedures..... 86
4.	Data collection 88
a.	The use of Zoom 88
b.	Security and privacy 89
c.	Visual tools 89
d.	Video recording 90
E.	Case Study 2: Inclusive Translation and Dissemination of Special Olympics Health Data 91
1.	Background 91
2.	Research aim and procedures 92
a.	Collaboration with co-researchers 92
b.	Changes to the research protocol after the outbreak of the COVID-19 pandemic 94
3.	Recruitment and consent procedures..... 95

TABLE OF CONTENTS (continued)

CHAPTER

PAGE

	4. Data collection.....	95
F.	Conclusion	97
	1. Benefits of inclusive online research with people with intellectual and developmental disabilities	98
	2. Barriers to inclusive online research with people with intellectual and developmental disabilities	99
	3. Future directions.....	100
V.	ARTS-BASED APPRECIATIVE INQUIRY WITH ARTISTS LABELED/WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: “SO THEY KNOW WHAT WE WANT IN THE FUTURE.”	
	A. Abstract	102
	B. Introduction.....	102
	C. Literature Review	103
	D. Methods	105
	1. Arts-based appreciative inquiry.....	105
E.	Research Design	106
	1. Background	106
	2. Recruitment	107
	3. Participant observation	108
	4. Individual interviews	108
	5. Art-based focus groups.....	109
	6. Analysis	112
F.	Findings	112
	1. The most important parts of the studio.....	113
	2. Desires for the future of the studio	118
G.	Discussion of Findings.....	123
H.	Conclusion	126
VI.	ARTISTS LABELED/WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN STUDIO PRACTICE: STORIES OF SOCIAL CONNECTION AND MUTUAL SUPPORT	
	A. Introduction.....	129
	B. Study Background.....	131
	C. Studios for Artists labeled/with Intellectual and Developmental Disabilities	132
	1. Studio frameworks	134
D.	Artists’ Stories	138
	1. Stories from C	139
	2. Stories from W	142
	3. Stories from B	144
	4. Stories from T.....	145

TABLE OF CONTENTS (continued)

<u>CHAPTER</u>	<u>PAGE</u>
E. Conclusion	147
VII. DISCUSSION	149
A. Researcher Reflection	149
B. Research Questions	151
1. What do the artists value about and want for the future of their studio community?.....	151
2. Is arts-based appreciative inquiry an effective method to include artists labeled/with intellectual and developmental disabilities in evaluation of their studio programming?	153
C. Methodological Discussion.....	157
D. Limitations	160
E. Future Directions for Research	162
F. Policy Implications	163
G. Conclusion	164
 APPENDICES	
APPENDIX A	166
APPENDIX B	169
APPENDIX B	170
APPENDIX C	171
APPENDIX D	173
APPENDIX E	182
APPENDIX F	187
APPENDIX G	192
APPENDIX H	194
APPENDIX I	196
APPENDIX J	198
APPENDIX K.....	200
APPENDIX L	212
APPENDIX M	214
APPENDIX N.....	216
APPENDIX O.....	218
APPENDIX P.....	219
APPENDIX Q.....	220
APPENDIX R.....	221
APPENDIX S.....	224
APPENDIX T	225
APPENDIX U.....	228
 CITED LITERATURE.....	 231

TABLE OF CONTENTS (continued)

<u>CHAPTER</u>	<u>PAGE</u>
VITA	247

LIST OF TABLES

<u>TABLE</u>	<u>PAGE</u>
I. RECRUITMENT AND DATA COLLECTION TIMELINE	60
II. CORE IDEAS IN INCLUSIVE RESEARCH APPLIED TO THIS STUDY ...	159
III. APPENDICES	166

LIST OF FIGURES

<u>FIGURE</u>	<u>PAGE</u>
1. Portrait of My Mother and Myself	1
2. Christmas in purgatory	29
3. Photo changers	30
4. Jars	32
5. Timeline of disability inclusion and arts policy in the United States	35
6. Thematic map 1.....	74
7. Thematic map 2.....	75
8. A Flower by C.....	113
9. Untitled by B.....	114
10. People Going for a Walk by M.....	116
11. Workspace by Z.....	117
12. A Party by C.....	119
13. Money by B.....	121
14. A New Car by M.....	122

LIST OF ABBREVIATIONS

AAIDD	American Association on Intellectual and Developmental Disabilities
ADA	Americans with Disabilities Act
ADHD	Attention Deficit Hyperactivity Disorder
AI	Appreciative inquiry
ASD	Autism Spectrum Disorders
CDC	Centers for Disease Control
CCDC	Consortium for Citizens with Developmental Disabilities
CCD	Consortium for Citizens with Disabilities
DSM	Diagnostic and Statistical Manual for Mental Disorders
HCBS	Home and Community-Based Services
IDD	Intellectual and Developmental Disability
IDHS	Illinois Department of Human Services
NARC	National Association for Retarded Citizens
NEA	National Endowment for the Arts
PAR	Participatory action research
R&E	Special Olympics Research and Evaluation
SABE	Self-Advocates Becoming Empowered
SARTAC	Self Advocacy Resource and Technical Assistance Center
SPI	Special Olympics International
TBI	Traumatic Brain Injury
VOIP	Voice over internet protocol

SUMMARY

In alignment with self-advocates and the self-advocacy movement, this project begins with an assumption that people labeled/with intellectual and developmental disabilities have important insight and agency in their lives, situating them as not only capable, but also essential in the evaluation and improvement of the programs in which they engage. This dissertation explores the experiences and perspectives of a small group of artists labeled/with IDD in a community-based studio setting. Using online inclusive methods and arts-based appreciative inquiry, a participatory program-evaluation framework, the project aims to: 1) understand what the artists value about and want for the future of their studio community; and 2) evaluate the efficacy of art-based appreciative inquiry to include artists labeled/with IDD in evaluation of their studio programming.

The artists contribute both stories and artwork that illustrate what is important to them about their studio experiences, which includes the people at the studio, both staff and other artists labeled/with IDD, and the ability to create *their* artwork, artwork using materials and themes that the artists choose. In the future, the artists desire more opportunities for social connection including exhibitions and parties, to have more money, to get out into the community more, and to have more choices and options in terms of materials and training in the arts. The artists' accounts position them as contributing members of a socially connected studio community, challenging historical framings of people labeled/with IDD as lacking social awareness and inviting exploration into the relationship between impairment, collaboration and IDD. Their desires for more social connection and community inclusion point to their valuable insider knowledge about the strengths and needs of the studio community. The study supports future research using arts based appreciative inquiry that is more inclusive and artist-driven to include artists in evaluation of studio programs.

The first chapter of this dissertation introduces the reader to studio where this study took place and acknowledges the impact of the COVID-19 pandemic. The second chapter reviews literature, covering the causes and impact of ableist stereotypes depicting people labeled/with intellectual and developmental disability (IDD) broadly as “unknowing subjects” (Carlson, 2010a, p. 320) incapable of self-representation and self-determination in their lives. The literature review highlights how people labeled/with IDD, especially self-advocates and artists, have challenged harmful and negative stereotypes.

Chapters III, IV, and V describe the methodology and methods used in the study including art-based appreciative inquiry and online inclusive methods. The research protocol is described in detail in chapter III and an explanation of how the study responded and adapted to the COVID-19 pandemic by shifting to online methods is described in Chapter IV. Chapter V provides the reader with the artists reported values and wishes for the studio and includes the artists images created during focus groups.

Chapter VI discusses how artists labeled/with IDD are positioned within disability studies and common frameworks present in studios for artists labeled/with IDD. Artist stories are shared in order to explore the relationship between assumptions about impairment and the mutual support described by the artists in the studio. The artists’ insight and awareness points to a community of social connection and collaboration in the studio. The discussion of finding includes implications for the studio under study and for studios for artists labeled/with IDD broadly. Limitations of this study and future directions for research are discussed in chapter VII.

I. INTRODUCTION

A. Introduction



Figure 1. Steffen, Charles P. *Portrait of My Mother and Myself*. 1991. Shown with permission from The Estate of Charles Steffen (Appendix O).

In 2018, I went to an exhibition of the work of Charles Steffen (1927-1995). I remember being puzzled, not by the work itself which had a wonderfully sinewy and bodily quality, but by the way it was curated. A biography of Steffen, who is categorized as an “Outsider artist,” accompanied the exhibition and described aspects of his life, including a period of institutionalization. I noted that the biography stated “After leaving the hospital, unable to take a job, Steffen went to live with his mother...” While the historical fact of his institutionalization may have been accurate, what struck me was the way this framing of Steffen contradicted Steffen’s own handwritten text embedded in the images. In a *Portrait of My Mother and Myself*, 1991 (Figure 1), Steffen drew himself “wheeling her [his mother] to the bathroom.” He says, “she is cute in her way.” While the biography told a story of Steffen’s institutionalization and dependency, Steffen seemed to be telling a story of mutual care. The disconnection between what the biographer wrote and what Steffen reported about his life raised questions for me. Why wasn’t Steffen’s own written account acknowledged? In what ways does Steffen’s perspective, shared through his art, challenge stereotypes about institutionalized people? How does Steffen’s description of himself as his mother’s caregiver unsettle assumptions about his disability? What did the exhibition's biography reveal about the way “outsider artists” like Steffen are perceived? This dissertation follows these questions into the studio practice of artists labeled/with IDD. Like Steffen, what the artists in the study show is that they can tell and illustrate their own stories, and that their stories reveal important, often unrecognized, knowledge and insight about their lives, their relationships, and their communities.

B. **Research Aims**

People labeled/with intellectual and developmental disabilities (IDD) are frequently depicted as lacking the capacity to be knowing subjects, making them a group whose perspectives are consistently ignored and discounted (Carlson, 2010a). Positioning people

labeled/with IDD as incompetent and undependable reporters of their own lives effectively silences this group (Goodley & Rapley, 2001). The result is that others assume knowledge, control, and decision-making power while people labeled/with IDD are denied choice and control over many aspects of their lives. Self-advocates and allies in the self-advocacy movement, the political movement of people labeled/with IDD in the United States, directly challenge this narrative. Through their position statement that defines self-determination as “speaking up for our rights and responsibilities and empowering ourselves to stand up for what we believe in,” the national self-advocacy organization Self-Advocates Becoming Empowered (SABE) asserts that people labeled/with IDD can and should have choice and control over where and under what conditions they live, work, and socialize (Self Advocates Becoming Empowered, n.d.).

In alignment with self-advocates and the self-advocacy movement, this project begins with an assumption that people labeled/with IDD have insight and agency in their lives. Using an art-based, participatory program-evaluation framework, appreciative inquiry, this project explores the insights, desires, and hopes of a small group of artists labeled/with IDD in a community-based studio setting. The project aims to: 1) understand what the artists value about and want for the future of their studio community; and 2) explore the use of art making through appreciative inquiry to support their participation in evaluating the studio.

C. **Terms and Labels**

Naming and labeling are important topics for disability studies scholars, particularly, as Margaret Price writes, “when considered in the context of disabilities of the mind, for often the very terms used to name persons with mental disabilities have explicitly foreclosed our status *as* persons” (2011, p. 9). Terms used to label people with IDD are sometimes used interchangeably or inaccurately, making them confusing. These terms have also changed over time and are

different in different locations (Carey, 2009). For example, between 1908 and 2008 The American Association on Intellectual and Developmental Disability, (AAIDD) updated its definition of intellectual disability ten times (Carey, 2009, p. 191). In the United Kingdom, the term “learning disability” is used to label persons diagnosed in childhood with difficulty coping independently or learning and understanding information (National Health Service, 2017.). This section will define labels used to describe IDD in the United States, discuss the ways self-advocates and allies have critiqued labels, and explain the choice of term “labeled/with IDD” used in this study.

Arts of Life, the studio where this study is conducted, is a non-profit artist collective and alternative day program that supports artists with “intellectual and developmental disabilities” to expand their art practice and leadership skills (Arts of Life, n.d.). People with intellectual disabilities and developmental disabilities are often lumped together in this way and are frequently referred to as people with “intellectual and developmental disabilities” or “IDD” (US Department of Health and Human Services: NIH, 2016). Despite frequently being grouped together, “intellectual disability” and “developmental disability” are distinct terms. “Intellectual disability” refers specifically to people with limitations in intellectual functioning (usually measured by an IQ test) *and* limitations in adaptive functioning that emerge before the age of 18 (AAIDD, n.d.; CDC, 2020). This can include people who acquire a traumatic brain injury (TBI) before the age of 18.

“Developmental disability” is a much broader umbrella term that includes people with intellectual disabilities and/or people with a wide range of sensory and physical disabilities that originate before the age of 22 and result in functional limitations that usually last throughout the life course (AAIDD, n.d.; CDC, 2020). Developmental disabilities can be cognitive or physical

or both (AAIDD, n.d.). Developmental disabilities include, but are not limited to, Down syndrome, Fragile X syndrome, Fetal alcohol syndrome, autism, epilepsy, and cerebral palsy (CDC, 2020). While people labeled/with IDD are perceived as a homogenous group with predictable, usually negative characteristics, Carlson argues that in actuality they make up an immensely heterogeneous group (2001).

Labels and definitions used to describe people labeled/with IDD have changed over time and are impacted by social and political factors. Prior to 1975, intellectual disability, cerebral palsy, and epilepsy were not categorized under the umbrella term developmental disability. It was not until 1975, under the Developmentally Disabled Assistance and Bill of Rights Act, that the definition of ‘developmental disability’ was expanded to include several different diagnoses including intellectual disability (then called ‘mental retardation’), cerebral palsy, epilepsy, and other neurological conditions which originated before age 22. This re-labeling initiative was intended to unite the then-called National Association for Retarded Citizens (NARC), United Cerebral Palsy, and the Epilepsy Foundation under one large, potentially more politically impactful umbrella (Carey, 2009). As a united group, these organizations would become founding members of the Consortium for Citizens with Developmental Disabilities (CCDD), later called the Consortium for Citizens with Disabilities (CCD), and would influence the passage of legislation through the second half of the 20th century, including the 1990 Americans with Disabilities Act (ADA) (Pelka, 2012). This politicization of terms points to their flexibility and instability.

People labeled/with IDD have also influenced the terms used to describe them. Self-advocates have advocated against the use of terms considered to be harmful and damaging (Carey, 2009; Pelka, 2012; Wehmeyer, 2013). For example, self-advocates and their allies

successfully brought attention to the problematic nature of the term “mental retardation” with their “spread the word to end the word” campaign (Spread the word, n.d.). The American Association on Mental Retardation, the nation's oldest professional organization focusing on the topic of IDD, changed their title to The American Association on Intellectual and Developmental Disabilities (Carlson, 2010b p. 107). In 2010, President Barack Obama signed “Rosa's Law,” which removes the terms "mental retardation" and "mentally retarded" from federal health, education, and labor policy and replaces them with “individual with an intellectual disability” and “intellectual disability” (Federal Register, 2017). In 2013, “Mental retardation” was removed from the Diagnostic and Statistical Manual for Mental Disorders (DSM) (American Psychiatric Association).

Some advocates and allies, particularly from the autism community, have advocated for a shift toward new descriptive terms, including the term “neurodiverse.” The neurodiversity paradigm draws attention to the ways in which diverse cognition is marginalized, and “normal” or “typical” cognition is privileged (Strand, 2017). Proponents of neurodiversity argue that people with autism, epilepsy, intellectual and developmental disabilities, and mental illness (to name only a few) fall within the broad spectrum of human variation (Strand, 2017).

The neurodiversity paradigm is not alone in challenging the boundaries between labels associated with IDD and mental illness. Price uses the term “mental disability” to describe disabilities that “affect the mind,” subdivided into mental illnesses, cognitive disabilities, autism spectrum disorders and learning disabilities (Price, 2010, p. 118). Price outlines the boundaries of the term “mental disability” to include mental illness in order to understand the privileging of cognition and language in a particular location, academia (Price, 2011).

This study aims to understand the experiences and perspectives of a group of people labeled/with IDD in a community-based studio. The label of IDD carries important meaning in studio spaces. The availability of some services, as well as funding for those services, depends upon the use of the IDD label. Without this label, or with a different label, access to some studios would be denied to some people. In this sense, having the label of IDD can be a privileged position. But access is complex. Being labeled with IDD and being the recipient of services designated for people with the label of IDD have often been accompanied by assumptions of dependence and need for professional control and surveillance (Carey, 2009).

Many people labeled/with IDD, especially self-advocates who are part of the self-advocacy movement, prefer person-first language. In fact, the self-advocacy movement is sometimes referred to as the “People First” movement. However, Titchkosky argues that the promotion of “people first” language in Canada (i.e., person with a disability) separates the individual from the disability while simultaneously making disability an individual problem (Titchkosky, 2001, p. 135). Many disability activists and advocates as well as a growing number of self-advocates use “identify first” language that aligns with the social model of disability and claims disability identity first, for example ‘disabled person’ (Bogart & Dunn, 2019). Others prefer not to have any labels, nor to define themselves in any way related to disability or “labeled people,” exemplified by self-advocates who use the slogan “label jars, not people” (Carlson, 2010b, p. 107).

In acknowledgement of the changing nature and potential harms associated with the medicalized labels that stigmatize cognitive difference, and with respect to person-first language advocated for by leaders in the IDD community, for example in the mission statement of SABE, this study uses the term people or person “labeled/with IDD.” The choice to use “labeled/with

IDD” in this study both challenges assumptions of homogeneity in this group and respects an individual person’s right and capacity to define and label themselves. As Spagnuolo writes, the terminology “labelled/with intellectual disabilities” reflects an attempt to acknowledge people who accept the diagnostic label and those people who disagree with that label (2016, para. 1). Research participants in this study are invited to choose and use terms to describe and label their disability (or not). This study does not intend to directly address the many complex ways that people labeled/with IDD are named or name themselves or how research participants relate to those labels. Instead, this work attempts to understand the values, aspirations, and knowledge of a community of artists so-labeled in a particular location at a particular time.

D. **COVID-19**

Acknowledgement of this “particular time” must recognize the significant and ongoing impact of the worldwide coronavirus pandemic on both the studio and the lives of the artists. People labeled/with IDD have faced a unique set of challenges during the pandemic. People labeled/with IDD more frequently live in institutional or institution-like settings and receive personal care and support in these settings, all of which have been compromised by the pandemic (Constantino, Sahin, Piven, Rodgers, & Tschida, 2020). They also have higher rates of pre-existing health conditions and have historically had more difficulty finding medical professionals trained in supporting their needs (Krahn, Hammond, & Turner, 2006). Further, policies proposed or implemented during the pandemic exposed ableist societal attitudes towards people labeled/with IDD including rationing or restricting their use of life-saving measures, including ventilators (Constantino et al., 2020). Additionally, in some cases closures and quarantine measures specifically targeting people labeled/with IDD extended beyond closures affecting the general population. For example, the Illinois Department of Human Services (IDHS) closed in-person community day programming for people labeled/with IDD from March 2020 until July

2020. The rest of the state moved to phase 4 in June 2020, allowing for indoor dining, health and fitness clubs, movies, museums and parks, retail spaces, offices, and salons to open with capacity limits (NBC Chicago, 2020). In response, executive director of Arts of Life, Denise Fisher wrote:

Although we share DHS's commitment to safety, we disagree with grouping our artists in with seniors and with the assumptions associated with that decision... A foundational tenant of Arts of Life is the Dignity of Risk: the idea that self-determination and the right to take reasonable risks are essential for dignity and self-esteem. This right should not be impeded by excessively-cautious caregivers concerned about their duty of care. As the State enters Phase 3, our artists should be allowed the same opportunity as all Illinois residents to decide how and when they return to work. (2020)

Fisher's response points toward a protectionist philosophy that denies the capacity of people to be informed and make decisions about their own safety.

In an opinion piece for the Washington Post in March 2020 entitled, "Isolation isn't new for those with intellectual disabilities, but COVID 19 still poses a threat," Timothy Shriver, chairman of Special Olympics, noted that the extent and impact of isolation of people labeled/with IDD has only intensified during the pandemic. Headlines in Boston, "Isolated from their families, children and adults in group homes struggle for normalcy" (Murphy, 2020), New Jersey, "NJ group home residents with disabilities have been isolated too long, advocates say" (Myers, 2020), and Texas "Texans with developmental disabilities in state homes still don't have visitors. Their parents worry they don't know why" (Jones & Nagmabadi, 2020) reported stories of extended isolation and separation of individuals labeled/with IDD, especially those living in institutions and group homes, from their families, service providers, and support systems.

In late July 2020, the state of Illinois approved in-person, community-based day programming with limited capacity and COVID-19 safety measures in place (handwashing, temperature checks, social distancing, increased cleaning, and mask wearing). Arts of Life began welcoming artists and staff back into the studio with limited capacity in August 2020. Still, at the

time of this writing in March 2021, some artists, including one of the artists from this study, had not been able to return to the studio due to quarantine restrictions enforced by his group home. At the time of this writing, it marked one year since he had in-person contact with many of his closest friends and core supporters, with whom he used to meet daily.

E. **Arts of Life**

1. **Mission and values**

Arts of Life was co-founded in 2000 in Chicago by Denise Fisher and Veronica “Granny” Cuculich, an artist labeled/with IDD who was institutionalized for most of her life (Uribe, 2011). The mission of Arts of Life is to advance “the creative arts community by providing artists with intellectual and developmental disabilities a collective space to expand their practice and strengthen their leadership” (Arts of Life, n.d.). Arts of Life meets this mission through four key values:

- Inspiring Artistic Expression: The Arts of Life model supports creative decision-making and experimentation, creating a safe place to take risks while promoting self-confidence, critical thinking, and problem-solving.
- Building Community: Arts of Life is a collective of professional artists built upon a foundation of collaborative decision-making and mutual respect.
- Promoting Self-Respect: Everyone at Arts of Life has both strengths and weaknesses. Within the community, we are fully accepted and encouraged to develop a deeper understanding of ourselves.
- Developing Independence: Our community members gain a sense of inner freedom through their creative practice and professional development, enabling us all to trust our own judgment and take personal and artistic risks. (Arts of Life, n.d.)

A core tenet of Arts of Life is to situate the artists as true professionals (Arts of Life, n.d.). Arts of Life recognizes that many people labeled/with IDD are not given the opportunity to pursue the profession of their choice and are instead employed doing menial labor -- if employed at all. The goal of the studio is to provide an opportunity for meaningful work in a work environment of equity. To realize this vision of equity, the artists have a “voting voice” in every

aspect of the studio, including professional development, curriculum, staff hiring, and daily activities. They also receive a monthly stipend and receive 60% of the revenue from the work they sell (Arts of Life, n.d.).

2. **Funding**

Because Arts of Life is, according to their 2019 financial report, almost 50% funded by the state of Illinois, a brief discussion of how community-based programming in Illinois is structured and funded is warranted. Whenever an organization is a state funded entity, the labels that pertain to that organization become highly significant. “The Division of Developmental Disabilities (Division) has oversight for the Illinois system of programs and services specifically designed for individuals with developmental disabilities” (IDHS, n.d.). Community-based services like day programs are funded by the state of Illinois under the “Medicaid waiver for adults with developmental disabilities.” To qualify for the Illinois Medicaid Waiver for adults with developmental disabilities, and for state funded services at Arts of Life, an individual must be a resident of Illinois and must have a diagnosis of developmental disability (Medicaid Waiver, n.d.).

The Medicaid waiver is important because while Medicaid provides care for people in institutions, the Adults with Developmental Disabilities Waiver funds services for persons aged 18 or older with developmental disabilities who want to receive services *in the community*. Importantly, the number of waivers given in Illinois is dependent on state resources. Unless they are in crisis (examples of crisis include homelessness or abuse), individuals and families can expect to wait 5-7 years before receiving Medicaid waiver services in Illinois list (Medicaid Waiver, n.d.). About 20,000 people currently receive Medicaid Waiver services in Illinois;

currently about 24,000 people are waiting for waivers on the Illinois Medicaid waiver waiting list (Medicaid Waiver, n.d.).

Day programs which are part of the Home and Community-Based Services (HCBS) Medicaid waiver include “Developmental Training (DT),” “Supported Employment (SEP)” and “Adult Day Care (ADC)” services. “These services are provided by community-based agencies and organizations to individuals throughout Illinois” (IDHS, n.d.). Arts of Life bills the state of Illinois for 55D, “personal support” and 30U “Other Day Program” services which provide individual programming for people that choose “alternative” day programming (IDHS, n.d.).

3. **The studio spaces**

Arts of Life has two studio locations that support the work of around 60 artists labeled/with IDD. The Chicago studio is in an arts district downtown; the Glenview studio, where this study took place, is located in a suburban industrial park. My first contact with Arts of Life was a visit to the Chicago studio in 2008. I scheduled an appointment to visit the studio on a weekday. When I arrived at the address, I knew I was in the right place because the front door of the studio led directly into a small room with a table covered in marketing materials for current and upcoming gallery shows. Behind the table was the artwork and photograph of Veronica “Ronnie” Cuculich, “a self-taught, unconventional artist” with an intellectual disability. Cuculich is credited with co-founding Arts of Life with now executive director Denise Fisher (Arts of Life, n.d.). This space also boasted an “Artists of the month” wall with a photograph, artist statement, and the work of one of the artists from the studio.

Past this room was a large gallery space painted pristine gallery white. In the years since my first visit to the Chicago Arts of Life studio, including the eight months that I volunteered there in 2017-2018, I never saw the gallery empty. Arts of Life exhibitions boasted professional

photographs of the artists, framing of the work, coherent marketing/publicity materials, and notably, artists' statements focused on the aesthetics of their work rather than their disabilities.

In line with one of the studio's core philosophies, "the studio belongs to the artists," one of the artists led my studio tour. My guide was an experienced tour guide and an enthusiastic studio advocate. It became clear that my guide was a community leader who seemed to have a connection with every studio member, laughing and sharing friendly comments with them as we went along. The artist walked me through the studio "café," pointed out a computer workstation, and directed my attention to the wall where many of the studio's art supplies were neatly shelved. We walked past the artists' workstations which were divided into five color-coded "pods," each with its own tablet in a protective case. About 20 artists were working at their desks. Some artists were working with the support of staff members or volunteers, but many artists were busy working independently at tables or easels. The atmosphere was friendly, and I felt welcome.

Aside from its suburban location, the Glenview Arts of Life studio is a close copy of its Chicago counterpart. I visited the Glenview studio for the first time in Nov 2019 to begin planning for this dissertation project. Like the Chicago studio, the gallery welcomes guests as they enter the Glenview studio. Past the gallery, the studio workspace is large and industrial with concrete floors and exposed steel beams. Artwork from the studio artists lines the walls. During my visit in November, about 20 artists worked at individual desks or shared tables. Again, some worked with staff or volunteers, while many worked independently.

While I intended to spend more time in the physical studio space at Glenview once this study began, I have not had a chance to return in person. The rest of my contact with the studio has been virtual, through Zoom. My exposure to the studio has been limited to what I can discern in the background of the small square boxes on the screen. The artists have informed me of

COVID-19 protocols, including mask wearing, temperature checks, and instructions to go directly to their station during their time at the studio. Stations are set up six feet apart, spilling into the gallery space which has otherwise gone unused since all exhibitions were moved online. Some plastic sheeting has also been installed to separate artist workstations. While these changes have undoubtedly impacted the communal feel of the studio that I remember from my visit, much of the same energy is still present in the studio. This energy translates into the virtual world and is visible through Zoom. The artists, especially those that have not yet been able to return to the studio in-person, take advantage of Zoom studio programming to check in with each other. They laugh, chat, and make art much the same way they always have. From my observation, the Zoom studio programming is a dynamic place where the creative practice of the artists is still proceeding and where the spirit of the studio community continues to be felt.

F. **Overview of Chapters**

1. **Chapter I: Introduction**

This chapter introduces the reader to the terms used in this study. Further, this chapter introduces the reader to Arts of Life studios, both the physical studios and the virtual studio where this study took place. Finally, this section discusses briefly what is contained in each chapter. In addition to literature review and methods chapters, this dissertation includes three chapters written as papers designated for publication. These papers are targeted for publication in the journals named below.

2. **Chapter II: Literature review**

This chapter includes a literature review that examines the causes and impact of ableism that impacts the lives of people labeled/with IDD. The literature review challenges common depictions of people labeled/with IDD as lacking awareness and agency, depictions which are challenged through self-advocacy and by the creative practices of artists labeled/with IDD. The

literature review also describes historical and current philosophical approaches to studio programming with artists labeled/with IDD.

3. **Chapter III: Methods**

This chapter describes the researcher's positionality including professional experience and exposure to ideological frameworks that influenced the study. This chapter also outlines disability theory that attends to the social construction of disability and impairment. Finally, the chapter discusses methods used in this study, including their potentials and limitations. It describes the protocols used in this study in detail.

4. **Chapter IV: Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: Technological adaptations**

Chapter IV is a co-authored paper with Lieke van Heumen. The paper describes the process of moving two inclusive studies, which were originally designed to be conducted in-person, to online formats due to the COVID-19 pandemic. Process findings are outlined to support the inclusion of people labeled/with IDD in future online research.

This paper has been published in a peer reviewed journal with Emerald Insight (Miller & van Heumen, 2021). The publication is in the *Journal for Enabling Technologies* in 2021 in a special issue that explores "The Value and Potential of Enabling Technologies for People with Disabilities During COVID-19." *The Journal of Enabling Technologies* has an international and multidisciplinary audience that explores how technologies can be used in health, social care, and education (Emerald Publishing, n.d.). Publisher permission to include the Author Accepted Manuscript is available in Appendix S.

5. **Chapter V: Arts-based appreciative inquiry with artists labeled/with intellectual and developmental disabilities: “So they know what we want in the future.”**

Chapter V reports on the findings of the arts-based appreciative inquiry at the studio -- what the artists said is most important about the studio and what they want in the future. This chapter also evaluates the effectiveness of arts-based appreciative inquiry with artists labeled/with IDD. This paper was written for the *Journal of Applied Arts and Health* special issue on “Arts-based research in health and well-being during the pandemic” slated for publication in August 2021. This chapter will be submitted to the journal before the June 1, 2021, submission deadline. *The Journal of Applied Arts in Health* is an international, peer-reviewed journal that profiles the effectiveness of art-based inquiry in interdisciplinary health fields. The journal provides a platform for evidence of and debate about the impact of the arts on health outcomes. Health is defined broadly and includes physical, mental, social, spiritual, occupational and community health (Intellect Books, n.d.).

6. **Chapter VI: Artists labeled/with intellectual and developmental disabilities in studio practice: Stories of social connection and mutual support**

This chapter explores how artists labeled/with IDD are situated in disability studies, disability art, and studio frameworks. This chapter records the artists’ stories, which inform a social and relational epistemology of impairment. This paper was originally submitted to the *Journal of Literary and Cultural Disability Studies* for a special issue on learning disability in November 2019. The focus of the journal is on literary and cultural representation of disability. Peer reviewers of my manuscript offered the critique that the voices of artists labeled/with IDD should be included. With permission of the editors, my submission was

retracted so that the perspectives of the artists in this study could be included in the manuscript. The paper will be resubmitted to the journal upon completion of the dissertation.

7. **Chapter VII: Discussion**

The discussion section begins with a reflection from the researcher. It revisits the aims of the study and the research questions posed by the study. It evaluates methodological approaches used in the study and discusses directions for future research.

II. LITERATURE REVIEW

This literature review will examine the causes and impact of ableist stereotypes depicting people labeled/with intellectual and developmental disability (IDD) broadly as what Carlson has called, “unknowing subjects” (Carlson, 2010a, p. 320) incapable of self-representation and self-determination. In addition to examining these harmful representations of people labeled/with IDD, it also highlights how self-advocates and artists have challenged harmful and negative stereotypes. Outlining how people labeled/with IDD have historically been represented, especially when juxtaposed with how they represent themselves, provides insight into attitudes, policies and practices that impact the lives of people labeled/with IDD, including artists labeled/with IDD in studio practice. This review will cover important events in community integration legislation and arts facilitation in the United States that led to the formation of community-based studios for artists labeled/with IDD and will review common frameworks present in studio practice. Chapter III follows with a discussion of this study’s theoretical framework and methods used to engage artists labeled/with IDD in an arts-based evaluation of their community-based studio programming.

A. Ableism and Intellectual and Developmental Disability

The term ableism describes systemic discrimination against people classified as disabled, regardless of type or visibility of the disability (Nario-Redmond, 2020). Ableism reflects the oppression of disabled people, including the denial of rights and stigmatization (Gill, 2015). Largely under-researched, ableism presumes ablebodiedness, rendering people with disabilities as marginalized and essentially invisible (Bogart & Dunn, 2019). Naming ableism brings attention to social attitudes and institutional structures that lead to the oppression of people with disabilities including barriers to employment, education, healthcare, and access to public spaces

(Nario-Redmond, 2020). Cognitive ableism, described by philosopher Licia Carlson, is ableism directed towards individuals “who are believed not to actually or potentially possess” certain cognitive abilities (2001, p. 140).

Ableism is complex and composed of interacting factors. Nario-Redmond calls these interacting factors the “A,B,Cs of ableism” (Nario-Redmond, 2020, p. 6). They include: 1) affective emotions or attitudinal reactions; 2) behavioral actions/practices; and 3) cognitive beliefs and stereotypes (Nario-Redmond, 2020, p. 6). How specific groups are perceived impacts how people feel and behave towards them, as well as how stereotypes about those groups develop (Fisk, Cuddy, Glick, & Xu, 2002). For example, people labeled/with IDD are often perceived as having lower status and less competence than people without IDD, leading to feelings of pity and protectiveness towards them (Nario-Redmond, 2020). Pity towards people labeled/with IDD, which implies superiority, leads to behavioral responses and social practices of subordination and control (Nario-Redmond, 2020). These institutionalized attitudes and practices that people labeled/with IDD encounter enforce their inferior position in “all or almost all” of their social settings – schools, jobs, churches -- and their relationships (Carey, 2009, p. 25). In her co-authored journal article “Positive you: A self-advocates art-based approach for building self-esteem,” self-advocate Leah Jones describes how teachers, doctors, and other professionals had low expectations of her life and future (French & Jones, 2019). She explains:

For learning disabled people, maintaining a positive sense of self may be particularly difficult as we have (or are believed to have) qualities that marks us as different and this leads us to be ‘devalued in the eyes of others’ (French & Jones, 2019, p. 192).

Cognitive ableism is perpetuated by assumptions of the homogeneity of people labeled/with IDD (Carlson, 2001). Despite remarkably broad and historically flexible categorizations of IDD, broad assumptions result in concrete forms of oppression (Carlson, 2001). These broad

assumptions emerged from authority granted to professionals and professional organizations who have historically enjoyed the epistemic privilege to categorize and define people labeled/with IDD in scientific, positivist terms. Uncovering or “unmasking” and problematizing the historical authority assumed by professionals and professional organizations is “both critical and productive” (Carlson, 2010b, p. 107). What follows describes: 1) how ideological attitudes in the social and medical sciences set the stage for the essentialized and inherently negative categorization of people labeled/with IDD; 2) how stereotypical cultural representations continue to reinforce those categorizations; and 3) how categories created in the medical and social sciences combined with cultural representations impact social policy and practice. According to Nario-Redmond (2020), these interacting factors -- attitudes, stereotypes, and practices -- comprise ableism. These factors are discussed in this chapter because they impact whether people labeled/with IDD have access to community spaces, including community-based studios, and whether their perspectives are included in research about issues important to them. Self-advocates have asserted that people labeled/with IDD have a right to community inclusion and important knowledge and insight that should be included in discussion about issues that impact their lives (SABE, n.d.).

1. **Causes and impact of ableism in the lives of people labeled/with intellectual and developmental disabilities**

The medical and social sciences have contributed to the creation of categories of difference that impact the lives of people labeled/with IDD in important ways including how they are labeled, where they live, work, and recreate, and how they are perceived by others. In the United States, categorization and labeling has been deeply influenced by the eugenics movement. Between 1880 and 1920, American social scientists, physicians, philanthropists, and

many public figures forwarded eugenics as the pursuit of “human perfection” (Trent, 2017). Eugenics asserted that the study of heredity could be used to prevent “inferior” human stock.

Professionals in the medical and social sciences were empowered to do the work of labeling and sorting members of society deemed productive from those deemed unproductive (Trent, 2017). To categorize those deemed unfit and unproductive, eugenicists used “Feeble-mindedness,” a catch-all label used to describe people with cognitive differences, immigrants, people of color, the poor, and sometimes women (Carey, 2009). To reinforce this categorization in the cultural sphere, eugenicists produced media depictions of people labeled feeble-minded as dangerous to society, for example in the 1918 film *The Black Stork*, later renamed *Are You Fit to Marry?* (Pernick, 1996). A public narrative formed characterizing the so-called feeble-minded as menaces at the root of crime and poverty and the cause of social decline (Carey, 2009; Trent, 2017; Wehmeyer, 2013). Concerns about population quality fueled the transformation of feeble-mindedness into a pressing national concern (Carey, 2009). Public health policies and practices were implemented to manage the ‘crisis,’ including euthanasia, forced sterilization, and marriage restrictions on those considered “unfit” (Pernick, 1996; 1997). Additionally, many of those deemed unproductive were separated and controlled through institutionalization which escalated sharply at the turn of the 20th century. Between 1904 and 1910, institutionalization increased 44.5 %; and between 1910 and 1923, institutionalization increased another 107.2 % (Carey, 2009, p. 52).

In addition to institutionalization, mental testing was another emerging scientific arena in the early 20th century, empowered to make knowledge claims about people labeled/with IDD (Carlson, 2010b). Medical, psychological, and educational fields of study associated with defining intellectual disability have historically leaned on the notion that intelligence can be

objectively measured in a singular individualized quotient, IQ (Kliewer, Biklen, & Peterson, 2015). Alfred Binet, the originator of the earliest intelligence tests in 1905, was himself aware that intelligence was neither fixed nor innate and, until his sudden death in 1911, he remained concerned about the way his test was being used to assert hierarchies of human worth and value (Kliewer et al., 2015). Despite this, when Binet's intelligence test reached Ellis Island, it was used to corroborate eugenics assumptions about immigrants. Forty to fifty percent of those tested met the criteria for feeble-mindedness (Carey, 2009).

Towards the middle of the 20th century, parent groups in the United States began to form a "parents' movement" that advocated for more services and supports for their children with disabilities (Pelka, 2012). Parents forwarded a "need-based" argument that government had an obligation to care for "dependent citizens" (Carey, 2009, p. 105). This early advocacy sought better service provision, but not necessarily more autonomy for people labeled/with IDD, leaving control to professionals and parents (Callus, 2013; Hayden 2004; Zames Fleischer & Zames, 2011).

Along with legislative successes that expanded community-based programs and services for people with disabilities, parents forwarded a new narrative of people labeled/with IDD as "special," angelic, and childlike (Carey, 2009; Nario-Redmond, 2020, Pelka, 2012). These new characterizations were reinforced by widely read novels of the period written by parents of children labeled/with IDD including *The Child Who Never Grew* (Buck, 1950) and *Angel Unaware* (Evans, 1953). While seemingly diametrically opposed to 'violent' and 'dangerous' stereotypes forwarded by eugenicists, characterization as eternally childlike continued to essentialize people labeled/with IDD as lacking the capacity for self-direction, choice, and control in their own lives, and still in need of life-long care and control from others.

Polarizing representations of people labeled/with IDD as either dangerous or childlike persist in contemporary culture and are visible through everyday conversation and cultural representations found in books, film, tv, and social media (Nario-Redmond, 2020). According to Yar and Rafter, “movies do cultural work” that both reflects and promotes ideas that viewers draw on to form opinions (Yar & Rafter, 2014, p. 795). In their qualitative analysis of crime films with characters with intellectual disabilities filmed since the mid-20th century, Yar and Rafter point to representations of characters with intellectual disabilities that oscillate between innately criminal or childlike and innocent (2014, p. 791). Dangerous and criminalistic characterizations are embodied in characters like Lenny from the 1939 film adaptation of John Steinbeck’s novel (with remakes in 1982 and 1992) *Of Mice and Men*, and Carl Childers from the 1996 film *Sling Blade* (Yar & Rafter, 2014). At the same time, *To Kill a Mockingbird* (1960) and the *Green Mile* (1990) depict characters labeled/with or assumed to be labeled/with IDD as childlike and innocent (Yar & Rafter, 2014, p. 802). While paradoxical, these representations share a characterization of people labeled/with IDD as incapable of having self- control and therefore self-direction. Both the characters of Lenny and Carl Childers commit violent acts: Lenny seemingly out of animalistic naivete caused by his disability, and Carl, who similarly “cannot see another way to handle the situation” (Yar & Rafter, 2014, p 802). Representations that depict people labeled/with IDD as childlike delimit their capacity to have choice and control over their lives. In other words, “The disabled cannot simultaneously be both innocent *and* knowing” thereby reinforcing the role of caretakers (Yar & Rafter, 2014, p. 801). The presence of both innocent and menacing representations of people labeled/with IDD in films at the end of the century, decades after the emergence of the parents’ movement and even longer since the

height of eugenics, points to the power of these representations and their hold on the American perception of people labeled/with IDD.

Because cultural representations of disability, often negative, may be the only exposure that nondisabled people have with people with disability, they have resonance and real-life consequences (Bogart & Dunn, 2019, p. 656). For example, Yar and Rafter, argue that inequities in the criminal justice system that impact people labeled/with IDD are exacerbated by cultural framings, specifically depictions of people labeled/with IDD in film (2014). “If the only available constructions are negative, then it is difficult for people to shift to a new way of framing experiences and analyzing human rights issues” (Yar & Rafter, 2014, p. 795). In the United States, rights under the law are afforded to citizens who can demonstrate both rationality and autonomy (Carey, 2009), both presumed absent under eugenic and paternalistic characterizations of people labeled/with IDD. As a result, US citizens labeled/with IDD have historically been afforded unequal status and denied the rights of citizenship, including the right to vote, marry, have children, and hold property (Carey, 2009). For example, in his examination of how the sexuality of people labeled/with IDD is represented in media and how those representations impacted attitudes, practices, and policy in medicine, education, and the courts, scholar Michael Gill points to the ways in which people labeled/with IDD are constructed as being “unable to live and act in sexually deliberate ways” (2015, p. 147). This depiction has consequences in how the sexual lives of people labeled/with IDD are controlled and denied (Gill, 2015), as is evident in legislation around the sexual rights of people labeled/with IDD. Until 1968, 27 states had sterilization laws that authorized the sterilization of people labeled/with IDD, and thirty states currently ban or restrict the rights of disabled people to marry (Nario-Redmond, 2020, p. 84).

Eugenic thinking established and advanced the role of professionals in the lives of people labeled/with IDD (Nario-Redmond, 2020). Professional systems were strengthened, intergroup boundaries fortified, and social inequality justified by bolstering the claim that some groups of people naturally need more protection and/or control (Nario-Redmond, 2020, p. 16). These claims were reinforced in the public's mind through stereotypes represented in film, TV, and literature. Professional and cultural narratives impact laws and policy applied to people labeled/with IDD. Once a person is identified as having an intellectual disability, "a singular discourse of educational, sociocultural, and intellectual incompetence and perpetual disconnectedness" is attached to them (Kliewer et al., 2015, p. 2). Through their own acts of self-advocacy and self-representation, people labeled/with IDD challenge these notions; instead, representing themselves as knowledgeable about and aware of their social positioning and capable of imagining and working towards more equitable futures.

B. Collective Resistance: Self-Advocacy and Art

Ideological frameworks and cultural stereotypes representing people labeled/with IDD as lacking competence (Goodley, 2017), self-awareness (Bérubé, 2016) and social connection (Kliewer et al., 2015) are prevalent, but they have been and continue to be challenged by people labeled/with IDD. This section explores how the self-advocacy movement, the movement of people labeled/with IDD in the United States seeking recognition and rights, challenges negative assumptions. Further, this section explores how artists labeled/with IDD, and their work disrupts ableist ideologies and stereotypes.

As discussed above, in the 1940's and 50's, parents in the US began to form advocacy groups with the goal of improving conditions for people labeled/with IDD (Dybwad & Bersani, 1996). Into the 1960's and early 70's, these efforts continued and ran parallel chronologically, but rarely joined together with the broader disability rights movement which mostly advanced

the concerns of people with physical disabilities (Carey, 2009). Because parents primarily sought more services, and not more autonomy for people/labeled with IDD, services for people labeled/with IDD remained under the control of professionals and parents and not people labeled/with IDD themselves (Callus, 2013; Hayden 2004; Zames Fleischer & Zames, 2011). It wasn't until the mid-1970's that newly established legislation and public attitudinal shifts towards deinstitutionalization, community integration, and normalization, began to open doors for people labeled/with IDD to form their own advocacy groups and speak up for themselves, and the self-advocacy movement emerged. Ray Loomis, founder of one of the earliest self-advocacy groups, named his newly forming organization "Project Two;" according to Loomis, Project Two was the successor of the already established parents' movement which he considered the first advocacy project for people labeled/with IDD (Dybwad & Bersani, 1996; Pelka, 2012).

One of the earliest groups of people labeled/with IDD advocating for self-determination, choice, and self-direction in their lives was a small group in Oregon, who are credited with saying, "We are people first" (Schaff & Bersani, 1996). The phrase "people first" was significant because it claimed personhood and voice, making it possible for people with IDD to explore positive disability identity (Caldwell, 2011). Members of the first chapter of the People First movement were former residents of one of Oregon's large institutional living facilities, Fairview Training Center. Reverend Dennis Heath, a former Fairview Training Center staff member, supported former residents to meet to discuss issues that were important to them. In five years, this small group would grow from eight members to a 1000-member-strong self-advocacy organization in Oregon alone (Dybwad & Bersani, 1996). Today the Self Advocacy Resource and Technical Assistance Center (SARTAC) estimates that over 1200 local self-

advocacy chapters exist in the United States (SARTAC, 2021). Additionally, a national self-advocacy organization, Self-Advocates Becoming Empowered (SABE) has formed (Self Advocates Becoming Empowered, n.d.).

The self-advocacy movement is a key example of how people labeled/with IDD worked together collectively to demonstrate their agency and capacity for self-representation. This kind of collectivist action is a strategy used by people with devalued identities to cope with marginalization (Nario-Redmond, 2020). Collectivist strategies include both *social change strategies* like the self-advocacy movement that addresses social inequities and injustice, and *social creativity strategies* that work to redefine the group in more affirming and positive terms (Nario-Redmond, 2020). One key *social creativity strategy* is disability art. According to Swain and French's (2008) "affirmation model of disability," disability art, art about the disability experience created by disabled people (Solvang, 2012), advances a more affirming disability identity. The disability art and culture movement, which emerged in the mid 1970's alongside the disability rights movement (Yi, 2018), generates inquiry, empowerment, and cultural identity, and is intrinsically linked with the development of a shared disability culture (Bartlett, Black & Northen; 2011; Sandahl, 2009; Solvang, 2012).

Art is an important tool for transmitting ideas about disability (Sandahl, 2009); however, mainstream art rarely aligns with the lived experiences of people with disabilities. Mainstream representations typically characterize disability as a problem to be solved, something "gone amiss with the known world" (Mitchell & Snyder, 2013, p. 226). Disability art critiques inaccurate stereotypes and generates complex, even sometimes ambivalent representations of disability that "cannot be neatly stereotyped" (Sandahl, 2009, p. 266). For example, in "Weightless?: Disrupting relations of power in/through photographic imagery of persons with

intellectual disabilities” (2014), Ann Fudge Schormans describes how a group of self-advocates first critiqued public photos of people labeled/with IDD and then transformed them through photo editing. The self-advocates reported that photos depicting labeled people as powerless reflected their own experiences of disempowerment. They reclaimed power both by inspecting and critiquing the images and by creating new imagery that challenged representations of IDD as “weightless,” without influence or power. For example, the self-advocates examined a photograph from a photographic essay of abuse that occurred in institutions entitled *Christmas in Purgatory* (Figure 2) (Blatt & Kaplan, 1966). The image depicts a young girl sitting in a chair with her hands and arms in a restraining shirt or jacket. A black rectangle has been added to the image over the girls’ eyes. The child is perceived by the group as being unjustly cast out; her feelings cast aside because of her disability.



Figure 2. Blatt, B., Kaplan, F. (1974) Christmas In Purgatory, Page 20. Shown with permission from The Center on Human Policy, Syracuse University (Appendix P).

In response, the group created Figure 3. Figure 3 depicts a white man with his arms and hands restrained in front of him, similarly to the young girl in Figure 1. He too has a black rectangular box covering his eyes. Fudge Schormans writes:

Turning the tables on those in positions of power, the group instructed the digital media consultant to find a man – they insisted he be a white able-bodied bureaucrat – who was responsible for such treatment of labeled people and put him in a straitjacket. Their transformation re-paints the man as being as powerless as the child in the image. (2014, p. 707)



Figure 3. Photograph from Fudge Schormans, A. (2014). “Weightless?: Disrupting relations in/through photographic imagery of persons with intellectual disabilities.” Permission Requested from Photochangers. Permission from Taylor & Francis Online (Appendix Q).

The new image recognizes wrong-doing and communicates anger towards the non-disabled others who failed to care for the needs of the girl in Figure 2. Fudge Schormans argues that their art is a powerful form of retribution that was shared in public exhibition to both disabled and non-disabled audiences (Fudge Schormans, 2014).

The art of people labeled/with IDD also works to disrupt their invisibility. Throughout most of the 20th century, people labeled/with IDD were physically removed from society through institutionalization. Even with law and policy over the last 50 years supporting

deinstitutionalization, people labeled/with IDD are still excluded from many aspects of society. They remain relatively *unseen*, at least outside a medicalized and clinical context (Fraser, 2018). The art of people labeled/with IDD, especially public art, draws attention to them and to this invisibility (Fraser, 2018). For example, in “Trazos Singulares [Singular Strokes],” an exhibition that took place in a metro station in Madrid Spain, artists labeled/with IDD created and exhibited 60 works depicting the metro station, other aspects of the transportation system, and the broader city itself. Fraser argues that through the “Trazos Singulares” exhibition, both the physical presence of artists labeled/with IDD (creating art in the space) and their lingering metaphorical presence (the art on exhibit), combat their invisibility (Fraser, 2018).

Another example of the creative work of people labeled/with IDD disrupting space is the *Measures of Bodies Exhibition* by the Rocket Artists (University of Brighton, 2010). The Rocket Artists are a progressive studio, meaning that artists labeled/with IDD work alongside artists without IDD collaboratively. In the *Jars* installation at the Museum of Medicine in Brussels, 60 specimen jars were filled with autobiographical text and body sculptures about the Rocket artists and collaborating non-disabled artists. Specimens that recalled a history of being under the clinical gaze were replaced by the artist's own self-representations. This exhibit took place in a Museum of Medicine for an audience of medical professionals, demonstrating how artists labeled/with IDD can and do use art to directly critique and challenge medicalized representations (Figure 4).



Figure 4. *60 Jars* from Fox, A., & Macpherson, H. (2015). *Inclusive Arts Practice and Research: A Critical Manifesto*. Shown with permission from Taylor & Francis, (Appendix R).

All three projects described above, and most studio-based practices of people labeled/with IDD, include some level of collaboration with non-disabled helpers (Perring, 2005). While seemingly in line with disability art, the relationship between what artists labeled/with IDD do and disability art is unclear (Fox & Macpherson, 2015; French, 2017, p. 25). Aspects of the disability art paradigm rely on separation from the non-disabled mainstream to generate and cultivate disability culture and values (Kuppers & Wakefield, 2009). This prescribed freedom from non-disabled professional oversight is complicated for artists labeled/with IDD which are often supported by non-disabled helpers, “muddying the waters around autonomy and authorship” (French, 2017, p. 25).

Fraser (2018) has argued that the visual art of people labeled/with IDD brings attention to the material and social aspects of impairment (Fraser, 2018). The collaborative artistic practices of people labeled/with IDD, specifically the way they make art with non-disabled helpers, amplify the ways that support is received and supplied in relationships, disrupting the script of disability as an individual problem or tragedy. Art, like life, is collaborative and invites questioning about how dominant culture perceives autonomy and interdependence (Rice, Chandler, Rinaldi, Changfoot, Liddiard, Mykitiuk, & Mündel, 2017). Given the potentials of personal narrative and art and the importance of an ongoing exploration into the relationship between impairment and IDD, greater attention to the locations where people labeled/with IDD are engaged in creative practice, like community-based studios, is warranted.

C. **Community-Based Studios for Artists Labeled/with Intellectual and Developmental Disabilities**

In 1995, Elaine Wilson and Lois Curtis, two women labeled/with IDD living in an institution in Georgia, used the Americans with Disabilities Act (ADA) to successfully sue the State of Georgia for their right to live in and be a part of their community. The resulting Olmstead Decision in 1999 allowed other individuals living in institutions across the country to demand that they have a chance to live in the community setting of their choice. Curtis, now an artist, lives in Atlanta and has dedicated her life to art and advocacy (Weddle, 2021). Paralleling Curtis, Veronica “Ronnie” or “Granny” Cuculich (1930-2010), a co-founder of Arts of Life, lived in institutions almost her entire life (Uribe, 2011). In the 1990’s, when Cuculich was in her sixties, she was supported to move into the community. Cuculich and her ally Denise Fisher (current executive director of Arts of Life) quickly realized the importance of her creative practice and worked to establish an artist community with nine other people unhappy with their

current day programming. With Cuculich's leadership, The Arts of Life Chicago studio opened in 2000 (Cuculich, 2011).

The ADA and later the Olmstead Decision opened the door for people like Curtis and Cuculich to be able to live and participate in their communities. Without these foundational pieces of legislation, community-based studios of artists with IDD would not be possible. Equally important was the simultaneous development of national policy in the arts. Between 1965 and 1999, community integration and inclusion efforts intertwined with legislation and arts policy, allowing the studio art movement supporting the work of artists labeled/with IDD to blossom in the United States (Figure 5).

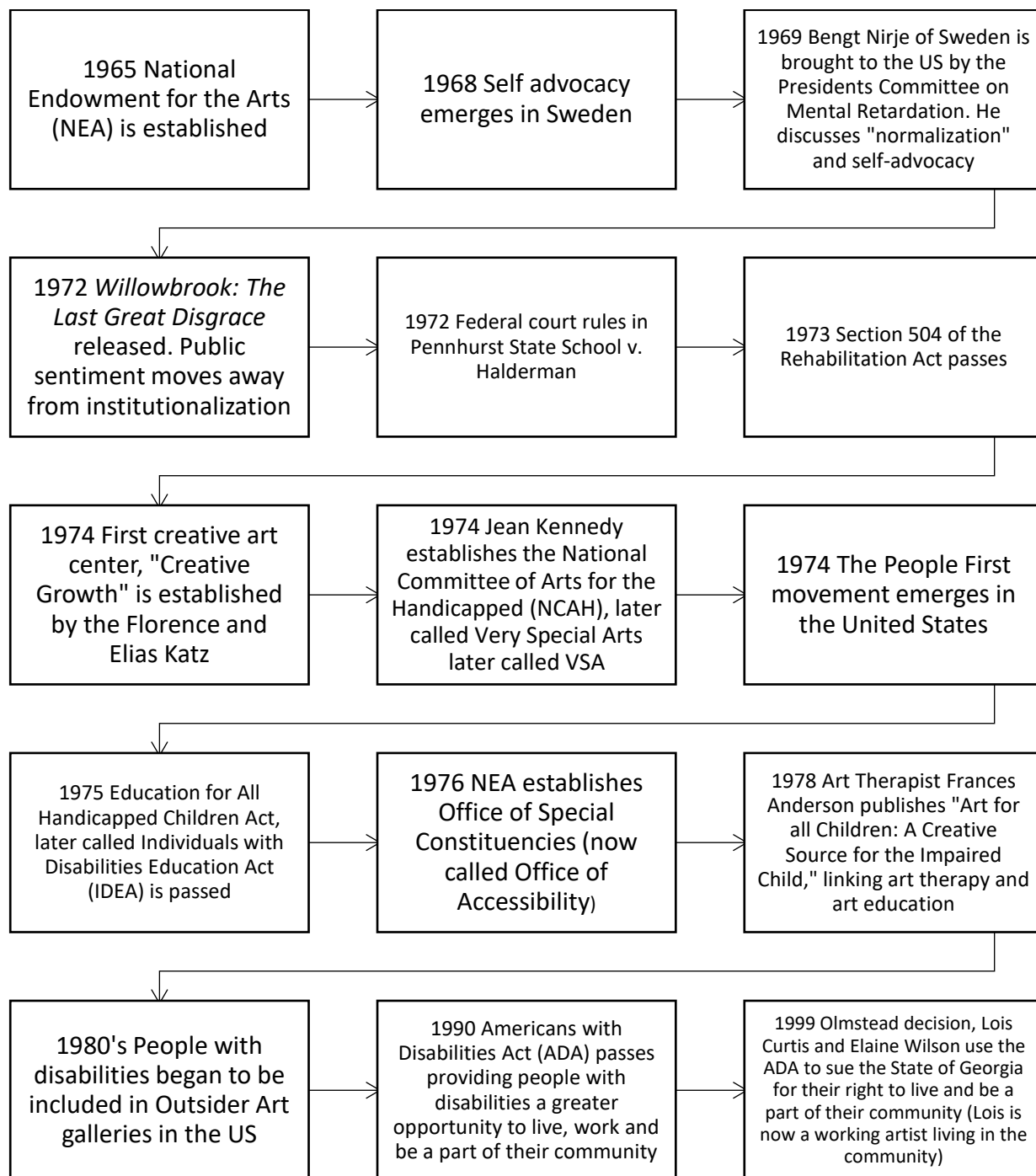


Figure 5. Timeline of disability inclusion and arts policy in the United States

Today, people labeled/with IDD are involved in studio-based arts practices all over the United States (Sellen, 2008). Recent estimates place the number of studios today between 120 (Finley, 2013) and 148 (Ortiz & Donahue, n.d. in Pittman, 2019; Sellen, 2008 in Pittman, 2019). These studios have a wide range of frameworks reflected in their differing names, including “workshops,” “open studios” (Vick, 2016), “creative arts centers” (Ludins-Katz & Katz, 1989), and “progressive art studios” (Ortiz & Donahue, n.d.), to name only a few. The artists labeled/with IDD that participate in these studios also have multiple and intersecting labels including “outsider,” “folk,” “self-taught,” “visionary,” and “naive” (Sellen, 2008). Very broadly speaking, studios and art centers oriented towards the work of people labeled/with IDD provide art materials, space to create art, and sometimes art-based skills training and contact with artists both with and without disabilities (Sellen, 2008). They often share an underlying goal of supporting the inclusion of people labeled/with IDD in the community (Lister, Tanguay, Snow, & D’Amico, 2009; Ludins-Katz & Katz, 1989; Wexler & Derby, 2011) and typically endeavor to have a positive impact on the personal and economic lives of the artists.

These generalities belie their capriciousness. Studios that support the work of people labeled/with IDD are “dynamic” and “idiosyncratic places” (Vick, 2016, p. 830) with a wide range of practices and philosophical underpinnings depending on how both disability and arts practices are conceptualized (Solvang, 2018, p. 240). This creates immense variability and impacts how the work is approached and perceived; for example, art making as a form of treatment or art making as a form of resistance against oppression (Solvang, 2018). A series of scholars have attempted to outline frameworks, discourses, and forms of engagement in studio programs for artists labeled/with IDD. Perring (2005, p. 185-186) identified three major modes of engagement based on interviews with non-disabled arts facilitators in London: normalizing,

post-therapeutic, and countercultural. Solvang (2018) identified four “discourses” around studios. These include art therapy, outsider art, disability art, and disability aesthetics. Finley (2013), identified five types of art programming in the US, including art as recreation, independent and creative art centers, art for employment, art therapy, and arts education. These categorizations are intertwined historically (Figure 5), and in practice ideas and influences overlap, but their underlying assumptions impact administration and facilitation in studio spaces (Perring, 185; Solvang, 2018). Different studio frameworks are, therefore, important to differentiate and understand (Miller, 2020), particularly because people labeled/with IDD are almost always working with the support of, or in collaboration with, non-disabled helpers. The way non-disabled helpers engage with people labeled/with IDD in the arts has bearing on how much subjectivity is present in the work of the artists labeled/with IDD (Perring, 2005).

This section will combine and collapse previous categorizations in order to examine studio frameworks by their intended *purpose*: 1) art for employment, education, and recreation which are linked together under normalization; 2) art for therapy; and 3) art for social change.

1. **Art for employment, education, and recreation (normalization)**

The emergence of studios for artists labeled/with IDD was a convergence of the arrival of “outsider art” (called Art Brut in Europe) and deinstitutionalization in the United States in the 1970’s (Vick, 2016, p. 831). Some of the earliest studios, Creative Growth, Creativity Explored, and the National Institute on Art and Disability, were established to support the needs of adults with disabilities leaving institutions (Vick, 2016). Deinstitutionalization was spurred by “normalization,” a concept developed in Sweden by Dr. Bengt Njire and championed in the US by Wolfensberger and Koch (Carey, 2009). Normalization and Wolfensberger’s *Social Role Theory* asserted that people labeled/with IDD should live in an environment that is “as close as

possible to the norms and patterns of the mainstream of society” (Carey, 2009, p. 141). This includes employment, education, and recreation. In normalizing-oriented studios, people labeled/with IDD are referred to as “artists,” or “students” and are encouraged to think of art making as an activity and profession available to them that “normal people” might also pursue (Ludins-Katz & Katz, 1989).

Florence Ludins Katz and Elias Katz were at the forefront of the studio movement, publishing their seminal work *Art & disabilities: Establishing the creative art center for people with disabilities* in 1989. They advocated for communities to work together to establish “creative art centers” with the purpose of reducing the exclusion of people with disabilities in society (Ludins-Katz & Katz, 1989). Exhibition is a key strategy used in Creative Art Centers to reduce stigma and change societal attitudes about people labeled/with IDD (Ludins-Katz & Katz, 1989; Ortiz & Donahue). Exhibition and employment, through sale of their work, demonstrate that “disabled people are a positive force and have much to contribute and share with their society” (Ludins-Katz & Katz, 1989, p. 95).

Despite its role in deinstitutionalization, Carey argues that normalization has been critiqued for reinforcing the role of professionals and professional systems in the lives of people with disabilities (Carey, 2009, p. 178). Perring describes normalization in studios as a standpoint that brings artists with IDD into “mainstream performance discourse, often through the application of mainstream production values and aesthetic criteria” (Perring, 2005, p. 185). It says: “Bring people inside the existing margins!” thereby centralizing mainstream aesthetics instead of challenging them (Perring, 2005, p. 186).

Studios influenced by normalization and the goal of including people labeled/with IDD in the norms of society, including gainful employment, often do so through the Outsider art genre.

Some studio artists labeled/with IDD have achieved international acclaim and financial success as Outsider artists, including Judith Scott, Dan Miller, and Marlon Mullen (Ortiz & Donahue, 2015). It is somewhat ironic that achieving “outsider artist” status can launch artists labeled/with IDD into societal recognition. Promoters of the Outsider art genre have historically distanced Outsider artists from formalized art practices. In Outsider art, the artist's level of separation or distance outside the modern art world demonstrates their level of authenticity (Fine, 2003, p. 176). Classically, outsider artists were characterized: as untrained or self-taught (Cohen 2016; Peiry, 2001); as isolated loners (Peiry, 2001; Wexler, 2005); as idiosyncratic, sometimes even mystic; as unable to adapt socially; as indifferent to recognition and commercial success in the art world; as poor; and as filled with boundless inventiveness (Peiry, 2001).

Prinz traces the obsession with seclusion in Outsider art to the emergence of “primitive” art, a label used prevalently in the early 1900’s to describe African works. According to Prinz, this work was “not meant to be demeaning, but rather reflected the belief that art had greater authenticity and expressive power prior to the advent of civilization” (2017, p. 256). Intentions notwithstanding, stylistic appropriations reinforced the separation between what was considered “inside” and “outside” of cultured thought (Prinz, 2017, p. 256).

Nevertheless, Outsider art has brought artists on the margins into public view in a way that might otherwise have been impossible. Even today, the art-world, which is typically sealed off from people without the proper training and “pedigree” (Prinz, 2017, p. 270), has opened to the work of outsider artists. “Artists who were once hidden from view because of disability or disadvantage are now actively sought” (Prinz, 2017, p. 270). But questions remain about who has the power and privilege to label, profit, and promote outsider art (Fine, 2003; Prinz, 2017).

Dubuffet, like Katz and Ludins-Katz, argued against conflating artists' diagnosis with their work. Dubuffet claimed that these were "Brilliant works that... testify to an exalted mental state not a sick one...far from being 'pathological' is instead an impressive flowering" (Peiry, 2001, p. 157). To distance themselves from medicalized narratives associated with institutionalization, many studios claim, "we do not do art therapy!" (Vick & Sexton-Radek, 2008, p. 4). However, while not overtly in alignment with medicalization, many studios working under principles of normalization still operate as state and federally funded rehabilitation and developmental training centers. The artists who attend art centers often live in institutional or institutional-like settings. This means that artists are sometimes subject to institutional practices such as ongoing clinical evaluation, restrictive rules around physical contact and sometimes limited personal space and property.

2. Art for therapy

The relationship between art and medicine is expansive. It includes everything from attention to aesthetics in healthcare settings to community initiatives to improve the health and well-being of groups (Solvang, 2018). The utilization of art in healthcare is perhaps most concentrated around the field of art therapy (Solvang, 2018). Art therapy is most prominently known today as a component of treatment towards the remission of diagnosable symptoms of mental or physical illness or disease (Solvang, 2018; Vick, 2016). This framing is partly due to the history of art therapy and its connection with the art of institutionalized psychiatric patients, which began in the early 1900's. Hans Prinzhorn, the historian and psychiatrist who collected one of the earliest and most influential collections of *Bildnerei des Geisteskranken* (Artistry of the Mentally Ill), has been called the "uncle of art therapy." His collections were later sought after by Debuffet in his search for Art Brut. (Cohen, 2017, p. 41). Prinzhorn and many of his

colleagues were interested in how making artwork impacted the psychological health of patients receiving treatment in asylums (Cohen, 2017).

Art therapy positions itself as a critique of talk-based psychotherapy. It recognizes that verbal communication is often insufficient to meet the needs of diverse groups. As a result, art therapy has been utilized to support the therapeutic goals of people with a wide range of communication and adaptive needs, including attention deficit hyperactivity disorder (ADHD), autism spectrum disorders (ASD), learning difficulties, IDD, and other developmental disabilities (Luzzatto, Bruno, Cosco, Del Curatolo, Frigenti, & Macchioni, 2017).

While art therapy has gained recognition for its ability to make clinical services more accessible for people labeled/with IDD, one downside of its growth is that people labeled/with IDD can be *placed* in therapy they do not need, instead of being provided access to recreational art, art education, and/or professional art training. This occurs in some day centers where people labeled/with IDD often have their time managed, and where “art therapy” is a practice that occurs on a specific day at a specific time without any real meaningful connection to the needs or wants of people/artists labeled/with IDD (Swain & French, 2008, p. 96). Prevailing assumptions that all services for people living with IDD need to be therapeutic are related to a stigma about sickness and cure assigned to all people labeled/with IDD (Cohen, 2017). Lack of clarity about what art therapy is and how particular art therapists’ practice can lead to clinical “treatment” where it is not wanted or warranted; conversely, it can also lead to too little clinical support where it is needed.

Even when needed and wanted, the history of therapeutic and clinical practice in the lives of people labeled/with IDD is troubled. Psychiatry and psychology have been criticized for characterizing and pathologizing people with mental disabilities as “irrational, therefore

incapable of productivity, and therefore, subhuman” (Wexler & Derby, 2011, p. 97). The historically damaging relationship between psychiatry, psychology, and people with disabilities has created a valid tension between art therapy and disability advocates (Miller, 2020). Art therapy is still linked with medicalization and pathologizing (Vick & Sexton-Radek, 2008). To participate and make important contributions in studios for artists labeled/with IDD, art therapist Randy Vick argues that “We must put aside many of the cherished trappings of the psychotherapy model—the client/ therapist relationship, the nomenclature, the exploratory dialogues, being the ‘expert’” (Vick, 2016, p. 837), and reexamine the traditional therapy model including how exhibition, sale of work, and profits align with art therapy ethics (Vick & Sexton-Radek, 2008).

Some art therapists argue that a medicalized focus too narrowly defines the field (Cohen, 2017; Vick, 2016). Not every art therapist has “treatment in mind” (Cohen, 2017, p. 17). For example, art therapists have promoted art as a *normalizing* social practice (Solvang, 2018, p. 241) in which people with disabilities are not seen as “sick” or “disabled” but as “socially devalued” (Vick & Sexton-Radek, 2008, p. 4). Miller, Ludwick & Colucy (2020) argue for art therapy to acknowledge and examine its medicalized influences in order to develop practice with people labeled/with IDD that: 1) respects and promotes autonomy, self-direction, and self-advocacy; 2) fosters reciprocal trust through a recognition of power dynamics; and 3) recognizes that clinical boundary-setting must be respectful of the ways that people labeled/with ID function and thrive. For example, art therapist should recognize the need to remain flexible about the start and end-time for sessions as well as the pace of therapy.

In addition to (or perhaps because of) its too-strong linkage with medicalization, art therapists also often suffer from a lack of connection to the contemporary art world (Cohen,

2017). This leaves issues of aesthetics almost completely out of art therapy practice. Therapeutic objectives typically dictate a focus on the process of art making at the expense of the product. “Such practice does not always see itself as ‘art’ or accord the role of artist to participants” (Perring, 2005, p. 186). Vick calls the claim that it “doesn’t matter what it looks like,” a “woefully misguided aphorism” in art therapy (2016, p. 837). He advocates for a reexamination of art therapy paradigms which do not currently cover the ethics of art produced for the purpose of being exhibited and sold (Vick, 2016).

3. **Art for social change**

Practices in studios, particularly studios that espouse “progressive practice” (Ortiz & Donahue, 2015) or “inclusive arts practice” (Fox & Macpherson, 2015) also can have a political or social impact. Progressive and socially engaged studios support people labeled/with IDD to have ownership over the studio space and their creative practice; to participate and be included in their community; and to collaborate as equals with others (Fox & Macpherson, 2015; Ortiz & Donahue, 2015). These practices run contrary to and challenge the way that people labeled/with IDD are typically engaged: as recipients of services, care and instruction designed and delineated by others. The art itself also has the potential to challenge perceptions of IDD. Artists labeled/with IDD depict their interests, illustrate what they value, imagine new worlds, and envision possible futures. They challenge notions of disconnection and vacancy. Through their creative work, people labeled/with IDD negotiate their right to space and assert their value in the world (Goodley & Moore, 2002).

Further, art making by people labeled/with IDD expands inquiry into *aesthetics*. Aesthetics is defined by Siebers as “how some bodies feel in the presence of other bodies” (2010). *Disability aesthetics* is a recognition of the presence and impact of disabled bodies in art

forms (Siebers, 2010). *Cognitive disability aesthetics* expands this recognition into how cognition and cognitive disability are perceived, represented, and analyzed in the arts and humanities (Fraser, 2018). The emergence of Outsider art and Art Brut represented a period of disrupting aesthetic values in twentieth century culture (Peiry, 2001). Dubuffet, in his search for artists “untouched” by contemporary art practice, was critiquing the art world. While not necessarily a social practice, disability aesthetics relates to social practice art (Solvang, 2018, p. 251) because it challenges the assumption that the “healthy body” is the sole determinant aesthetic of “harmony, integrity, and beauty” (Siebers, 2010, p. 3). This rejection of hegemonic interpretations of health and beauty has implications in the real world for disabled people who face marginalization because of disability and physical difference (Siebers, 2010, p. 23).

Perring understands art-based engagement of people labeled/with IDD as attending to, “an objective that challenges mainstream cultural and aesthetic precepts and views about disability” (Perring, 2005, p. 185). Disability art elevates the lived experiences of artists with disabilities for the purposes of articulating disability culture and identity (Solvang, 2018; Swain & French, 2008). The formation of both disability identity and disability culture is seen as an important element of disability rights activism (Longmore, 2003; Swain & French, 2008); however, as noted above, the disability art and culture movement largely prioritizes the experiences of people with *physical disabilities*. “Cognitive disabilities...have tended to remain disproportionality unseen” in disability art and the humanities just as they remain relatively invisible in society (Fraser, 2018, p. 29).

D. **Conclusion**

Self-advocate Tia Nelis and advocate Mary Hayden (2002, p. 221) assert that everyone has the potential for self-advocacy and resilience. Self-advocacy is also a “product of the contexts in which it can emerge” (Goodley, 2004, p. 334). A major aim of this project is to

involve the artists themselves in the evaluation of studio frameworks and practices, to understand what they like and what they want to change. This literature review aimed first to unearth assumptions that have limited the participation of people labeled/with IDD in evaluation, and to explain why they have been so rarely invited to contribute their perspectives; and second, to highlight the valuable insight that people labeled/with IDD contribute when they are included.

Categories established by the medical and social sciences, influenced by eugenics in the early part of 20th century, positioned people labeled/with IDD as *dangerously* unfit to participate in society. Characterizing people labeled/with IDD as unfit supported their control by professionals and professional systems. Cultural representations depicting people labeled/with IDD as dangerous and criminalistic worked to reinforce categorizations, social attitudes, and policy. Mid-century, parents began to frame their children with disabilities as *in-need* which served to improve services but did little to shift agency and control to people labeled/with IDD. People labeled/with IDD themselves, particularly self-advocates and artists, critique limiting attitudes, practices, and historical representations in important ways. Self-advocates have worked to establish the *personhood* of people labeled/with IDD and to demonstrate their insight and authority into their own needs. Artists labeled/with IDD directly critique medicalized representations in media and create new representations that assert their awareness and knowledge, not just about themselves but about how they are socially positioned. These insights point to the importance of the participation of people labeled/with IDD in the evaluation and development of the systems in which they engage. The following chapters outline how artists labeled/with IDD in the studio were engaged in this evaluation through participatory and art-based methods. Findings describe the values and desires the artists articulated and illustrated and considers the potential implications of their contributions on their studio and on studio practice

more broadly. This work contributes to the assertion of self-advocates that people labeled/with IDD are knowing and important informants about the services and supports they receive. This work also contributes to the body of knowledge in inclusive research that works to expand the participation of people labeled/with IDD in research practice and knowledge production.

III. METHODS

A. Researcher Orientation

People labeled/with intellectual and developmental disabilities (IDD) are often denied epistemic privilege, the right to make meaning and knowledge claims from their own experiences (Carlson, 2010a). Participatory and inclusive research methods, like the ones used in this study and described below, attempt to shift from speaking *for* to speaking *with* people labeled/with IDD. Promoting the authority of people labeled/with IDD in this way requires researcher reflexivity, having awareness of privilege, personal values, and bias. To that end, this chapter will begin with a reflection on this researcher's background, how it influenced the research design and implementation and the steps I took to return authority to the artists that participated in the study.

Prior to becoming a PhD student, I spent more than 10 years practicing as a counselor and art therapist in community-based mental health settings. Most of that time was spent in agencies serving adults labeled/with IDD. In these agencies, I observed policy and practices that reinforced a dangerous and pervasive myth, that people labeled/with IDD lack awareness and insight and the capacity for choice and control in their lives. My relationships with people labeled/with IDD and our many hours talking about their experiences, values and wishes for the future directly countered this myth. This project is designed to support people labeled/with IDD to speak back to those limiting ideas.

Even as this project critiques antiquated clinical ideas; I recognize my therapist self in the work. I noticed myself asking the artists a lot of questions about how the artists "feel." While not necessarily bad questions, they reveal some of my beliefs and assumptions about disability and art. In other words, my psychology and art therapy roots were showing. I wrote in my reflective journal, "THERE I AM, right in the middle of my research project!" At times, my experience as

a clinician and art therapist supported the project. I was able to make prompts and questions more accessible by using plain language, slower pacing, and rephrasing, all skills I learned working as a therapist with people labeled/with IDD. Through this research, I have come to realize that the purpose was not that I rid myself of a clinical orientation, but that I recognize that it is an orientation that influences me and that it has specific historical and contemporary significance to people labeled/with IDD.

The study design leans heavily on inclusive practices. I spent time before and during the project critically thinking about how to position the artists as having authority over the research process and reflected on places this could have been improved after the project was finished. I consulted with more experienced inclusive researchers and disability studies scholars about ethical challenges and dilemmas, especially when the COVID-19 pandemic upended the project. It is difficult to imagine anything more impactful than a global pandemic, and while I wanted to cling to *my plan*, centering the artists meant recognizing that their lives had changed, and so the study had to change too.

The use of reflective writing helped me to sort out “my stuff” from what the research participants were trying to communicate. Additionally, I regularly repeated what I thought I had heard back to the artists, “so you are saying -----,” and gave them a chance to refute my claim(s). More formal member checking, a process by which findings are validated by research participants, occurred in the final focus group when broad themes were shared with the artists and they were given an opportunity to amend, add or challenge the research findings. This kind of exchange is only possible if a relationship of trust and safety is established through consistently respecting and honoring choice. I made efforts to honor even small choices that the participants made – such as the choice to be called by a nickname or to ignore one of my

questions -- so they could feel free to assert themselves in bigger ways as the research progressed. I encouraged them to tell me that I had misunderstood or had gotten something they said wrong.

Still, with all these measures in place, this study acknowledges what Natalie Spagnuolo calls “limited knowledge claims” (2016). As a researcher without a label of IDD, I cannot know or communicate the direct experience of living with/being an artist with IDD. I can only communicate what I understand from my standpoint of being in relationship with the artists labeled/with IDD who participated in the study.

B. **Research Aims**

Arts of Life is a community-based organization supporting 60 artists labeled/with IDD in two different studio locations in the Chicagoland area. This study was conducted at the suburban studio location, Arts of Life Glenview. Arts of Life offers artists labeled/with IDD “a collective space to expand their practice and strengthen their leadership” (“Who we are,” n.d.). Arts of Life is one of over 120 studios supporting the work of artists labeled/with IDD across the country (Finley, 2013; Ortiz & Donahue, n.d. in Pittman, 2019; Sellen, 2008 in Pittman, 2019). While professionals and academics have recorded the history of studios, their current frameworks, and the impact they have on the artists that participate in them¹, little is known about what the artists value and/or want for the future of these studios. People labeled/with IDD are often left out of the assessment and evaluation of services they receive (Robinson, Fisher, & Strike, 2014).

The aims of this project were two-fold: 1) To learn what artists think is important about their studio and what they want to change in the future; and 2) to explore the use of arts-based

¹ For scholarly work that examines the relationship between studios for artists labeled/with IDD: In art education see Wexler, 2005 and Wexler & Derby, 2011; In art therapy see Vick & Sexton-Radeck, 2008 and Vick, 2016; In disability studies see Solvang, 2018.

appreciative inquiry as a method to include artists labeled/with IDD in evaluations of studio programming. Following a participatory methodology, appreciative inquiry, this project situates people with IDD as not only *capable*, but also *essential* in the evaluation and improvement of the programs in which they engage. This stance complicates and resists stereotypical social constructions of people labeled/with IDD as unaware and incapable of self-direction.

This chapter describes the methods used in the study. First, it will situate the study within disability studies and disability theory, describing the influence of disability theory on the selection of terminology and methodology. Second, participatory, and inclusive frameworks are introduced. Arts-based appreciative inquiry, a participatory approach to program evaluation, is described. Finally, I have included a detailed description of the study design.

C. **Disability Theory**

The theoretical foundation of this study is situated in disability theory and is aligned with the disability rights movement and its rallying cry, “Nothing about us without us.” Disability theory examines structures of power that marginalize disabled people, challenges notions of autonomy and emphasizes interdependence and collaboration (Jarman & Kafer, 2014). Disability theory also critically intervenes in cultural theorizing; acts as a “lever to elevate debate” (Siebers, 2008, p. 2). For example, the “social model” of disability, which emerged in the UK in the 1980’s, introduced the then radical conceptualization of disability as a social construction and people with disabilities as members of a marginalized group. The social model and its US counterpart, the “minority model,” drew attention to the role of society in creating disabling physical and social barriers (Longmore, 2003; Oliver, 1996). The social model was critical in early disability rights efforts because it paved the way for coalition-building between disabled people (Shakespeare, 2006).

While exploration of the social construction of disability was a key aspect of disability rights discourse and the emergence of disability studies, some disability studies scholars have argued that the social model constructed a binary between disability and impairment that is reinforced by the social model² The social model asserts that impairment refers to physical or mental limitation, while disability refers to physical and social barriers that result from that limitation (Kafer, 2013). While the social model challenged dominant individual tragedy narratives of disability, it may also have cordoned off impairment from disability.

In the last 20 years, disability studies has taken a “turn” towards impairment, with “refocused epistemological attention into *impairment*” (Goodley, 2001, p. 208). For example, Tobin Siebers’ articulation of “complex embodiment” understands disability as a complex experience, both social and physical (2008, p. 22). It recognizes that disability is a valuable form of human variation and that within that variation, bodies hold important situated knowledges (Siebers, 2008, p. 25). Here bodily and experiential knowledge are considered valuable and potentially powerful, even a form of theory itself.

Kafer’s political/relational model also draws attention to disability *and* impairment, bringing attention to the ways that both are socially and politically constructed (Kafer, 2013). Kafer’s model points towards a recognition of how impairment is relational and dependent on social contexts. This is particularly meaningful for theorizing about IDD because intelligence and intellectual disability are often perceived as measurable, immutable, and located within an individual (Kliewer et al., 2015).

In 2001, Goodley noted that even in “The Turn to impairment,” the social construction of intellectual disability is underexplored in disability studies and remains perceived as a

² See Kafer (2013) and Siebers (2008) for an expanded discussion of the relationship between disability and impairment.

naturalized deficit (2001). Goodley pointed to “social structures, practices and relationships” that naturalize the notion of impairment in the lives of people labeled/with IDD. Similarly, philosopher Licia Carlson has observed that despite the many socially constructed barriers to inclusion in society that people labeled/with intellectual and developmental disabilities (IDD) face, intellectual disability remains firmly rooted in biomedical, genetic, and medical discourse and is usually thought of in terms of impairment (2010b). Goodley forwarded a challenge to epistemological assumptions about people labeled/with IDD that interrogates labels attached to people labeled/with IDD. Goodley argued for inviting people labeled/with IDD to tell their own stories, stories that “locate impairment in, and as, personal and social narratives” and articulate resilient and socially connected cultures and communities of people labeled/with IDD (Goodley, 2001, p. 207). Through this social lens, intellectual disability and cognitive impairment can be read as contextual, not concrete, and not located within an individual person.

Disability theory therefore directs this study toward: 1) a literature review that emphasizes the social impact of labels while simultaneously challenging the validity of the social construction of labels; 2) the advancement of disability theory that attends to the social construction of IDD and the social experience of cognitive impairment; and 3) inclusion of people labeled/with IDD, their stories and their insight, in research about a topic important to them.

D. Inclusive Research and Evaluation

Participatory action research (PAR) encompasses a broad range of research practices that emphasize community involvement and community action (Ngwenya, 2017). PAR engages people from the researched community in all aspects of the research process (Kramer, Kramer, García-Irarte, & Hammel, 2011). It focuses on issues important to the community and is designed collaboratively with community members. A range of terms are used in conjunction

with or in place of PAR, reflecting the broad spectrum of approaches and types of community participation involved. Inclusive research, a term coined by Walmsley (2001), is a participatory and action approach to research in which people with and without IDD engage in collaborative research practice together (Bigby, Frawley, & Ramcharan, 2014; Strnadová & Walmsley, 2018). In inclusive research, community members labeled/with IDD actively work with researchers without IDD to identify problems, collect and analyze data, and turn the results into action (Kramer et al., 2011). This collaborative approach can be juxtaposed against research in which people labeled/with IDD participate as subjects of study without any active role (Embregts, Taminiau, Heerkens, Schippers, & van Hove, 2018). Inclusive research draws from the experiences of people labeled/with IDD, focuses on issues important to them, and recognizes the strengths, skills, and unique contributions that people labeled/with ID can make to research (Walmsley, Strnadová & Johnson, 2018).

Inclusive practices were preceded by a long history of people labeled/with IDD being merely subjects of study and sometimes harmed as a result of being studied (Kidney & McDonald, 2014; Martino & Fudge Schormans, 2018). One of the most infamous examples is the hepatitis experiments conducted at Willowbrook, a New York State residential school, in which people labeled/with IDD were intentionally infected with the virus. According to Iacono, every researcher intending to include people with IDD in research is working in the “shadow of Willowbrook” (2006, p. 173). Many of the policies and ethics that currently govern human subjects research were developed as a direct response to Willowbrook as well as other researchers’ abuses of people with disabilities (Carlson, 2013). Even when not directly exploitive, early research was primarily *about* people labeled/with IDD, not *in collaboration* with them.

Researchers with and without IDD working together in inclusive research report important personal benefits for people labeled/with IDD actively engaged in inclusive research including the development of a new skill set; increased confidence and self-esteem; social benefits, such as being able to help others and feel valued; and practical benefits, such as having paid work (Embregts et al., 2018). People with IDD “bring something unique to the research enterprise” (Walmsley et al., 2018, p. 753). The inclusion of people labeled/with IDD improves or “adds value” to research by bringing attention to issues important to people labeled/with IDD, reaching participants and communities that might not otherwise be reached, producing findings that are recognized as authentic by people labeled/with IDD, that reflects the insider knowledge of people labeled/with IDD, and that has an impact on the lives of people labeled/with IDD (Walmsley et al., 2018).

Evaluation, which is sometimes called evaluation research or program evaluation, is a kind of research that engages people in the process of determining the quality or effectiveness of the programs in which they participate (Mertens, 2008). *Inclusive* evaluation engages people labeled/with IDD and other groups who have historically been marginalized in the evaluation process (Mertens, 2005). Inclusive evaluation shares some of these same values of inclusive disability research described above, but its disciplinary starting point is transformative evaluation theory (Robinson et al., 2014). In transformative evaluation theory, evaluation is seen as a vehicle for social change (Mertens, 1999; 2005) and community members’ control over the evaluation process is emphasized (Simons & McCormack, 2007).

Evaluation frameworks increasingly focus on and value the perspectives of individual people and their experiences in programs, thus requiring the development of qualitative approaches to data collection, including interviews and focus groups, observation, and document

analysis (Simons & McCormak, 2007). Despite this, people labeled/with IDD are often not included in evaluation research, and there is little literature about their experiences participating in evaluation (Robinson et al., 2014). Several factors contribute to this exclusion. First, people labeled/with IDD are ideologically positioned as “unknowing subjects” (Carlson, 2010a, p. 320) and undependable reporters of their lives (Goodley & Rapley, 2001). Their viewpoints, thoughts, feelings, and perspectives are often silenced or ignored (Welsby & Horsfall, 2011). Second, ethical, and logistical concerns about conducting research with people labeled/with IDD are a major factor in limiting their inclusion (Maynard, 2015). Among the most pertinent ethical issues are informed consent and ensuring meaningful participation (Kidney & McDonald, 2014). Finally, researchers may perceive accommodations for people labeled/with IDD in research as too time-consuming, too difficult (Maynard, 2015), or too costly because they sometimes require the involvement of more people and more resources (Walmsley, 2018). For example, researchers and evaluators working with people labeled/with IDD may need to develop plain language versions of recruitment flyers and consent forms that are more accessible and understandable for participants. Researchers may not feel the necessary confidence to adapt research methods, particularly data collection methods, to the needs of people labeled/with IDD (Maynard, 2015). The absence of people labeled/with IDD in research and evaluation can be traced to the privileging of language-based forms of data collection. Some people labeled/with IDD have difficulty participating in research projects that rely on language alone (Heffron, Spassiani, Angell, & Hammel, 2018). Alternative and innovative research strategies are needed to include the perspectives of people labeled/with IDD in research (Booth & Booth, 1996).

E. **Arts-based Appreciative Inquiry**

Arts-based approaches can increase accessibility and expand participation of people labeled/with IDD in research and evaluation (Coemans & Hannes, 2017; Sinding, Gray, &

Nisker, 2008). Photovoice, a research method that uses photography to help people share their stories and perspectives, has been used by researchers to increase the inclusion of people labeled/with IDD in research with positive results (Williamson, van Heumen, & Schwartz, 2020). Aspects of photovoice, including a simplified version of the SHOWed method used to analyze photographs (Wang & Burris, 1997), have already been adapted by inclusive researchers working with people labeled/with IDD (Heffron et al., 2018). Other arts-based approaches to research with people labeled/with IDD have shown that art making increases inclusion by helping people feel more comfortable and by assisting them in organizing their thoughts (Welsby & Horsfall, 2011).

Appreciative inquiry (AI) is a participatory approach to organizational and community evaluation and change (Cooperrider, Whitney & Stavros, 2008). In order to bring about change, AI orients community members and organizational members towards their assets, the “life giving potentials, relationships, partnerships, alliances, and ever-expanding webs of knowledge and action” in the organization or community (Whitney & Cooperrider, 2005, p. 1). In AI, community members are engaged in a four-phase structured process. The phases include: 1) Discovery- identifying the strengths of the organization or community; 2) Dreaming- imagining what the community could be in an ideal world; 3) Designing- hypothesizing about how the ideal can be achieved; and 4) Delivery/Destiny- creating a plan for how the community can achieve the ideal (Whitney & Cooperrider, 2005). This framework supports communities to understand themselves through a strengths-based lens, emphasizing the community culture and developing meaningful strategies to move towards imagined futures.

AI is grounded in “the artful creation of positive imagery” (Cooperrider, 2001, p. 32). While this is achieved through talking in most AI projects (Nissley, 2004), AI leans heavily on

personal narratives that can be depicted using the arts (Graham-Pole & Lander, 2009). These kinds of arts-based approaches allow for tacit or implicit knowledge about what is best in an organization or community and what constitutes a positive future to emerge (Nissley 2004). While kinesthetic and sensory knowledge is largely erased and devalued in research (Leavy, 2015; Osei-Kofi, 2013), disability studies recognizes that attention to the body can be generative and knowledge producing (Ignagni & Church, 2008; Siebers, 2008). Researchers who use the arts-in- inquiry approach argue that important aspects of life relate directly to feelings, and that the arts hold special power to uncover those aspects of life (Eisner, 2008).

The use of the arts in knowledge production does not have a strong foothold in contemporary philosophical thought (Eisner, 2008). The legitimacy of art as a form of knowledge production hinges on the work of arts-based researchers to attend to existing limitations in the field and to address methodological challenges that emerge in arts-based work including questions about confidentiality and representation.

Confidentiality is one of most salient ethical challenges facing arts-based researchers. For example, how and when should art be shared with others, or the artist named in public exhibition (Coemans & Hannes, 2017)? Ethical review boards might demand that the confidentiality be maintained, but anonymity might run contrary to social justice aims of researchers working with marginalized and excluded groups of people (Mykitiuk, Chapklick, & Rice, 2015). Anonymity also may run contrary to artists goals of exhibition and recognition for their creative practices.

Issues of confidentiality, ownership and public display of work are complex and multi-layered. They require attention early in the development of arts-based research projects and should be attended to throughout. Repeatedly addressing and attending to these issues may be especially important with people labeled/with IDD who may require more time to process

information and make informed decisions. However, artists labeled/with IDD who are already familiar with the experience of exhibiting their art may be better able to understand and balance the benefits and risks.

Arts-based projects with people labeled/with IDD must also bring awareness to how representations of disability impact people with disabilities in society. Representations of disability as a medicalized problem conveying inadequacy and deficit are so prevalent that they are usually accepted without challenge (Mykituk et al., 2015). A danger of arts-based research is that because art is not “precise” (Eisner, 2008), there is a potential for arts-based research products to be misunderstood and contribute to stigmatization and marginalization even if that was not the intention (Coemans & Hannes, 2017). An example of this is when art produced in research is automatically perceived to have a therapeutic purpose.

To address questions about representation arts-based researchers should engage with people represented before work is published or exhibited. “Endorsing such a process implies not that each suggestion or demand be taken up but rather that persistent concerns or critiques have a platform” (Sinding et al., 2008, p. 466). Researchers may need to change, omit, or edit their work in response to the community feedback or present a counter narrative alongside their work that acknowledges the existing tension. It is important to give people labeled/with IDD the authority to judge images that represent them (Fudge Schormans, 2014).

F. **Research Design**

1. **Background**

This study was originally designed to take place in-person at Arts of Life Glenview, a 6,000 square foot studio and gallery in the Chicago suburbs. Thirty-one artists attended in-person programming five days a week at the studio before the pandemic. Institutional

Review Board (IRB) approval was received for in-person recruitment, consent procedures, participant observation, individual interviews, and focus groups on May 12, 2020 (Appendix T). As a result of the COVID-19 pandemic, in-person programming at the studio stopped completely in March 2020 and reopened only to limited capacity in August 2020. For the duration of this study, no volunteers, students, or researchers were permitted in the studio.

In response to closures and limitations in in-person programming, the studio launched online programming via Zoom in April 2020. Online studio programming on Zoom included guided meditation; art-making prompts; opportunities for artists to share artwork with each other; problem solve art projects with staff members and volunteers; physical exercise with prompting and support; “viewing and discussion” of the work of other artists, both in the studio artists and artists outside the studio; virtual studio and museum visits; and self-advocacy and leadership training. Additionally, the studio dedicated 15 minutes every day for “login/tech help” which supported the artists to use the Zoom platform and engage in virtual programming.

Exposure and technical assistance to use Zoom paved the way for this study to be reimagined using online formats. With careful consideration for the ethical and logistical challenges and the potential benefits of online inclusive research, online methods were added to the research protocol and were approved by the University Institutional Review Board (IRB) in July 2020 (Appendix U). Because the studio underwent so many changes between in-person and online formats during the recruitment phase, the researcher reduced recruitment goals. Initial plans included the recruitment of 25 participants from the studio for observation only and six participants for observation, interviews and focus groups. Ultimately, recruitment was scaled back to include only six participants for online observation, online interviews, and online focus groups. In TABLE I the RECRUITMENT AND DATA COLLECTION TIMELINE describes

the timeline of events in the study including receipt of IRB approval, the completion of recruitment and consent procedures, the simultaneous initiation of individual interviews and observation and when each of the three focus groups was held. This figure also links the phase of the appreciative inquiry model to the data collection in the study.

TABLE I
RECRUITMENT AND DATA COLLECTION TIMELINE

July	August	September	October	November	December
<i>-(Initial protocol approved 5/12/2020 by UIC IRB, Appendix T), 7/20/2020 Amendment to include online methods approved, Appendix U -7/22/2020 recruitment begins</i>	-Consent for participants obtained by 9/19/2020	-First individual interview takes place on 9/23/2020 -Participant observation begins on 9/28/2020	-Participant observation ends on 10/26/2020 -Last individual interview takes place on 10/21/2020	-Focus Group 1 11/4/2020 -Focus Group 2 11/11/2020 -Verbatim transcription of interviews and focus groups completed on 12/5/2020	-Focus Group 3 12/9/2020 -Line-by-line coding of transcript on completed by January 3
		<i>Discovery phase of appreciative Inquiry model</i>	<i>Discovery phase of appreciative inquiry model</i>	<i>Discovery and Dreaming phase of appreciative inquiry model</i>	<i>Designing and Delivery/ Destiny phase of appreciative inquiry model</i>

2. **Recruitment and consent procedures**

To inform eligible participants about the study, staff distributed the researcher's accessible image-based participant recruitment flyer (Appendix A: Accessible Participant Recruitment Flyer). Staff were also provided with a plain language recruitment script (Appendix B: Recruitment Script). To be eligible to participate in the study participants needed to have regular attendance in the physical studio or virtual studio. The purpose of this eligibility criteria was to recruit participants who would have sufficient knowledge about the programming at Arts of Life. All six participants recruited attended in person programming 5 days per week before COVID-19. By August when recruitment for this study had concluded, only 1 person attended in-person programming at the studio 5 days per week. This person was engaged in interviews and focus groups from the physical studio via Zoom. One person attended the Zoom studio 5 days per week from their group home. This person was engaged in interviews and focus groups from their group home via Zoom. Three people attended the studio in person at least 1 day per week. One of these people was engaged in one interview from the studio via Zoom and the rest of the interviews by phone from their residence, the other two were engaged in interviews and focus groups from their home via Zoom. The final study participant was engaged in all four interviews from his family's home via Zoom but returned to live at his group home in November and attended both focus groups from the studio via Zoom.

A second eligibility criteria was the ability to respond to questions confirming consent adapted from Horner-Johnson and Bailey's (2013) research evaluating the consent capacity of people labeled/with IDD participating in health promotion research (Appendix C: Participant Eligibility Checklist). These questions were asked during the consent process and helped the researcher ensure participants' understanding of the study before they agreed to participate.

The final eligibility criteria was placement in one of three tracks within the Arts of Life Artist Enterprise programming model. The three tracks are “Career,” “Curator,” and “Educator.” According to the studio manager, the artists in these three tracks were more advanced in their creative practice and more likely to have leadership and self-advocacy experience. The career track is designated for artists focused on exhibiting and selling their own artwork who are engaged in opportunities that directly involve and advance their own careers. The educator track is designated for artists interested in learning and sharing of new artmaking skills. They attend demos, art history groups, and art talks, support peers in group settings. The curator track is for artists who concentrate on the exhibition of artwork—their own work as well as the work of others. They attend exhibitions, participate in gallery prep, and learn and discuss art history. There are two other tracks at Arts of Life, “Foundations” and “Maker.” These tracks support the work of artists who are newer to Arts of Life or to art making and are less likely to have had leadership experience in the studio.

Staff provided the names and contact information of six eligible participants and their guardians to the researcher. Only one interested participant did not have a guardian. To obtain consent from participants with guardians, the researcher first contacted the guardians by phone to briefly describe the study. Afterwards, three-way meetings were scheduled with the guardians and potential study participants to obtain consent/assent. Guardians and participants selected the platform for this meeting, either by phone or Zoom. Most decided to schedule this meeting via Zoom, but one guardian felt more comfortable with a phone call. Before the meeting, the researcher mailed the guardians and potential research participants a copy of the consent form and a self-addressed stamped envelope (Appendix D: Behavioral Consent-Assent Form). The consent form was accompanied by an accessible handout explaining the timeline of the study and

its potential risks and benefits through images and plain language (Appendix E: Accessible Consent-Assent Handout). This handout was designed to support research participants' understanding of the consent process. The participants were invited to use this document during the consent/assent meeting. Both the guardian and the participant signed and returned the Behavioral Consent-Assent Form by mail. The participant without a guardian was contacted directly. When she confirmed her interest in the study, the Behavioral Consent-Assent Form and the Accessible Consent-Assent handout were sent to her with a self-addressed stamped envelope. A second meeting was scheduled to discuss the material and obtain consent. This meeting was held by phone per the participants request. The Behavioral Consent Form was signed and returned by mail to the researcher.

Some demographic information was gathered at recruitment. The studio manager provided information about gender and age of participants. The artist's birthdays and preferred pronouns are also listed on the artists' studio profile page available publicly. All the artists in this study used either she/her/hers or he/him/his pronouns in their profile. During individual interviews, participants were asked to identify their race and/or ethnicity, but not all participants chose to disclose their race or ethnicity. Participant ages ranged from 25-62. There were two male participants and four female participants. One participant identified as being black. One participant identified as being Latino. Two participants identified as being white, and two participants did not disclose their racial or ethnic identity.

3. **Participant observation**

The researcher observed 15 hours of virtual programming offered by the studio using the observation scales instrument developed for this study as a guide for noting observation (Appendix F: Observation Scales). Notes included the daily schedule of activities; the duration

and quality of research participants' engagement in online programming (i.e., focused, distracted, intermittent); who research participants talked to and what they talked about; the content of research participants' artwork; and how research participants shared their artwork with others. The researcher only made direct notation of the artists who had provided consent/assent (and had guardian consent if applicable).

Observation of the artists during online programming helped the researcher to gain a broader understanding of what day-to-day online programming entailed. Observations were also used to triangulate data collected during individual interviews, focus groups, and member checking. The researcher matched observations with what participants said about the studio and vice versa. This kind of triangulation increases the validity and reliability of findings and can also uncover contradictions (Denzin, 1978). For example, demonstrating continuity between the artists self-report and observation, one study participant reported missing contact with studio staff and artists since they were not able to attend in-person. The participant was observed using the Zoom studio programming to talk with staff and other artists, ask them how they were and tell them that he missed them. Participating in studio programming also provided the researcher an opportunity to begin to build rapport with research participants and to gain more familiarity with how they used the online platform and potential challenges with using the platform. For example, participants at the physical studio were at times engaged in the Zoom studio programming using a studio tablet. Because they were at the physical studio space, they were wearing masks which muffled their voice. The researcher observed that some artists used headsets to amplify their voice in this setting.

4. **Appreciative inquiry individual interviews**

Participant observation occurred between September and October 2020. During this same period individual interviews were conducted (TABLE I). The six research participants were engaged in four 30-minute individual interviews each. The short 30-minute time-period was chosen to accommodate participants labeled/with IDD with a shorter attention span or who might experience interview fatigue. Most participants were able to maintain focus for 30 minutes, but some interviews ended early because the participant appeared tired or distracted. The researcher asked participant throughout the interview if they wanted to stop or continue the interview, which created many opportunities for the participant to end the interview early. Still, this was a rare occurrence and no interview ended before 20 minutes. Most interviews were scheduled one week apart so that the researcher held approximately six per week. Most artists began and ended their interview series at the same time, but the interviews were not in sync. For example, one artist completed their second interview before the other artists started their first interview, and one artist had a scheduling conflict and completed their third and fourth interview in the same week.

At the beginning of each individual interview, participants were reminded that the interview would last no more than 30 minutes and that they could stop or take a break at any time. Further, to protect the participants privacy and the privacy of other people that might live with the participant or be in the same area as the participant, participants were asked if they were in a private space where other people were not likely to walk by and overhear them or be captured by the camera. For the one participant who engaged in individual interviews from the studio, this meant ensuring that she was sitting at least 6 feet away from other participants, which the studio's COVID-19 policy ensured, and that her camera was directed at her and did not

capture other studio members behind her. Participants were reminded that if internet or technology problems arose, the interview would briefly stop while the researcher helped them resolve the problem. Participants were also reminded that interviews could be rescheduled if problems with technology became too frustrating or were not solvable right away. Consent was obtained from participants for recording the interview before every interview.

Individual interviews are an important part of the appreciative inquiry process (Cooperrider, et al., 2008). In this study, they were primarily situated in the *discovery* phase of the AI four phase model, as an opportunity for the artists to reflect on themselves, their strengths, and their role in the studio community. To support this, the interviewer used the screen-sharing tool on Zoom to show the artists their body of work available online through the studio's website. The artists were invited to identify their favorite pieces; talk about the motivation for and construction of the work; describe their favorite subject and medium; and comment on what they felt was important or notable about their work. Further, the artists were prompted to identify their strengths and best qualities and describe a moment they felt proud, happy, or excited when they were in the studio. The questions supported the artists to reflect on any experience at Arts of Life including both in-person programming before the pandemic and in-person and virtual programming during the pandemic (Appendix G: Interview 1 Script and Protocol, Appendix H: Interview 2 Script and Protocol, Appendix I: Interview 3 Script and Protocol, Appendix J: Interview 4 Script and Protocol).

In AI, individual interviews support participants' ability to reflect on the unique strengths of the community and envision possible futures (Cooperrider et al., 2008). Early in the interview process in this study, the researcher introduced the artists to the upcoming focus group prompts: "What is the best or most important to you about the studio?" and "What do you want or wish for

the studio in the future?” Prompting discussion around these questions early and repeatedly during individual interviews, as well as asking the question in plain language in different ways, helped the artists prepare for the focus groups. The artists were also prompted to plan for the art-making aspect of the focus groups during individual interviews. They were asked what kinds of images they might make to represent their ideas and what materials they might need to create those images. The researcher helped the artists plan how they would obtain the materials they needed and have them available during the focus groups.

Individual interviews were semi-structured, meaning they followed a carefully constructed but flexible interview guide. Questions were open-ended and follow-up questions related to participants’ answers and feedback. For example, participants were asked to show the researcher their favorite art piece that they had created. This led to a broad range of discussions about the subject and medium choices made and why they were important to the artist. The flexible nature of semi-structured interviews also supported the researcher to rephrase a question if the participant did not understand and re-order research questions across the four interviews if the participant appeared fatigued, bored, or distracted.

5. **Appreciative inquiry focus groups**

Focus groups have been acknowledged as locations of “critical pedagogical practice”, places where Paulo Friere³, one of the early developers of participatory research methods, claimed groups do the work of “imagining and enacting the emancipatory political possibilities of collective work” (Kamberelis & Dimitriadis, 2005, p. 889). The four phase AI supports this framing of the focus group process. After individual interviews were completed, a series of three 60-minute focus groups was facilitated. All six participants attended the first two

³ For more on Friere’s philosophy see his seminal work, *Pedagogy of the Oppressed* (1970).

focus groups. One participant was visiting family during the third and final focus group and was not able to attend.

Three artists participated in the Focus Group 1 from the studio via Zoom using studio laptops or tablets and three artists participated via Zoom from their home computers, laptops, or tablets. Before each focus group, participants were reminded that they could stop or take a break at any time. Consent for video recording was obtained from each participant before each group. To protect the privacy of group members, members were reminded not to repeat what other group members said outside of the group. Group members were also asked to take a moment to assess whether they were in a private location where others could not overhear them or walk past the camera.

The first focus group continued the *discovery* phase of the AI four phase model (Appendix L: Focus Group 1 Script and Protocol). The artists were asked to create art about “the best or most important part(s) of the studio.” First, the researcher facilitated a brief discussion in which participants verbalized their answers to the prompt and asked clarifying questions. Following Louw, Grobler, and Cowden’s (2018) appreciative inquiry research with people labeled/with IDD and their families, the question was asked a few different ways to increase the participants ability to respond to the question. For example, the question was rephrased as “What do you like about the studio?” or “Tell me something about the studio that makes you feel happy.” Some of the artists benefited from the researcher reminding them of their answer to the prompt during individual interviews and how they had initially planned to depict their response using art. After the discussion, the researcher prompted the group to begin art making.

As described above, the researcher had helped the artists prepare during individual interviews to have art materials they would need ready for the focus group. The artists

participating from the studio had white paper and markers and pencils at their desks. Two artists had these materials ready when the focus group started, one artist requested these materials from a studio staff member at the beginning of the focus group. The three artists participating from home had materials ready before the focus group began. Two of these group members used white paper, markers, and pencils. One group member who participated from home used pencil and acrylic paint on a canvas. After 30 minutes of art making, finished images and images-in-progress were shared with the group. The artists held their images in front of the camera. Five artists showed finished pieces and one artist showed an unfinished piece. Each artist was invited to give their art piece a label or title as well as offer context about the piece. Artists were asked by the researcher to describe what they see in their art, what is happening in their art, and how it relates to their lives. This “contextualization” approach was adapted from Wang and Burris (1997) by Heffron, Spassiani, Angell, & Hammel (2018) to increase the participation of people labeled/with IDD in analysis of a photo-based art in research. The researcher was joined by the other artists who also asked questions about each piece including how it was made and what motivated the artist’s decision to use certain materials and colors. At times, the researcher prompted the other artists to ask questions by asking, “Does anyone else have anything they want to ask X about their work?” Other times group interaction about artwork was spontaneous and initiated by the artists.

The second focus group aligned with the *dreaming* phase of the AI four-phase model (Appendix M: Focus Group 2 Script and Protocol). As with the first focus group, three artists participated via Zoom while in-person at the studio and three artists participated via Zoom from home. The topic of the second focus group was different from the first focus group. The artists were asked what they “wished for or wanted for the studio in the future.” Again, following

Louw, Grobler, and Cowden (2018), the question was rephrased as needed to increase participants understanding; “What would the studio look like in the future if you were granted three wishes to make the studio better?” “If all your dreams come true, what would the studio be like in the future?” After a brief period of discussion about the topic, the artists were prompted to engage in a 30-minute period of art making. Five artists created an entirely new art piece during this second focus group, but one artist continued working on the art piece she started during the first focus group. After the 30-minute art making period, each artist was again invited to provide context for their image. The researcher was again joined by group members in asking questions about the artists motivation and choices during the creation of the piece.

At the end of the second focus group, the artists were asked “Who should we share your artwork and stories with?” and “Who needs to know about how you feel about the studio?” Responses were recorded. The group was reminded that their responses from the interviews and focus groups would be combined into an initial “report” that would be shared with them for member checking at the third/final focus group.

After both art making focus groups, the artists were given the option to send a picture of their art to the researcher. The quality of images captured from Zoom were grainy and the art was sometimes cut off in the camera frame. Four artists sent a picture of their art from both focus groups to the researcher. Two artists requested help from a studio staff member to photograph and email images from both focus groups to the researcher. One artist requested help from a studio staff member to photograph and email the image she created during the first focus group but sent her image from the second focus group to the researcher directly via text. A fourth artist sent images from both focus groups to the researcher directly via email. Two artists

did not send their images to the researcher. The researcher relied on still frames from the Zoom video during data analysis.

After individual interviews and the first two focus groups were transcribed, each individual interview and focus group transcript was transferred into a master excel spreadsheet using Osborg Ose's (2016) method for qualitative analysis using Excel. Using Excel allowed for the researcher to search the entire data set for phrases based on prevalence and later to systematically code and organize data line-by-line. Initial themes and subthemes were identified by the researcher based on a search of the entire data set for the prevalence of key words in the focus group prompts: "best," "important," "like," "love," "want," "wish," and "change." Further, the researcher used the art and the artist's contextualization of their art as a touchstone. For example, when asked to draw the most important or best thing about the Arts of Life, one artist drew her worktable at the studio. No one else specifically named their studio workspace as important, but the researcher prioritized this piece of data because it emerged from the art. A list of initial themes and subthemes and the artists images that illustrated these themes was developed. This list was put into a PowerPoint slideshow presentation (Appendix K- Presentation of Findings at Final Focus Group). Because this initial transcription and analysis was a lengthy process, the third and final focus group was held one month after the completion of the second focus group.

During the third focus group, the researcher shared the PowerPoint presentation with themes one-by-one and asked: Did I understand you correctly? Is this what you said or meant to say? Is this true? Would you change or add anything? Is there anything else that is important to say or add? Participants provided feedback and the PowerPoint presentation was amended to include their insights (Appendix N: Focus Group 3 Script and Protocol).

In alignment with the *designing* and *discovery* phases of the AI process, during the final focus group, participants were also asked to think about how they might achieve their wishes and goals. These responses were recorded in the artists' own words on the PowerPoint in screen-sharing mode during the focus group (Appendix K: Presentation of Findings at Final Focus Group). Two copies of the final PowerPoint -- with amendments made during the member-checking, including the artists' ideas about how to achieve their goals -- were printed and were sent to each artist to share with whomever they chose.

6. **Data analysis**

The first stage of data analysis began with the artist's contextualization, their telling stories and offering meaning and context about their artwork described in more detail above. The second stage of analysis involved "codifying" images and text-based data from this project. This was done using Braun and Clark's six-phase thematic analysis method (2006) which includes: 1) familiarizing yourself with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report (2006). This second stage of data analysis followed inductive and realist frameworks and attempted to stay as close to the meanings and realities of participants as was possible. Initial line-by-line coding used the participants' own words. Three hundred and seventy-three codes were initially generated from the data. The entire data set was then collated by code and the researcher began the process of searching for themes. This process led to a reduction in the number of codes because some codes appeared redundant or not supported by enough data. A preliminary thematic map of candidate themes and subthemes was generated.

At this stage, greater attention to observation notes, artwork and my own personal reflections throughout the study were brought into analysis. For example, one artist in the study

made a lot of jokes during the study and during online studio programming. While sometimes his jokes elicited laughs, sometimes his peers appeared irritated by their frequency. His peers demonstrated their annoyance by ignoring him or making irritated noises, for example groans. Their irritation was never discussed outright, but it was present and observable. Additionally, at this point a more intentionally interpretative and constructionist analysis was employed where how the meanings, realities and experiences of the artists are affected by their social positioning was considered (Braun & Clarke, 2006). For example, the artists expressed an interest in more opportunities to be social. One artist described limited opportunities to be social due to transportation barriers. Analysis explored how the exclusion of people labeled/with IDD in aspects of society, for example limited options for accessible transportation, impacted their expressed values and desires for the future. Thematic maps were developed that most accurately represented the data set as a whole (Figure 6 and Figure 7).

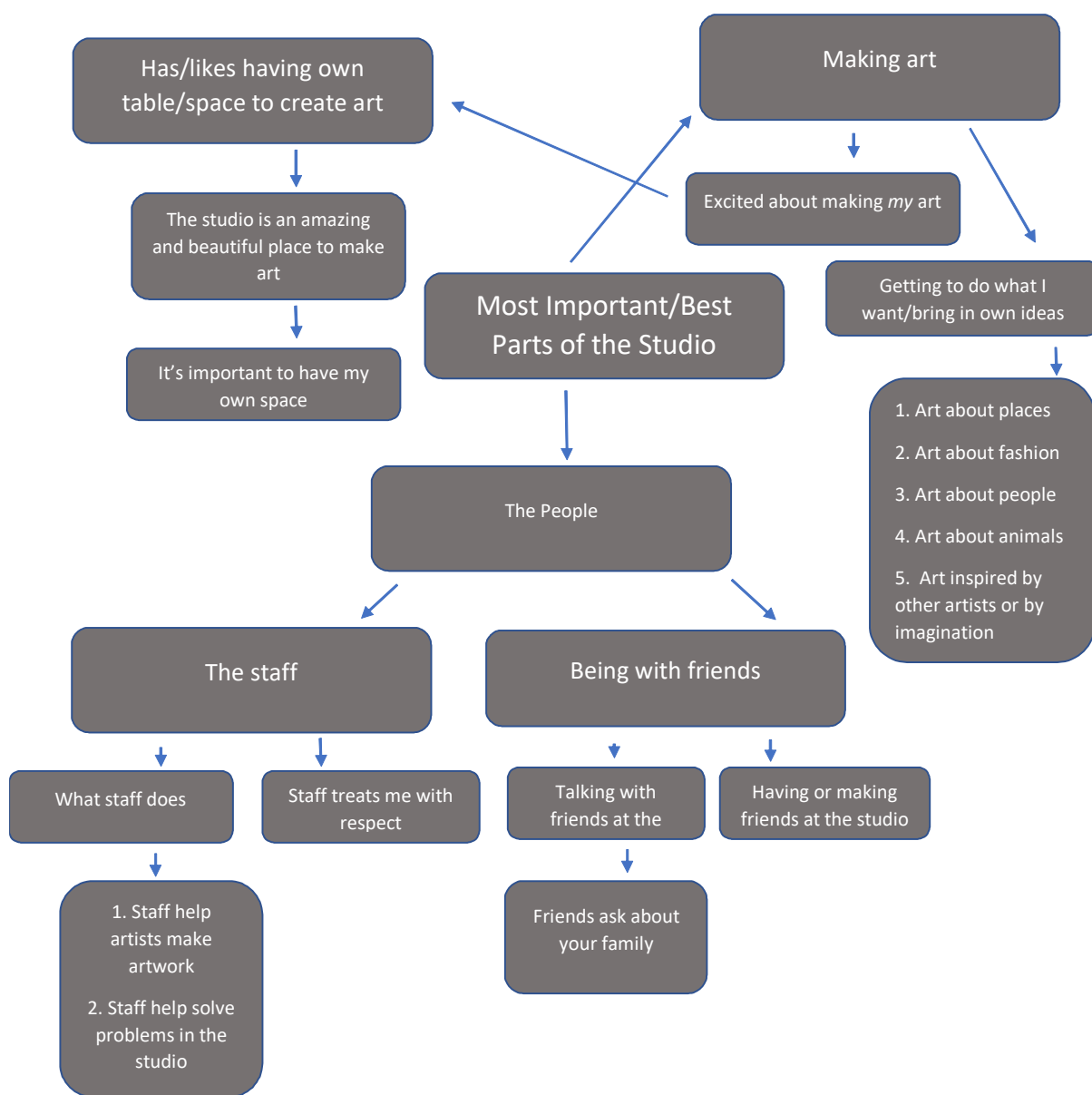


Figure 6. Thematic map 1

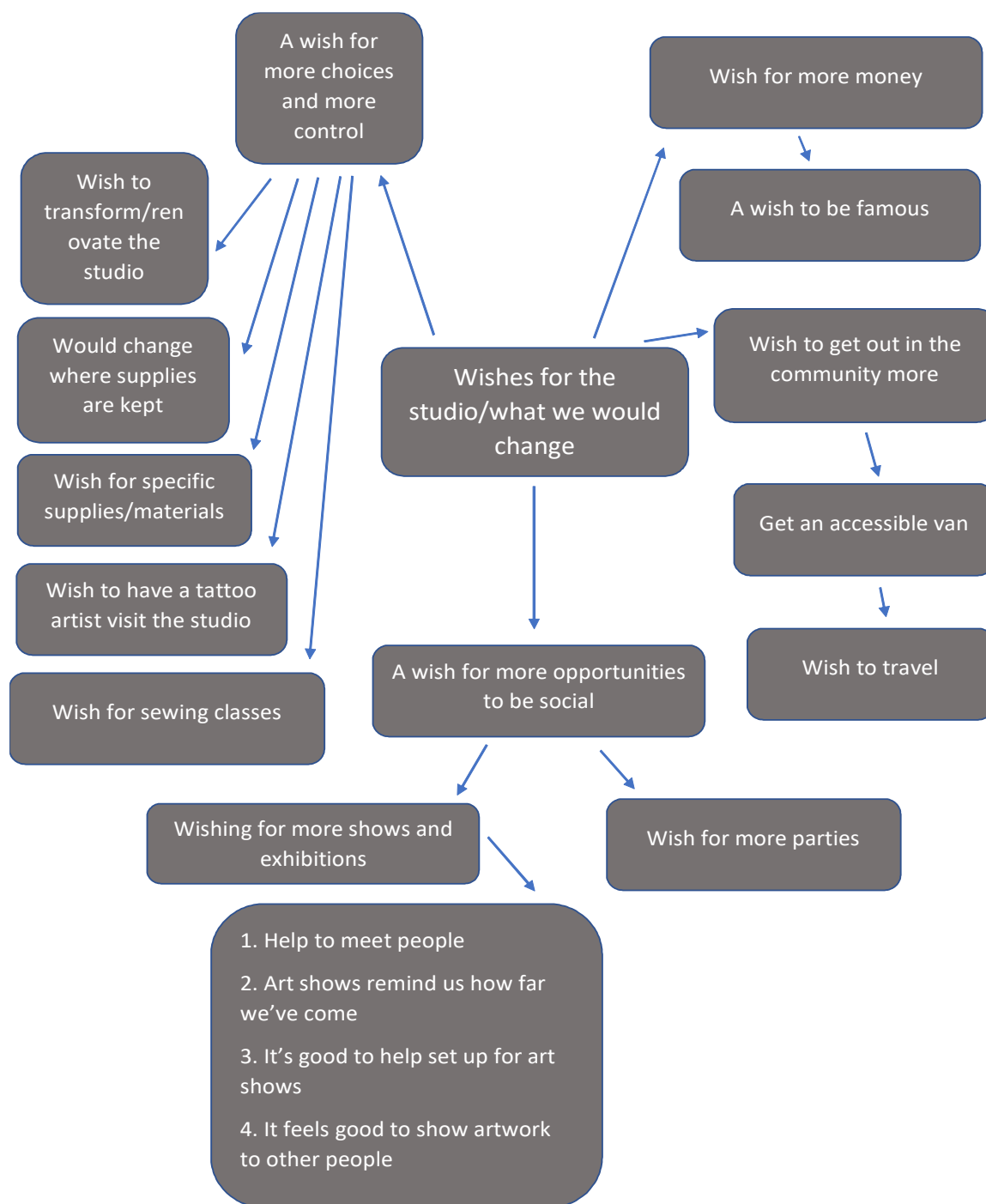


Figure 7. Thematic map 2

7. **Dissemination of findings**

Participatory and inclusive methodologies are not only asked to generate research that creates positive and meaningful change in the lives of people with disabilities, but also to make research findings accessible to disabled people (Grace, 2013) The final PowerPoint shared with participants during the third focus group, and then amended with their insights and action plans, was written in plain language, mostly in their own words. The artists received two copies of a listing of their expressed values and desires, in the form of a printed PowerPoint, as indicated in the IRB approved protocol. At the third and final focus group, the artists were reminded who they identified they would like to share the report with, including family members, guardians, and staff members. To protect confidentiality, all identifying information including names, artwork and direct quotes were left out of this report, and the artists were reminded not to reveal the names or contributions of other group members when sharing the report with others.

The researcher followed up with phone calls to each artist to make sure that they received the report in the mail. During these calls, the researcher learned that many of the artists planned to follow through with their desire to share the document with others. About a month after the final focus group, the Arts of Life studio manager reported to the researcher that she had received a copy of the document from one of the artists and that a group of the artists planned to share their wishes and desires for the studio at the next monthly online studio meeting held via Zoom. The researcher was invited to this meeting as a guest, not a facilitator.

Five artists who participated in the study attended the studio meeting. One artist from the study was not present due to a scheduling conflict. A total of 11 artists, including the five artists

from the study were also present at the studio meeting. Additionally, six staff members and the studio's Director of Development were present.

During the studio meeting, the studio manager introduced wishes and desires from the list the group had generated. The studio manager did not directly call on any of the artists from the study to talk about their wishes and desires, but all five artists involved in the study spoke up immediately to describe why the desire or wish would be beneficial to the studio. The studio manager facilitated a vote by show of hands (staff did not vote) that measured the groups interest in the idea. If the idea was supported by at least 50% of the group, action items were discussed to make the desire become a reality. For example, one of the artists from the study described her desire to learn about tattooing. More than half of the other studio artists confirmed their interest by raising their hands. The group discussed who they knew that might be able to provide a tattoo demonstration. Another artist recalled that a volunteer had experience as a tattoo artist and some experience teaching. The studio manager planned to follow up with that person about their availability to provide a tattoo demonstration at the studio.

8. **Data management and confidentiality**

Conducting individual interviews and focus groups via Zoom required special attention to privacy and confidentiality. Some of the participants engaged in interviews and focus groups from their homes or from the studio, raising questions about who might be nearby and potentially overhear their conversation. Further, Zoom sessions were recorded. Research participants were informed and provided consent to be recorded, but other people in the same location who might walk past the camera might not be comfortable being recorded. To address this, research participants were instructed to engage in individual interviews and focus groups from a private location where non-research participants were not likely to overhear the interview

and were not likely to be captured by the camera without their knowledge. For example, if the research participant was engaged in an individual interview from their home, they were coached to sit in a private space with a door, or at least in a low traffic area with a wall behind them. Participants were reminded/supported to follow this protocol at the beginning of each interview and focus group. All Zoom interviews and focus groups were also password protected. Videos were deleted quickly from Zoom cloud storage and participants' names were replaced with coded identifiers.

9. **Participant compensation**

All research participants received \$55 for their participation in the study.

Participants received \$5 in cash after their fourth interview and \$50 in cash after the second focus group. The decision was made to send payment after the second focus group instead of the third because the third focus group was held a full month after the second focus group. It was hoped that sending payment after the second focus group would reduce the potential for anxiety related to not getting paid. Participants received compensation by mail. Participant and guardian mailing addresses were gathered during the consent/assent process. The researcher called each participant to ensure they received payment. One participant did not receive payment and was sent a second payment which they confirmed was received.

IV. INCLUSIVE ONLINE RESEARCH WITH PEOPLE LABELED WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES DURING THE COVID-19 PANDEMIC: TECHNOLOGICAL ADAPTATIONS

This article has been published in the *Journal of Enabling Technologies* special issue on the value and potential of enabling technologies for people with disabilities during COVID-19 available at <https://doi/10.1108/JET-12-2020-0051/full/html>.

A. Structured Abstract

This paper reports process findings of two online inclusive research projects with people with intellectual and developmental disabilities (IDD). It includes a discussion of the potential benefits and barriers of online inclusive research and its impact on the future of inclusive research. Two researchers describe the transition of their inclusive research projects from in-person to online formats and highlight how they operationalized the principles of inclusive research throughout these transitions. Potential benefits of inclusive research include enabling participation of research participants with IDD when in-person methods are not safe or feasible, increasing participant control of the research environment, stimulating participants' online skill development, and reducing geographic and support barriers to participation in research. A barrier to participation in online inclusive research includes people with IDD's lack of access to online spaces and web-enabled devices. Additionally, people with IDD have support and communication needs that are not always accommodated by online skills training and access to the internet. To conclude, inclusive researchers need to develop skills and reflexivity specific to online research environments. Inclusive online research with people with IDD brings unique ethical and methodological challenges that have not been well explored in the literature. Engaging people with IDD in research using online tools expands the terrain of inclusive research, opening possibilities for even greater inclusion and participation.

B. **Inclusive Abstract**

Two researchers could not do their research studies because of the pandemic. They did them online. The studies were with people with disabilities. Being online can make it easier for people with disabilities to be a part of a study. They can choose how to be a part of the study. They can also learn more skills. Being online can be hard for people with disabilities. Some do not have a computer or smartphone. Some do not know how to use them. Researchers may not know how to help people with disabilities to be a part of an online study.

C. **Introduction**

In March 2020, as the COVID-19 pandemic was beginning to have widespread effects on everyday life in the U.S., the authors of this paper were in the implementation stages of two separate inclusive research projects conducted with people labeled with intellectual and developmental disabilities⁴ (IDD). The authors were challenged to consider how their research projects could continue or be re-imagined in online formats during an extended period of restricted in-person contact. In this paper the authors discuss the transition of their research projects with people with IDD to an online environment. They highlight how they operationalized the principles of inclusive research throughout this transition, taking into account the technology and online access barriers many people with IDD experience. Additionally, they reflect on the impact of online research on the future of inclusive research methods.

⁴ Self Advocates Becoming Empowered, the largest self-advocacy organization for people with intellectual and developmental disabilities prefer person-first language and therefore is used in this paper (Self Advocates Becoming Empowered, n.d.). The authors also acknowledge that IDD is a socially constructed label (Rapley, 2004).

1. **The impact of the COVID-19 pandemic on people with intellectual and developmental disabilities**

Sixty-one million adults, 24% of the U.S. population, have a disability (Centers for Disease Control and Prevention, 2020). This includes approximately 7.4 million Americans with IDD (Larson, Eschenbacher, Anderson, Taylor, Pettingell, Hewitt, Sowers, & Bourne, 2008). Throughout history people with IDD have endured widespread abuse, neglect, segregation, and institutionalization (Braddock & Parish, 2001). Despite advances in public policy and destigmatization of disability, many people with IDD still experience marginalization, have low levels of participation in society and small social networks (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). They also experience barriers to good health, are less likely to be physically active and are less likely to receive preventative care (Havercamp, 2015).

The consequences of long-standing inequities are resulting in dire outcomes for people with IDD during the COVID-19 pandemic. They are at increased risk of infection with COVID-19 and are negatively impacted by complicated health outcomes of infection. Many have lost support from an already limited pool of trained caregivers and community service providers, and are increasingly socially isolated (Constantino et al., 2020).

2. **Technology and online access for people with intellectual and developmental disabilities**

Access to the internet and electronic devices influences educational, economic and community participation opportunities (Chadwick, Wesson, & Fullwood, 2013). There are indications that young people with IDD use social media more than the IDD community overall (Borgström, Daneback, & Molin, 2019), but compared to other groups, people with IDD are least likely to have access to the internet and benefit from the opportunities it provides (Chadwick et

al., 2013). This is the result of financial and economic disadvantages, lack of attention to their needs in the development of technology, and the educational and training barriers they experience (Chadwick et al., 2013). Additionally, guardians, often family members who are court appointed to make legal decisions for adults with IDD, may limit online access because of fears about safety (Chadwick et al., 2013). As people increasingly live their lives online due to the COVID-19 pandemic, those with disabilities are yet again left behind due to persisting barriers to online access (SHADAC, 2020).

3. **Inclusive research with people with Intellectual and developmental disabilities**

Historically, research on IDD was *about* people with IDD (Hillier, Johnson, & Traustodittir, 2007). It often perpetuated their marginalization by justifying segregation, promoting eugenic ideas, and denying their human rights (Stone & Priestly, 1996). In the last several decades, the paradigm has shifted to prioritize inclusion of the perspectives of people with IDD in research. A growing body of research is conducted *with* people with IDD (Hillier et al., 2007). As a result, researchers have designed accessible and creative research methods that allow for the strengths of people with IDD to emerge (Booth & Booth, 1996). This includes research procedures in which people with IDD are included as more than just research subjects or respondents, also called ‘inclusive research’ (Walmsley, 2001).

Inclusive research is a philosophical approach that can be applied to any method (Williamson et al., 2020). It is an umbrella term that is used across fields and disciplines and embraces a range of research approaches including participatory, emancipatory, and community/peer-led research (Nind, 2014). When applied to IDD research, it captures collaborations in which community members with IDD work with researchers (Schwartz,

Kramer, Cohn, & McDonald, 2020), and in some cases are called co-researchers (Bigby et al., 2004). Inclusive research aims to contribute to social change and improve the quality of life and belonging of people with IDD. Inclusive research pursues issues that matter to people with IDD and draws on their experience to inform the research process and outcomes. Inclusive researchers stand as allies with people with IDD in exploring and investigating their issues. In inclusive research people with IDD are included in developing the research questions and procedures. Study materials and results are communicated in plain language that is short and clear and accessible to people with IDD.

To conclude, inclusive research recognizes, fosters and communicates the contributions people with IDD can make (Schwartz et al., 2020; Walmsley & Johnson, 2003; Walmsley et al., 2018). Participation in research *for* and *by* people with IDD is an avenue for this population to let their voices be heard, and to contribute to knowledge production that ultimately can benefit their lives and communities (Walmsley & Johnson, 2003; Walmsley et al., 2018). Such self-representation is key to the development of self-advocacy, the ability to speak up for oneself (SelfAdvocacy.net, 2021).

While online research methods were emerging as an important tool in qualitative research even before the COVID-19 pandemic began (Salmons, 2012), inclusive online research with people with IDD brings unique ethical and methodological challenges that have not been well explored in the literature. Inclusive researchers in online environments are responsible for attending to the accommodations that people with IDD need, such as using plain language and visual aids, to respond appropriately to the difficulty many people with IDD experience with written and verbal communication (Atkinson, Jackson, & Walmsley, 1997). Additionally, they need to address and respond to the social barriers that limit the participation of people with IDD

in research, such as resolving lack of access to the internet and accessible technology.

Researchers must consider how the online research environment might impact data collection with people with IDD, what barriers exist to this process and what opportunities it brings. Given the lack of data about best practices, operationalizing the principles of inclusive research is key to fostering its development (Schwartz et al., 2020) and process findings are as important as the research outcomes themselves (Walmsley et al., 2018). The two case studies below describe the process of recruitment, obtaining consent and data collection using online tools for two inclusive research projects.

D. **Case Study 1: Art-Based Participatory Program Evaluation with Artists with Intellectual and Developmental Disabilities**

1. **Background**

In the 1970's and 80's community-based art studios for artists with IDD, sometimes called 'creative art centers', began to emerge in the U.S. By 2013 there were over 120 studios across the country (Finley, 2013). Art studios for people with IDD typically offer art materials, a space to create art and staff that provide personal assistance, skills training, and professional development (Sellen, 2008). In the U.S., some studios also have a social service mission aimed at having a positive impact on the lives of the artists by fostering their social networks and community inclusion (Vick & Sexton-Radek, 2008).

Arts of Life is a creative arts community with two different studio locations in the Chicago area serving a total of 60 artists. Arts of Life provides artists with IDD a collective space, training, and support to practice as artists (Arts of Life, n.d.). Arts of Life was deeply impacted by the COVID-19 pandemic. Both studios were closed to in-person programming in March 2020. In August, the studio was able to reopen with restrictions on the number of artists and staff allowed in the studio at one time. No volunteers, students or researchers were permitted

in the studio. Many of the artists were unable to return to the studio even months after the studio's 'soft' reopening due, in some cases, to restrictions in community access enforced by group homes and other residential facilities where some artists live.

In response to the prospect of long-term closure and isolation of the artists, the studio launched full-day online programming via Zoom in April 2020. Zoom is a popular Voice-over Internet Protocol (VoIP) technology which allows for synchronous, real-time audio and visual exchange across devices (Zoom, n.d.). Online studio programming on Zoom included daily instruction on how to utilize the online platform, guided meditation, art making prompts, and opportunities for artists to share artwork with each other and virtual studio and museum tours.

2. **Research aim and procedures**

Aligned with the inclusive research principle of focusing on issues important to people with IDD, the aim of the study was to include artists with IDD in an evaluation of their studio programming. The study used an approach to evaluation called appreciative inquiry. Appreciative inquiry is an inclusive approach to organizational and community evaluation that draws from the unique insights of community members and invites them to identify the strengths of their community and what they would like to see in their community in the future (Cooperrider et al., 2008). Data is collected through individual interviews and group interviews (Cooperrider et al., 2008). The original goal of the study was to recruit 31 artists at one of the Arts of Life studios. Data collection was planned to include in-person interviews and focus groups with a subgroup of 6 of these 31 participants, with the remaining 25 participants only participating in the researcher's in-person observation at the studio. With in-person research no longer possible due to the COVID-19 pandemic, the research procedures were amended and

approved by the University's Institutional Review Board (IRB) to be conducted online through Zoom.

3. **Recruitment and consent procedures**

Staff at the Arts of Life studio agreed to assist with recruitment of participants. Staff distributed the researcher's accessible image-based recruitment flyers and plain language recruitment scripts to inform participants about the study. Inclusive researchers use plain language and image-based research materials to increase the comprehension and participation of research participants with IDD (Kidney & McDonald, 2014). Staff then provided the names and contact information of interested participants and their guardians to the researcher. During recruitment, participation in online programming dropped and was reduced to two hours per day as some artists moved back into the studio for in-person programming. The changes in programming and overall emotional toll of the COVID-19 pandemic caused strain on staff, artists, and the researcher. Even though the goal of the study was to recruit 31 participants, the researcher scaled back recruitment efforts to secure only six participants to not overextend the staff and artists and studio community overall.

Six participants were engaged in participant observation, four 30-minute individual interviews, and three one-hour focus groups. Thirty-minute interviews were designed to accommodate participants with a shorter attention span or who might experience interview fatigue especially on the Zoom platform. Most participants were able to maintain focus for 30 minutes, but some interviews ended early because the participant appeared tired or distracted. The researcher asked participants throughout the interview if they wanted to stop or continue the interview, which created many opportunities for the participant to end the interview early. During the one-hour focus group, one participant left the room and returned periodically,

indicating that it may have been difficult to maintain focus for a full-hour. The online format increased inclusivity in this case because it allowed for the participant to leave and return freely based on their needs.

All but one of the artists who were recruited for participation in the study had a guardian. Therefore, guardians had to provide consent for these artists to participate in the study, and the participants had to provide assent. Initially planned in-person, the consent/assent process for this project was moved to be completed by phone, Zoom and mail. The researcher first contacted the guardians by phone to briefly describe the study. Afterwards, three-way meetings were scheduled with the guardians and potential study participants to obtain consent/assent. Guardians and participants selected the platform for this meeting, either by phone or Zoom. Most decided to schedule this meeting via Zoom but some felt more comfortable with a phone call.

Before the meeting, the researcher sent the guardians and potential research participants a copy of the consent form and a self-addressed stamped envelope by mail. The consent form was accompanied by an accessible handout explaining the timeline of the study and its potential risks and benefits through images and plain language. This handout was designed to support research participants' understanding of the consent process. The participants were invited to use this document during the consent/assent meeting.

Conducting consent/assent meetings via Zoom helped prepare research participants to use the platform. The consent/assent process is an important opportunity for researchers to build rapport with participants with IDD (Cameron & Murphy, 2007) and can also be important for establishing and building rapport with staff members and guardians who often have a gatekeeping role in the participation of people with IDD in research (Carey & Griffiths, 2017). Building in accessible tools, scheduling multiple meetings, giving participants choice and

control about where and when they provide consent and making consent an ongoing process throughout the study served to reinforce inclusive research principles of accessibility, participation, and empowerment.

4. **Data collection**

a. **The use of Zoom**

Studies suggest that research participants' familiarity with the VoIP platform being used is a key factor in building trust and rapport in online research (Archibald, Ambagtsheer, Casey, & Lawless, 2019). Zoom was chosen for this study because participants were familiar with Zoom through their engagement in online programming designed by studio staff. This online programming included initial training conducted by studio staff and daily reminders on how to log-in and troubleshoot problems with the platform. This research project continued Zoom skills training by reminding participants how to troubleshoot technological problems before every interview and focus group. For example, participants were reminded to wait a few moments if their screen froze due to connectivity problems and were informed that the session could be rescheduled if connectivity problems persisted and were disruptive. Participants were tolerant of technological and connectivity problems. Freezing and pauses in the video stream were a persistent problem during some, and an occasional problem during most, individual interviews. All participants were given the option to have interviews conducted by phone, but only one participant selected this option. Connectivity issues also forced the researcher to ask questions more slowly and clearly and wait longer periods between responses, which may have been helpful for some participants who may have benefited from a slower pace that is more accessible to them.

b. **Security and privacy**

Security and privacy are important considerations in inclusive research. A feature of some VoIP platforms, including Zoom, is password protection. Researchers can send a personal invitation to participants with a password and link to join the meeting. This creates more privacy because only invited participants can join the meeting, but it also created barriers for some participants. Many participants in this study did not have a personal email address or their own personal web-enabled devices such as a computer, tablet, or smartphone. Those that did have access to a device and a personal email account were unsure how to use the device or sign into their email independently. Studio staff, residential staff, and guardians set up the computer, received the Zoom link and opened the Zoom session for the majority of participants. This created an additional task for staff members and guardians, already strained by the pandemic. It also emphasized the gatekeeping role that staff, and guardians can have in research with people with IDD. Without access to web-enabled devices and training to use those devices people with IDD must rely on others to participate in some online research.

Study participants were reminded how to protect their own privacy and the privacy of those around them while using the online platform. One of these reminders consisted of participants being instructed to find a private space with a door or to sit against a wall so that background activity was not captured by the camera. These are skills that could potentially support participants' safe engagement in online environments beyond the study.

c. **Visual tools**

Some people with IDD have communication challenges that limit their participation in primarily talk-based methods (Heffron et al., 2018). Visual illustrations in handouts, interview guides and consent materials are used in inclusive research to improve the

experience and understanding of people with IDD (Kidney & McDonald, 2014). Screen sharing, available through many VoIP platforms, makes this possible in the online research environment. The researcher used the screen sharing tool to show an image-based study timeline, to prompt discussion about specific works of art created by the artists and to provide visual prompts to questions. For example, when asking a question with multiple answers, possible answers were visually displayed on the screen and numbered or color-coded to differentiate them. Visual prompts at times were altered during the session to meet the needs of participants, for example, words were enlarged or language changed to better engage participants. Additionally, the screen sharing tool was used during the final focus group for member checking, a strategy used to increase the authorship of participants in inclusive research. The researcher presented emerging themes from the study and participants suggested edits which were made directly into the document which was viewable by the entire group.

d. **Video recording**

Many VoIP tools allow for video recording as well. In this study, participants were prompted to consent to being video recorded at the beginning of the interview and focus group both by the researcher and also by the VoIP platform. While video recording equipment might be awkward or distracting during an in-person interview, VoIP video recording was not noticeable to the researcher and perhaps equally unnoticeable to research participants. It has been suggested prior that participants in online interviews do not see, feel, or experience the difference between being recorded and the conversation not being recorded (Brown, 2018). Online researchers working with people with IDD should consider ongoing consent measures as an ethical component of inclusive research in which researchers remind participants they are

being recorded, conceptualizing informed consent as a process that is confirmed throughout interviews and focus groups.

Summary of strategies that increased inclusion in this online study:

- Consider limiting recruitment size to ensure that sufficient online support and accommodation can be provided to study participants.
- When necessary, work with guardians and caregivers to help participants log-in to online platforms.
- Support participants to manage their needs in online research, for example by taking breaks or turning off their video stream.
- Take time to address technological and online privacy issues.
- Use the screen sharing tool to share visual aids like question prompts and study timelines. Visual aids can be altered in real-time to accommodate individual needs.

E. **Case Study 2: Inclusive Translation and Dissemination of Special Olympics Health**

Data

1. **Background**

The mission of Special Olympics International (SOI) is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities. Over 170 local Special Olympics Programs implement a variety of sport, health, and education activities to facilitate inclusion of people with IDD in communities throughout the world (Special Olympics, n.d.). The Special Olympics Research and Evaluation (R&E) department measures the impact of SOI's strategic plan and local Special Olympics Program-led activities by collecting and analyzing health data and evaluating the implementation of new health programming (Special Olympics, n.d.).

The analysis of Special Olympics' health data shows that people with IDD have poor health. Almost half of athletes have hypertension (Schroeder, DuBois, Sadowsky, & Hilgenkamp, 2020) and they have as many chronic health conditions at age 20 as nondisabled people have at age 50 (Special Olympics, n.d.). Addressing health inequities experienced by

people with IDD requires their input. Research that engages with this community can impact the formulation of policy solutions that can benefit them (Cacari-Stone, Wallerstein, Garcia, & Minkler, 2014). Additionally, people with IDD need information about health that is accessible to them. There have been favorable reports on the reception and uptake of adapted health information by people with IDD and those who support them (Chinn & Homeyard, 2017).

2. **Research aim and procedures**

The goal of the collaboration between Special Olympics R&E and the University researcher was to increase the accessibility of SOI health data for a variety of audiences, including Special Olympics athletes themselves. The researcher reviewed the data reports published by SOI and developed a series of accessible resources in plain language and videos that explained the outcomes of SOI's health evaluation. Some of the topics included an introduction to Special Olympics R&E, blood pressure, oral health, and aging. The researcher created scripts which provided the foundation for brochures and videos.

The aim of the study was to acquire feedback from Special Olympics athletes on the accessible resources so that they could be more inclusive and effective. Before the outbreak of the COVID-19 pandemic the researcher had planned to host two sets of two focus groups with five Special Olympics athletes each.

a. **Collaboration with co-researchers**

The researcher recruited a Special Olympics athlete to serve as a paid co-researcher for this project. The co-researcher was able to independently complete the University's online human subjects research training in about eight hours. He met with the researcher twice to provide feedback on drafts of the scripts and accessible resources. The co-researcher indicated which word usage was preferred by athletes. Additionally, he helped rewrite

sections of scripts to make them more accessible by dictating sentences to the researcher. When the co-researcher received a full-time job offer, he had to withdraw from the project. The collaboration with a co-researcher with IDD was key to this project, and therefore the researcher recruited another Special Olympics athlete who was interested to serve as a co-researcher for the project. Both co-researchers had access to a web-enabled device and had internet access at their home and communicated with the researcher by email and through VoIP meetings both before and during the COVID-19 pandemic.

Several structural barriers complicated the inclusion of co-researchers in the project. The co-researchers had to be hired as consultants for Special Olympics as the University's HR department did not allow for individuals without prior research training to be hired. To ensure co-researchers with disabilities are paid appropriately, this barrier at Universities like the one this study was conducted at needs to be removed. Additionally, University mandated human subjects research training is often inaccessible to people with IDD. The second co-researcher (henceforth referred to as 'co-researcher') had to meet with the researcher five times (both in person and through Zoom) to complete the 17 modules of the training so she could participate and assist with data collection and analysis for the study. These meetings became part of the research training provided by the researcher to the co-researcher, and part of the research process (Strnadová et al., 2014).

During in-person and Zoom meetings and sometimes through email, the co-researcher reviewed the scripts and health topics, and provided feedback to the researcher on information that would be most useful and language that would be easily understood by people with IDD. The co-researcher also provided written feedback. For example, she recommended to tell athletes what they can do to keep their blood pressure in a normal range. Additionally, the co-researcher

provided feedback on the brochures and pencasted videos that were created after the completion of the scripts and gave insights into different learning and communication styles athletes with IDD may prefer. The researcher used the co-researcher's recommendations in producing final drafts of the scripts, brochures, and videos to share with a sample of Special Olympics athletes for feedback through focus groups. The researcher also met with the co-researcher to discuss the focus group protocol.

b. **Changes to the research protocol after the outbreak of the COVID-19 pandemic**

Immediately after recruitment for the focus groups with athletes from the Chicago area was completed, stay at home orders due to the COVID-19 pandemic were issued and in-person research was suspended. The researcher and co-researcher met through Zoom to discuss an alternative approach to completing the data collection as the focus groups could no longer be completed as planned. The first option discussed was to wait and conduct the focus groups when in-person research could resume. However, it was unclear how long this would take. Therefore, it was decided to explore options to complete the data collection through an online format. Both the researcher and co-researcher had some concerns about how to conduct a focus group with five individuals with IDD online while ensuring the participants would receive sufficient individual support to be able to successfully participate. The co-researcher also anticipated that participants who did not know each other might feel shy or uncomfortable in an online setting. Additionally, both the researcher and co-researcher did not have experience facilitating focus groups with people with IDD online. Therefore, they decided together to change the focus groups to online individual interviews with five athletes on a VoIP platform of their choosing to allow sufficient individual support being able to be provided to participants.

Each athlete would receive a stipend for participating in an interview. Accessible handouts were emailed to athletes to use during the interviews. They contained pictograms and short sentences to describe the interview questions and topics.

3. **Recruitment and consent procedures**

The co-researcher indicated that many Special Olympics athletes use social media. Therefore, information about the interviews was shared by Special Olympics International on a social media platform viewed by athletes. Interview participants were recruited nationally spanning several time zones. Five athletes contacted the researcher from their personal email addresses to express their interest in the study within a few hours after the social media post. As soon as recruitment was completed the social media post was closed. After recruitment, the researcher sent the participants the consent forms. Four of the five participants printed out the form from an email, signed it and sent it back by email or mail to the researcher. One participant could not print the form and received it by mail with a self-addressed envelope for return. Two participants had guardians and they independently obtained their guardian's signature for consent.

4. **Data collection**

The researcher sent the interview handouts, brochures and weblinks to the participants by email as well as the accessible resources for review. All participants were able to download the files and access and view the videos. Participants were given the option to complete the interview by phone, Zoom or Webex and all requested for the interview to be completed by Zoom as they had familiarity with the platform. Participants were asked to indicate when they were available for an interview. The researcher invited the participants to a scheduled

Zoom meeting including a link in an email for them to access the platform. All participants had a web-enabled device and internet access.

All participants lived independently or with a family member, versus in a group home or other residential facility. All but one of the participants participated in the interview individually without evidence of others present nearby. One participant had her mother participate in the interview with her. It is important in inclusive research to support individuals with IDD to participate in research on their terms, which includes the presence of an advocate or someone who supports them like a staff member or relative if they so choose. This approach recognizes the value of interdependence and support in providing accommodation for persons with intellectual disabilities in research participation (Caldwell, 2013).

The interviews started with an introduction to the study by the researcher who also asked participants for permission to record the meeting which was granted by all participants. Introductions were then exchanged. The co-researcher included in her introduction her involvement in Special Olympics. The presence of the co-researcher helped build rapport with the participant, as they shared the same community. The interview protocol was intentionally kept brief so that the interview length would be manageable for participants. The interviews lasted between 20 and 40 minutes. Participants remained focused for the duration of the interviews and did not express fatigue.

The co-researcher expressed interest in learning how to conduct research interviews independently. The interview with the first participant was conducted by the researcher and the co-researcher shadowed, during the second and third interview the co-researcher asked part of the questions. During the final interviews the co-researcher led the conversations and the researcher provided support when necessary. The researcher transcribed the interviews and took

the lead in editing the accessible resources to incorporate the athletes' feedback and reflect their preferences. This division of work reflects one of the main approaches in inclusive research when people with and without IDD work together based on their different skills and interest (Bigby et al., 2014).

Summary of strategies that increased inclusion in this online study:

- Choose online data collection strategies that are accessible and allow people with IDD to fully participate.
- When possible, choose an online platform that most participants are familiar with.
- Take into consideration the researcher and co-researcher's levels of technological skill.
- Do not neglect the need of participants with IDD to have a trusted individual of their choosing to support them in online research.
- Send visual aids with information about the study to research participants before data collection commences so they can be referenced while conducting the interview remotely.
- Keep interview protocols in online research brief so that they are manageable for participants with IDD.

F. **Conclusion**

The inclusive research projects presented in this paper reflect both the capacity of people with IDD to adapt to creative and unconventional ways of communicating and the flexibility of qualitative research methods. During a difficult time for both research participants and researchers dealing with stressors caused by the COVID-19 pandemic, both studies were able to be redesigned. Recruitment, consent, and interviews were transitioned by the research teams from in-person to online environments using online tools including VoIP (Zoom) and email. Participants in the first case study had less familiarity with Zoom, most had no personal email address or personal web-enabled device and, therefore, depended more heavily on staff members and guardians to connect them to the platform for the study. But, once connected, participants used the platform to communicate their perspectives to the researcher over the course of multiple interviews. They also used the online platform to connect with each other during focus groups

during an extended period of separation due to the pandemic. Several aspects of online research increased the studies' alignment with inclusive research principles including that participants had more opportunities to take breaks and that the screen sharing tool allowed visual aids to be altered and shared in real-time. Further, participants gained familiarity with troubleshooting technological challenges and protecting their privacy online.

In the second case study, research participants were more experienced with being online, had personal devices, email addresses and access to social media. Nevertheless, the researcher and co-researcher decided to use online individual interviews over focus groups. Online research supported the inclusion of participants with IDD in this project by allowing them to participate in the research on their own terms, which included selecting the online platform and someone to support them during the interview. Additionally, the inclusion of a co-researcher in the project helped build rapport with interview participants and increased a sense of comfort in an unfamiliar online space.

These differences in approaches by the research teams highlight the complexity of inclusive research. Key to successful inclusive research is being responsive to the heterogeneity of people with IDD (Stack & McDonald, 2014). This includes meeting their unique individual support needs, following their various communication styles and supporting their different preferences for participation. This is important both in in-person research as well as in online research.

1. **Benefits of inclusive online research with people with intellectual and developmental disabilities**

Some of the potential benefits of inclusive online research include allowing for participation when in-person methods are not safe or feasible and allowing for more participant

choice and control of the research environment. For example, some participants in the studies discussed in this paper engaged in interviews from their home in spaces familiar to them. Some participants walked away from the camera or turned off the camera when they needed a break, exercising control over their experience of being interviewed. Brown (2018) also observed the convenience of completing interviews online with individuals with physical disabilities, allowing for additional flexibility in scheduling and rescheduling and allowing for individuals to be in a comfortable space like their home. It is less invasive for participants to complete an online interview from their home than to actually have the researcher physically present in their home (Brown, 2018).

In some cases, online inclusive research also supports research participants with IDD to gain online skills. For example, procedures designed to protect the privacy of participants, being aware of what the camera captures behind them and that they are being recorded, are important to be aware of online in general. Teaching and practicing the use of online skills in research may support participation in online environments outside of the research context, potentially expanding the social networks of people with IDD (Cumming et al., 2014). Additionally, online methods have the potential to reduce geographic and support barriers to participation in research, a benefit which may extend to other marginalized groups. For example, many people with IDD depend on others for transportation and support in navigating the community. Without the burden of travel, it becomes easier to meet with disabled research participants (Brown, 2018).

2. **Barriers to inclusive online research with people with intellectual and developmental disabilities**

Despite the potential benefits, there are barriers for people with IDD to participate in online research. People with IDD generally have less access to online spaces and online skills

training than people without IDD. Supplying web-enabled devices and building online skills training into inclusive online protocols may help some people with IDD gain online skills but offering online skills training for relevant people in the lives of participants who will be helping them connect to online platforms or use and care for personal devices may also be necessary (Cumming et al., 2014). Such approaches add to the significant time and resources already required to conduct inclusive research (Stack & McDonald, 2014).

People with IDD sometimes have support and communication needs that require accommodations not always resolved by training alone. For example, some people with IDD have difficulty with the fine motor skills required to press the video or mute button on a screen. Inclusive researchers may have experience accommodating these kinds of needs in an in-person research environment but have not yet fully developed strategies for online research. Because access is a key value in inclusive research, inclusive online researchers need to engage with creating accessible online spaces that address these needs. Ultimately, online methods may not be best for or preferred by some people with IDD.

3. **Future directions**

Inclusive researchers need to develop new kinds of reflexivity specific to online research which allows participants to be interviewed from a wide range of settings including their private residences (Brown, 2018). Online inclusive research requires researchers to assess their own level of technological knowledge and comfort because this may impact their ability to build rapport in online research (Gray, Wong-Wylie, Rempel, & Cook, 2020). Inclusive researchers should recognize that working online has an impact on what data is gathered, for example, less body language is visible when the camera captures only the face and shoulders. Further, how researchers interpret data collected and how others perceive those interpretations

are also impacted (Carey & Griffiths, 2017). The online environment gives the data a new context, one that inclusive researchers may have little experience deciphering. For example, research participants may behave differently in their homes than in an office or university setting. This should be considered in the researcher's analysis of data. Reflection on data analysis and dissemination procedures and how those aspects of research are impacted by working online was beyond the scope of this paper but requires a close review.

To conclude, engaging people with IDD in research using online tools expands the terrain of inclusive research, opening possibilities for even greater inclusion and participation. To meet this goal, inclusive researchers must address access and support barriers that impact people with IDD and must expand their reflexivity to include unique aspects of online data collection, analysis and dissemination. This will require the inclusion of people with IDD in the development and implementation of innovative inclusive online research methods. The potential of inclusive online methods may be best explored post pandemic through flexible hybrid models that give people with IDD more choice and control by offering online and in-person options. Inclusive researchers should then engage in reflexive evaluation of the research process, inviting participants to describe their experiences and preferences to move the field forward.

V. ARTS-BASED APPRECIATIVE INQUIRY WITH ARTISTS LABELED/WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: “SO THEY KNOW WHAT WE WANT IN THE FUTURE.”

A. Abstract

People labeled/with intellectual and developmental disabilities (IDD) participate in community-based studio programming across the United States, yet their experiences and preferences for studio programming are not well known. The goal of this research was to learn what artists in a community-based studio think is important about their studio and what they want to change in the future. This study utilized arts-based appreciative inquiry to include the artists in evaluation. Artists talked and created artwork about “what is most important” in the studio and “what we want for the future” in online individual interviews and online focus groups. Participants were engaged in analysis through contextualization of their artwork and member checking. According to the artists, the most important aspects of the studio are the people, specifically the staff and their friends at the studio, and the opportunity to make *their* art, art that is motivated by their interests. The wishes expressed by the artists included increased opportunities to be social, to make more money, to have more access to the community, and to have more choice and control in the studio (i.e., more control over the physical space, more control over materials, and more options in terms of material and types of instruction offered). The artists were able to talk and make art about what is important to them and what they want in the future. Arts-based appreciative inquiry demonstrates promise as a tool for including the perspectives of artists labeled/with IDD in evaluation of their studio programming.

B. Introduction

Studios for artists labeled/with intellectual and developmental disabilities (IDD) began to emerge in the United States in the 1970’s (Vick, 2016). Today an estimated 148 studios

supporting the work of artists labeled/with IDD exist around the country (Ortiz & Donahue, n.d. in Pittman, 2019; Sellen, 2008 in Pittman, 2019). While there is professional and academic discourse around these studios, little is known about how the artists labeled/with IDD experience their participation in studios: what they like and what they would like to change. Evaluators recognize that individual people and their experiences are important to understand a program or organization (Simons & McCormack, 2007), but people labeled/with IDD are often left out of the evaluation of services they receive (Robinson et al., 2014).

In line with a recognition of the capacity of people labeled/with IDD forwarded by the self-advocacy movement, this project situates people labeled/with IDD as capable of understanding, responding to, and impacting the services and supports they receive. The purpose of the project was to learn what artists think is important about their studio and what they want to change in the future. In addition to a report of these findings, this paper will discuss process findings that evaluate the effectiveness of arts-based appreciative inquiry as a strategy for including artists labeled/with IDD in evaluation of their studio programming.

C. **Literature Review**

The first studios for artists labeled/with IDD in the United States emerged during a period of rapid deinstitutionalization in the 1970's (Vick, 2016). Some of the earliest studios, Creative Growth (founded 1974) and Gateway Arts (founded 1973) and the National Institute on Art and Disability (founded 1974) were established to support the needs of adults labeled/with IDD leaving institutions (Vick, 2016). Today, people labeled/with IDD participate in studio-based arts practices across the country (Sellen, 2008). Broadly speaking, studios for artists labeled/with IDD share a common goal of having a positive impact on the personal and economic lives of the artists. For example, artists may receive recognition and payment for the sale of their work (Finley, 2013). Art making and being part of a studio community can facilitate self-expression

and social connection (Finley, 2013) which is important for people labeled/with IDD who have smaller social networks and lower levels of participation and inclusion in society (Verdonschot et al., 2009). Expressive art forms are also potential avenues for people labeled/with IDD to engage in choice making, self-determination (Finley, 2013) and even political empowerment (Goodley & Moore, 2002).

While they share some common traits, studios for artists labeled/with IDD are “dynamic” and “idiosyncratic places” (Vick, 2016, p. 830). They have various names including “workshops” (Vick, 2016, p. 829), “open studios” (Vick, 2016, p. 829), “creative arts centers” (Ludins-Katz & Katz, 1989), and “progressive art studios” (Ortiz & Donahue, n.d.) to name only a few. The artists labeled/with IDD that participate in these studios also have multiple and intersecting labels including “outsider,” “folk,” “self-taught,” “visionary,” and “naive” (Sellen, 2008). These labels reflect varying practices and philosophical underpinnings that reflect how both disability and art is conceptualized in different settings (Solvang, 2018).

Some studios, especially US based studios designated as ‘art therapy,’ reflect a social service mission and endeavor to have personal or even therapeutic impact (Vick & Sexton-Radek, 2008). Art therapists may de-emphasize exhibition due to ethical issues around confidentiality and an emphasis on the creative process over the final product (Vick & Sexton-Radek, 2008). Other studios emphasize exhibition as a means to increase community inclusion and integration (Ludins-Katz & Katz, 1989), and work to develop progressive practices that challenge the devalued social positioning of artists (Fox & Macpherson, 2015; Ortiz & Donahue, 2015). Still other studios focus on art as a form of employment (Finley, 2013), a “normalizing” activity that can have a positive impact on the financial position of artists. A number of studio

artists labeled/with IDD have achieved international acclaim and financial success as Outsider Artists, including Judith Scott and Dan Miller (Ortiz & Donahue, 2015).

These frameworks have particular importance for artists labeled/with IDD because they are almost always working with the support of or in collaboration with non-disabled helpers. The type and amount of help provided by individual studio helpers and staff flows from the goals and general philosophy of the studio (Lige, 2011). For example, studios following an Outsider Art philosophy may not offer education or training, instead valorizing an untrained aesthetic; while studios focused on community integration may invite local artists into the studio as educators and teachers. The way non-disabled helpers engage with people labeled/with IDD in the arts has bearing on how much subjectivity is present in the work of artists with IDD (Perring, 2005). There are no clear boundaries between studio frameworks in practice. In most settings, they intermingle and are dependent on contextual factors like the location of the studio, funding sources, and the attitudes of staff and administrators. The artists also hold knowledge and insight that, if taken into account, can have an impact on practice in studio settings.

D. **Methods**

1. **Arts-based appreciative inquiry**

Approaches to evaluation increasingly value the perspectives of individual people and their experiences in programs (Simons & McCormak, 2007). Involving people in evaluation of the programs in which they participate increases the validity of evaluation findings and the capacity of participants to enact change (Coghlan, Preskill, & Tzavaras Catsambas, 2003). Appreciative Inquiry (AI) is a highly participatory approach to inquiry that has been used in evaluation with positive results (Cooperrider et al., 2008; Coghlan et al., 2003). The backbone of AI is its commitment to using a positive, strengths-based lens. Instead of focusing on problems, the AI process invites a reflection on resources (Coghlan et al., 2003; Whitney & Cooperrider,

2005). The four-stage model engages organization and community members in: 1) Discovery- identifying the strengths of the organization or community; 2) Dreaming- imagining what the community could be in an ideal world; 3) Designing- hypothesizing about how the ideal can be achieved; and finally, 4) Delivery/Destiny- creating a plan for how the community can achieve the ideal (Whitney & Cooperrider, 2005).

AI is grounded in ‘the artful creation of positive imagery’ (Cooperrider, 2001, p. 32). While this is achieved through talk in most AI projects (Nissley, 2004), AI leans heavily on personal narratives that can be depicted using the arts (Graham-Pole & Lander, 2009). These kinds of arts-based approaches to inquiry allow *tacit knowledge* about “what is best” in an organization or community and *what constitutes a positive future* to emerge (Nissley 2004). Further, arts-based approaches have the potential to increase accessibility and expand who can participate in research and evaluation (Coemans & Hannes, 2017; Sinding et al., 2008) since some people labeled/with IDD have difficulty with standard forms of data collection that rely on language alone (Heffron et al., 2018).

E. **Research Design**

1. **Background**

This study was designed to be conducted in person in a community-based studio located in the suburbs of a large city in the United States. Prior to the COVID-19 pandemic, 31 artists labeled/with IDD participated in in-person programming at the studio, programming that included individual and collaborative art making with the support of studio staff members and volunteers; the introduction of new art materials, mediums, and genres; opportunities for artists to share artwork with each other and in public exhibition; guided meditation and physical exercise; studio and museum visits; and self-advocacy training. This programming was deeply impacted by the COVID-19 pandemic. The studio closed to in-person programming in March

2020 and reopened with limited capacity in August 2020. In response to the prospect of long-term closure and isolation of the artists, the studio launched full-day online programming via Zoom in April 2020.

Initially in-person recruitment for this study was scheduled to begin in May 2020 with in-person individual interviews and focus groups to follow. In response to COVID-19 restrictions on face-to-face contact, the study was re-designed using online methods only. Approval was granted by the University Institutional Review Board (IRB) in July 2020; however, because the studio underwent so many changes between in-person and online formats during the recruitment phase, the researcher reduced recruitment goals. Initial plans included the recruitment of 25 participants from the studio for observation only and six participants for observation, interviews, and focus groups. Recruitment was scaled back to include only six participants for online observation, online interviews, and online focus groups.

2. **Recruitment**

The six artists recruited for the study were recruited from three “tracks” within the Arts of Life studio model: Career, Educator, and Curator. The career track is designated for artists most interested in selling their work. The educator track is designated for artists interested in teaching art making to others, and the curator track is designated for artists interested in learning how to exhibit artwork, both their own and others’. Artists were selected from these three tracks because artists in these tracks have typically been at the studio longer, are more advanced in their creative practices, and are more likely to have leadership and self-advocacy experience.

Staff distributed the researcher's accessible image-based recruitment flyer to artists to inform eligible participants about the study. Six participants expressed interests. It is notable that

because the studio had only recently re-opened to limited capacity when recruitment began, it is likely that some potential research participants had not returned to the studio and did not receive the recruitment flyer. Further, because people labeled/with IDD are less likely to have access to technology and the internet than other groups (Chadwick et al., 2013) some potential research participants may have been unable to participate in a study conducted online.

Assent was obtained from all six participants and consent was obtained from guardians/legally authorized representatives of participants. Only one participant did not have a legal guardian. Recruited participant ages ranged from 25-62. There were two male participants and four female participants. One participant identified as being black. One participant identified as being Latino. Two participants identified as being white, and two participants did not disclose their racial or ethnic identity.

3. **Participant observation**

The researcher participated in 15 hours of online programming offered by the studio. Online programming mirrored in-person programming and included: guided meditation; art making prompts; opportunities for artists to share artwork with each other; problem-solving art projects with staff members and volunteers; and virtual studio and museum visits. Additionally, the studio dedicated 15 minutes every day for “login/tech help” which assisted the artists with navigating Zoom as an online platform and engaging successfully in virtual programming.

4. **Individual interviews**

The research participants (referred to as artists henceforth) engaged in four 30-minute online individual interviews. Individual interviews aligned with the *discovery* phase of the AI four phase model. During individual interviews, the artists were prompted to reflect on

themselves and their role in the studio community. To support this, the interviewer used the screen sharing tool on Zoom to show the artist's body of work available online through the studio's website. The artists were invited to identify their favorite pieces; talk about the motivation and construction of the work; describe their favorite subject and medium; and comment on what they felt was important or notable about their work. Further, the artists were prompted to identify their strengths and best qualities, and to describe a moment in the studio when they felt proud, happy, or excited in the studio.

Individual interviews supported participants' ability to reflect on the unique strengths of the studio and envision possible futures for the studio (Cooperrider et al., 2008). Early in the interview process, the researcher introduced the artists to the upcoming focus group prompts: "What is the best or most important to you about the studio?" and "What do you want or wish for the studio in the future?" Prompting discussion around these questions early and repeatedly during individual interviews, as well as asking the question in plain language in different ways, helped the artists prepare for the focus groups. The artists were also prompted to plan for the art-making aspect of the focus groups during individual interviews. They were asked what kinds of images they might make to represent their ideas and what materials they might need to create those images. The researcher helped the artists plan how they would obtain the materials they needed and have them available during the focus groups. These inclusive strategies helped participants plan and process questions over a longer period of time.

5. **Art-based focus groups**

After individual interviews were completed, three 60-minute online focus groups were facilitated. All six participants attended the first two focus groups. One participant missed the third and final focus group because of another obligation. The first focus group continued the

discovery phase of the AI four phase model. The artists were asked to create art about “the best or most important part(s) of the studio.” First, the researcher facilitated a brief discussion in which participants verbalized their answers to the prompt and asked clarifying questions. Some of the artists benefited from the researcher reminding them of their answer to the prompt during individual interviews and how they had initially planned to depict their response using art. After the discussion, the researcher prompted the group to begin art making.

After 30 minutes of art making, finished images and images-in-progress were shared with the group using the Zoom platform by holding the image in front of the camera. Each artist was invited to give their art piece a label or title and offer context about the piece. Artists were asked to describe what they see in their art, what was happening/depicted in their art, and how it relates to their lives. This “contextualization” approach was adapted from Wang and Burris (1997) by Heffon, Spassiani, Angell, and Hammel (2018) to increase the participation of people labeled/with IDD in analysis of a photo-based research method, photovoice.

The second focus group aligned with the *dreaming* phase of the AI four phase model. Artists were asked to make art about what they “wished for or wanted for the studio in the future.” Again, after a brief period of discussion and a 30-minute period of art making, each artist was invited to contextualize their image. At the end of the second focus group, the artists were asked “Who should we share your artwork and stories with?” “Who needs to know about how you feel about the studio?” Responses were recorded. The group was reminded that their responses from the interviews and focus groups would be combined into an initial “report” that would be shared with them at the third focus group to check their accuracy, a process called member checking.

After analyzing individual interviews and the first two focus groups, the researcher identified initial themes and subthemes. Because the entire data set had not yet been coded, initial themes were developed based on the contextualization of artwork provided by the artists and a surface-level search of the data set for key words including: “best,” “important,” “like,” “love,” “want,” “wish,” and “change.” A PowerPoint slideshow was developed which presented these themes and subthemes accompanied by the artists’ artwork illustrating the theme. During the third focus group, the researcher shared the themes one-by-one and asked after each artist: 1) Did I understand you correctly? Is this what you said or meant to say? 2) Is this true? 3) Would you change or add anything? 4) Is there anything else that is important to say or add? Participants provided feedback and the PowerPoint presentation was amended to include their insights.

In alignment with the *designing* and *discovery* phases of the AI process, during the fourth and final focus group participants were asked to think about how they might achieve their wishes and goals. These responses were recorded in the artists’ own words on the PowerPoint in screen sharing mode during the focus group. The final PowerPoint, including the amendments made during the member checking and the artists’ ideas about how to achieve their goals, was printed and two copies were sent to each artist. Identifying information was removed from the PowerPoint and the artists were reminded to respect the confidentiality of their peers. The artists were encouraged to make their own decisions about with whom they wanted to share their work. Supporting the artists’ control over the report of their findings positioned them as both experts and owners of the material.

6. **Analysis**

The first stage of analysis began with the artists' contextualization of their artwork. They provided the researcher with a description of the work and how it related to the studio using the Wang and Burris (1997) approach to photovoice analysis adapted by Heffon, Spassiani, Angell, & Hammel (2018). The researcher did not do any additional visual coding of the images. The artists also provided feedback and made corrections to the initial themes developed by the researcher.

The second stage of analysis involved "codifying" images and text-based data. This was done using Braun and Clark's six-phase thematic analysis method (2006) which includes: 1) familiarizing yourself with the data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report (2006). Initial analysis followed inductive and realist frameworks. Line-by-line coding stayed close to the actual words of the participants, and the themes that emerged were linked directly to the data. After this initial coding, a more interpretative, constructionist analysis was employed where the meanings of the codes were considered in the context of the situation, the studio, and discourse around the social position of this group in society (Braun & Clarke, 2006). Concept mapping was used to review and redefine themes until they most accurately represented the data set as a whole.

F. **Findings**

The findings of the study are outlined below. In this first section, the findings stay as close as possible to the artists' own words and interpretations. Their images, what they said, and the meaning they provided are presented. Following this section, a more interpretive and constructionist analysis is offered. In the excerpts below, the letter "I" is used to identify the interviewer. The name of the studio is replaced in quotes with [The studio] and the name of the

artists in text is replaced with a letter as pseudonym. All reproducible images produced during the study are included in this discussion. Some images from the study were too blurry or grainy to reproduce.

1. **The most important parts of the studio**

The importance of the people at the studio was a prominent theme of the study. Staff were described as “respectful,” and “important.” The artists also emphasized the value of “being with friends.” Three artists drew people in response to the focus group prompt, “What is most important or best about the studio?” For example, in Figure 8, “A Flower,” C drew flowers to represent the people at the studio. C said that the choice to draw flowers and use of purple -- objects and colors the artist loves -- represented C’s love for the people at the studio.



Figure 8. “A Flower” by C. Image description: Three irregular shapes line the top of the paper. The shapes are created with circular lines of marker. One is predominantly blue, a second shape is green and gray and the third and largest shape is purple, green with a small amount of pink.

In the Figure 8, C was reflecting on positive feelings about people in the studio broadly, not differentiating between staff, volunteers, visitors, and artists. In Figure 9, B chose to draw people with different roles in the studio. B drew three people and identified them as herself (middle), a peer/fellow artist at the studio (left) and a staff member (right).



Figure 9. “Untitled” by B. Image description: Three figures drawn in colored pencil are lined up in the middle of the paper. The center figure is slightly larger than the other figures. The figures have different skin tones, eye colors, hair color and clothes.

The artists described the important and *distinct* roles of staff and fellow artists/friends at the studio. The artists reported that staff prompt art making, help with selection of images used as references for art, help with the construction of art, make suggestions for artwork, teach new skills, and provide instruction on how to use new materials. They also supply materials and

retrieve materials for the artists in the studio. Staff were identified as a key resource for solving problems regarding both the construction of art and about personal conflicts that come up in the studio. One artist noted that volunteers also help with the construction of art. Only one artist specifically differentiated between staff and volunteers, but the studio has a large volunteer workforce who share duties with staff. Some artists in this study may have been referring to both when they spoke of staff.

“Friends” played a different, but important role. The artists reported that they enjoyed spending time with and talking to their friends about their artwork, their families, their hobbies, and their day-to-day lives. M reported that the studio was special because they could have good friends there.

I: Do you guys think there’s anything special about [The studio] that you can't get anywhere else, but you can only get an [The studio]?

M: We have good friends.

The artists sometimes specifically referenced their fellow artists when talking about “friends,” but at other times it seemed they might also have been referring to staff and volunteers they considered as friends. According to M, C, and W, the studio’s daily walk was important because it was an opportunity to talk with friends. (Figure 10, “People Going for a Walk,” by M).

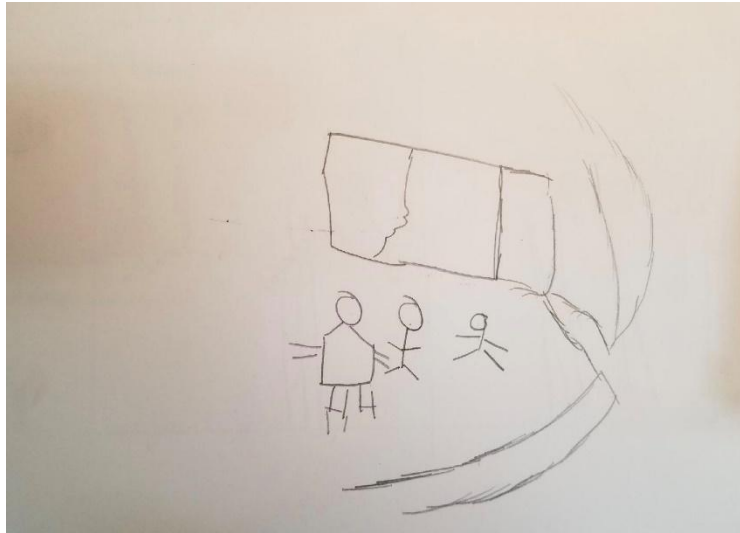


Figure 10. “People Going for a Walk” by M. Graphite drawing with three figures in front of a rectangular shape identified as the studio. Two curved lines run along the bottom and right-hand side of the image. These lines were identified as the street in front of the studio.

I: Tell me what’s happening in your drawing.

M: People going for a walk.

I: And how does that relate to you?

W: Close friends, right [M]?

M: Here at [The studio]. Yep,

I: Why was it important to add the street with you?

M: Because that’s where we walk around to. Do you want me to repeat it?

I: No, I heard it. That’s the street that you walk around to you said.

M: Yeah.

C: I love walking with you [N].

M: Oh, You like walking with me?

W: Go for walks (unknown) converse with people remember [N]?

Making art was also identified as important to the artists. More specifically, some artists emphasized that it was important to make *their* art, art that is motivated by their personal interests and ideas.

I: What are you excited about when you go in the morning into the studio?

T: Doing *my* art

The artists made art about a wide range of themes using a wide range of mediums. Topics included artwork about family members, famous people, locations of interest, fashion design, artwork about a specific genre or culture, artwork about animals, about significant current or historical events, and about abstract art and design. M described the studio as a place where you can “feel free.” She said,” [The studio] is very good because there’s no right or wrong for making art.”

In response to the prompt “What is most important or best about the studio?” Z drew a picture of her worktable at the studio (Figure 11. “My Fashion Business,” by Z). She explained that her workspace at the studio was where she started and ran her fashion business. She keeps a dress form at the space and a sketchbook to draw her fashion designs, both of which she included in her drawing. She said that it was important to have her own space.



Figure 11. “My Fashion Business” by Z. Mixed media drawing with marker and ink of a table with a chair and dress form next to it. On the table are books about fashion and art supplies including a sketchpad with a drawing of a figure wearing a pink dress.

2. Desires for the future of the studio

When asked to identify what they wanted in the future for the studio, the artists described a wide range of personal and professional wishes including (not listed in any particular order): 1) A wish for more parties and exhibitions-- grouped together as a desire for *more opportunities to be social*; 2) a desire for *money and/or fame*; 3) A desire for personal and professional travel and a wish to get out into the community more -- grouped together as a desire for *more access to the community* (local and international); and 4) a wish to transform or renovate the studio, to change how the supplies are set up, to obtain different kinds of materials and equipment for the studio, and wishes to have more classes and types of instruction at the studio -- grouped together as a desire *for more opportunities for choice and control* over the studio's physical space and the programs offered there.

When asked to describe a time when they felt happy or excited at the studio, all but one of the artists described a party, mostly birthday and holiday parties. When prompted to draw what they want for the future of the studio, Both C and W created images of a party. Figure 12, "A Party," by C. Parties are important to the artists because parties are an opportunity to dance, laugh, and meet new people.

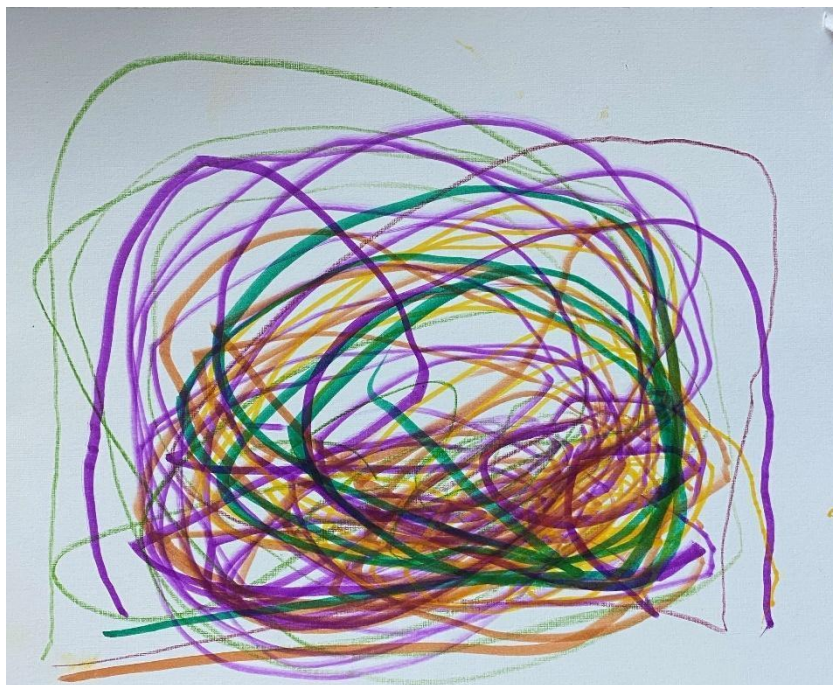


Figure 12. “A Party” by C. At the center of the paper taking up almost the entire page is a large circular shape made with multiple marker and pencil marks. Colors include green, purple, teal, yellow, orange, and green and the lines are overlapping and chaotic but merge together near the bottom of the circular shape into a dense focal point.

M: What's it a picture of [C]?

C: A party.

I: A party.

M: A party.

W: Ah.

I: [C] what do the different colors mean? What do the...?

C: Happiness.

I: Happiness? What's happening at the party [C]?

C: People are talking.

I: People are talking?

W: Yeah.

C: Yeah. people are talking.

I: What else is happening at the party?

C3: People are laughing.

I: People are laughing.

C: I love parties. I love parties.

Exhibitions and shows were another important opportunity for social connection, a chance to meet new people. They were also described as a source of pride, an opportunity to show their work to others and a chance to receive praise. T said that it is exciting to show family her artwork. M said, “It [exhibition] reminds me of how far I’ve come from making good art.”

W, who is on the curator track at the studio, described the process of curating an exhibition as an opportunity for social connection. W described working closely with a curatorial committee, which included both staff and other artists, to select artwork and set up for the exhibition. W also described public speaking at exhibitions before exhibition visitors.

All the artists in the study discussed the importance of money and of making money. For one artist, making money was only a secondary goal of creating art, but three artists in the study reported that making money is the primary reason they make art. One artist stated that if she did not make money, she would not continue to make art. It is perhaps no surprise that when asked what they wanted for the future of the studio, one artist, B, drew money (Figure 13). Notably, B clarified it was a desire for more money *for the artists at the studio*, not more money *for the studio*.



Figure 13. “Money” by B. Five 50-dollar bills and five 20-dollar bills are lined up next to each other on the page vertically. The number 20 or 50 is written in all four corners of each green rectangle signifying the bill.

In addition to a desire for more money, two artists expressed a wish to be famous. These themes are linked here because of the interactive relationship between money and social status; however, it was not clear in the study that the artists perceive this interaction as meaningful to them. A desire for more money was described as mostly practical, a desire to be able to obtain the things they want and need.

Five artists expressed a desire to travel. Three described a wish to travel with family and friends, to go on vacation. Two artists expressed a desire to travel to improve their artistic skills or knowledge, for example Z wanted to go to Paris fashion week. Every artist described a wish to go more places in their local community, to “get out” more. B said, “It’s good to get out because um, cause sometimes it’s, because it’s not good to stay home.”

None of the artists in this study owned or operated their own car, so they depended on public transportation or family and friends to get access to the community. The bus system that dropped many of the artists off and picked them up from the studio was described as an important service, but one with limitations: it is costly, it has a limited geographical service area, and it offers limited hours of service. To achieve the goal of increased access to their local community, M expressed a desire for “a new car” for the studio (Figure 14). “The new car,” M explained, would need to be an accessible minivan that would support studio artists who use wheelchairs. This drawing sparked a conversation during the focus group about a wide range of community spaces that the artists would like to visit.

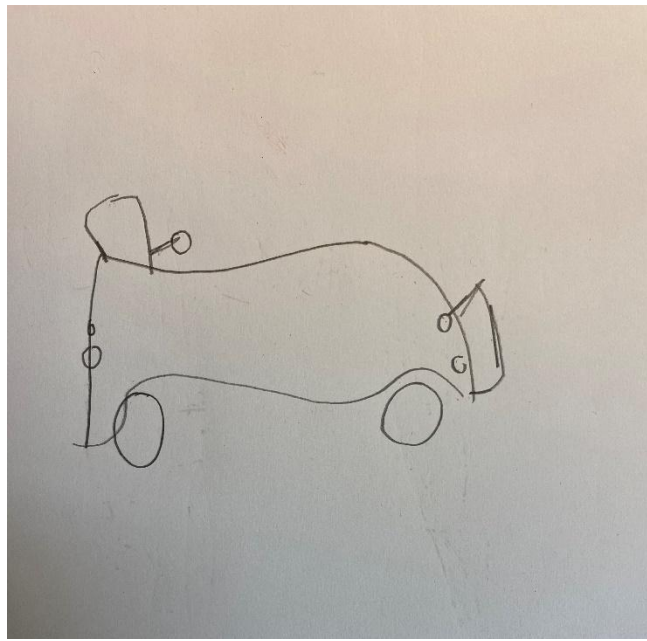


Figure 14. “A New Car” by M. Graphite pencil drawing of a vehicle drawn from the side. Visible are some detailed aspects of the vehicle including steering wheel and headlights.

A series of material and physical changes were also imagined. W described a desire to redecorate the studio with paint or wallpaper. In response to the prompt to draw what he wanted for the future; W drew the studio transformed into a banquet hall. The explanation of his drawing pointed to both aesthetic goals, making the studio more beautiful, and social goals. W said, “I worked on a banquet hall where people can sit at tables and people can talk and have dinner and then they can have dessert” (Image too grainy to reproduce).

Many of the artists articulated a desire to get specific supplies and types of instruction: C would like a kiln and more clay; M would like a weaving loom; Z wants to take sewing lessons and learn to tattoo. C articulated a desire to re-design the studio layout so that the artists could get materials more independently in the studio.

G. **Discussion of Findings**

The artists identified that the most important aspects of the studio were the people, specifically the staff and friends, as well as their ability to make art that reflects their interests. Desires for the future included more opportunities to be social, to make more money, to have more access to the community (both local and international), and to have more choice and control over materials and the arrangement of physical space in the studio. This section brings a more interpretive and constructionist analysis to these findings; exploring what meaning these wishes and desires have in the context of the studio and the artists social positioning more broadly.

The artists identified that social connection is important to them. They also identified a desire for more opportunities to develop social connections, to be social with one another more and to meet new people at parties and exhibitions. Exhibitions offer artists not only the opportunity to meet new people, but also the opportunity to make money and be celebrated and valued for their creative work, eliciting feelings of pride and reflection on personal growth.

Exhibitions may also be important because they offer opportunities for artists to develop leadership and self-advocacy skills, particularly when artists take on curatorial roles.

Participation in the curatorial process is a way that artists labeled/with IDD can represent and speak up for themselves and their community (French, 2017). Leadership requires specific kinds of social skills. Few opportunities for leadership are available and even fewer opportunities for leadership skill development exist for people labeled/with IDD (Caldwell, 2010).

The value that the artists place on the social and economic aspects of the studio points to experiences with social isolation and lack of employment opportunities outside of the studio. People labeled/with IDD typically have smaller social circles and lower levels of participation in many major life activities including employment (Verdonschot et al., 2009). The pandemic exacerbated many already existing problems with isolation and exclusion that people labeled/with IDD experience (Constantino et al., 2020). The artists' desire for more community participation may have been at the forefront of the artists' minds because of the pandemic. Pointing to the ways that transportation barriers inhibit community participation, one artist drew her desire for an accessible van for the studio. A studio van was her solution for increasing access to the community. The desire for a physical vehicle mirrors the way that the studio functions as a metaphorical vehicle for the artists; through their engagement at the studio, they gain access to spaces, material, people, and opportunities that they might not otherwise have access to.

By identifying the people as important, the artists bring attention to how the behavior of both staff and fellow artists impacts the studio environment and their experience there. Specifically, an attitude of respect from the staff creates a feeling of pride in the artists, and time spent talking and engaging in activities with peers creates close relationships. The artists'

recognition of the important and differing roles that staff and their friends play, points toward a recognition that the studio is co-created. The artists are not simply recipients of services; they are vital participants in the creation of the studio and to a feeling of family-like belonging, as one artist described it. Hall (2010) argues that experiences of belonging are important to break down the marginalization and exclusion of people labeled/with IDD. Feelings of belonging in the studio were juxtaposed with experiences outside the studio where the artists described feeling looked at as “different” or outsiders. One artist said that the studio is special because it was a place where close friendships could develop. This suggests that the studio is one of the few places in the artists’ lives, perhaps the only place, where they can develop close friendships and social connections with others.

The artists’ desire for changes to the physical space reflect a desire to have more ownership and control in the studio. One artist described aesthetic changes he would like to make to the studio (painting or putting up wallpaper). Another artist suggested that general supplies should be moved to a more accessible location so that the artists could get them more independently. Further, the artists desire for more supplies and training, and the value they place on being able to create *their* art, point to the importance the artists place on having choice in the studio. They reported that they value being able to make art about the things that interest them, signaling that they do have choice and control over some aspects of the studio and their creative practice. Given the wide range of practices within studios, it is likely that many studios do not support the artists’ sense of ownership over the studio space, or choice and control over their artistic production. It is also likely that *these artists* encounter many places and situations in their lives where they are afforded neither choice nor control. Perhaps that is one of the reasons why the artists in this study named *the people* at this studio as important. Together artists, staff, and

volunteers created an environment where the artists felt supported to pursue their creative interests.

H. **Conclusion**

The insights and perspectives of artists labeled/with IDD in studio programming are valuable and necessary to advance artist-centered practice in these spaces. Arts-based appreciative inquiry is a viable approach to artists labeled/with IDD in evaluation, but process findings reveal special considerations needed for how the art is made, analyzed, and disseminated.

Simmons and McCormack argue that to move participatory evaluation from tokenism to true engagement, evaluation methods must involve processes familiar to participants (2007). Art making is a strength of this group. The artists described their artistic practice as enjoyable, something they felt good doing. Some of their positive association with art may have translated into better outcomes for the study. For example, all the artists created artwork during both art-based focus groups, and their art informed study findings in important ways. For example, the artists' artwork was used during the third focus group for member checking. Inclusive researchers commonly use visuals to support inclusion of people labeled/with IDD in analysis (Kramer et al., 2011). In this case, it was the artists' own images that were used to represent developing themes and to check the researcher's accurate identification of those themes.

The art also grounded in-depth thematic analysis. For example, the image of an artist's studio space was an outlier, not specifically discussed by any of the other artists, but it guided the researcher into a deeper interpretation of the larger theme "it's important to make art." The artists' recognition of the importance of the space where work is created supported the researcher's recognition of the importance of choice and control over the circumstances in which

art is made. The initial theme of “it’s important to make art” became “it’s important to make *my* art,” a distinction that was supported by the rest of the data set.

A limitation to this method is that it prompted the artists to make art about specific topics, “what do you value about the studio?” and “what do you want for the future of the studio?” Prompting in this way, may have run contrary to the importance the artists emphasized in the study, the ability to make *their* art on their terms in the studio. The time frame allotted for art making may also have been problematic. The images in this study were completed within a 1-hour focus group. Many of the artists usually take much longer to complete artwork. One artist participating in the study was observed completing a work of art over a period of weeks. Because the timeframe *set by the researcher* was short, it may have decreased the artists’ ability to use art to effectively communicate their meaning. It may have also impacted the quality of the work, representing these artists as having far less artistic skill than they actually have, and reinforcing prevalent representations of people labeled/with IDD as inadequate and childlike. There remains a potential for art-based research products to be misunderstood and contribute to stigmatization and marginalization even if that was not the intention of the researcher (Coemans & Hannes, 2017). Future inclusive art-based research should involve artists more fully in the development of the art-making protocol (Fox & Macpherson, 2015). This an important consideration for future evaluators and researchers interested in using art-based methods with people labeled/with IDD. While appreciative inquiry does not dictate a timeframe, evaluation research is sometimes pressured to adhere to timeframes and outcomes that might be restrictive to people labeled/with IDD.

Online art making during the pandemic allowed for social connection when in-person contact was limited or prohibited. The online studio programming and research provided the

artists with an opportunity for social contact with each other, potentially reducing social isolation caused by the pandemic. This was perhaps especially true for those artists who could not rejoin the studio in person and whose only contact with their key support networks was online. This implies that in the future, online art-based programming may represent an opportunity to reduce exclusion and social isolation for *some* people labeled/with IDD (those with access to technology and the internet) long after this pandemic has passed. Future arts-based research with artists labeled/with IDD may also be able to advance online inclusive practices, connecting people and communities separated by great distances. The success of these innovative approaches to research and programming relies on the insight and knowledge of artists labeled/with IDD through their participation in evaluation. Future research into the efficacy of this and other evaluation research methods with people labeled/with IDD is needed.

VI. ARTISTS LABELED/WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN STUDIO PRACTICE: STORIES OF SOCIAL CONNECTION AND MUTUAL SUPPORT

A. Introduction⁵

The social model of disability, which draws attention to the role of society in creating disabling physical and social barriers (Oliver, 1996), has been a key aspect of disability rights discourse and a foundational tenant of disability studies. But, while some scholars argue that the social model is critical in disability rights efforts (See Oliver 1996; Shakespeare 2006), others have observed that social model constructs a problematic binary between disability and impairment where impairment refers to physical or mental limitation, while disability refers to physical and social barriers that result from that limitation (Kafer, 2013). In the last 20 years, disability studies scholars have taken up this problematic binary and questions about the experience of impairment in new and important ways. For example, Tobin Siebers' articulation of "complex embodiment" understands disability as a complex experience, both social and physical (2008, p. 22) and Kafer's political/relational model which draws attention to disability *and* impairment, bringing attention to the ways that both are socially and politically constructed.

Philosopher Licia Carlson has observed that despite the many socially constructed barriers to inclusion in society that people labeled/with intellectual and developmental disabilities (IDD) face, intellectual disability remains firmly rooted in biomedical, genetic, and medical discourse and is usually thought of in terms of impairment (Carlson, 2010b). In an analysis of representations of people labeled/with IDD in film, Callus (2019) observed that the difficulties that people labeled/with IDD were wrongly assumed to be a result of cognitive impairments, and not social and cultural factors. Even within disability studies, several scholars

⁵ Portions of this section describing disability theory and disability studies scholars is taken from Chapter III: Methods

have noted that there remains a lack of theorizing about intellectual disability as it relates to the social model⁶.

Some scholars, including Goodley (2001) and Boxall (2002), argue that the social model does have the potential to account for the experiences of people with intellectual disability but that further theorization, and the inclusion of people labeled/with IDD in that theorization, is needed. Dan Goodley forwarded an approach that both interrogates assumptions that “naturalize” impairment in people labeled/with IDD and welcomes people labeled/with IDD to tell their own stories, stories that “locate impairment in, and as, personal and social narratives” (2001, p. 207). According to Goodley, personal narratives help to articulate resilient and socially connected communities of people labeled/with IDD (2001). Further, Fraser (2018) argues that the visual art of people labeled/with IDD also brings attention to the material and social aspects of disability and impairment. Collaborative art making amplifies the ways that support is received and supplied between people. Further, Rice et al. (2017) observed that collaboration in the arts invites questioning into what the dominant culture assumes about autonomy and interdependence. The collaborative creative practices of people labeled/with IDD can reveal everyday experiences that disrupt notions of IDD as an individual problem or tragedy (Fraser, 2018).

Given the potentials of personal narrative and art to challenge dominant narratives about IDD and the importance of an ongoing exploration into the relationship between experiences of impairment and the social construction of IDD, greater scholarly attention to the locations where people labeled/with IDD are engaged in creative practice is warranted. After a discussion of the

⁶ Several Disability Studies scholars have discussed the historical lack of attention to intellectual disability in Disability Studies including Dan Goodley (2001), Kathy Boxall (2002); and more recently Stalker (2019).

qualitative, art-based study with artists labeled/with IDD in studio practice that informs this paper, a description of prominent studio frameworks in the studio where artists labeled/with IDD practice will be explored. Situating the studio within these frameworks, the personal accounts of four studio artists will be discussed. Taken as a whole, the artists' stories challenge depictions of IDD as an individual tragedy characterized by dependence on others, and instead describe the ways in which they both receive and supply help to others, articulate a distinctive curatorial voice, and have an important social role in their communities.

B. **Study Background**

This study was originally designed to take place in-person at a studio for artists labeled/with IDD in the suburbs of a large city the United States. As a result of the COVID-19 pandemic, in-person programming at the studio stopped completely in March 2020 and reopened only to limited capacity in August 2020. For the duration of this study, no volunteers or researchers were permitted to enter the studio in person.

In response to the prospect of long-term closure and potential isolation of the artists, the studio launched online programming via Zoom in April 2020. With careful consideration for the ethical and logistical challenges and the potential benefits of online research with people labeled/with IDD, this study was reimagined using online and remote formats (Zoom and phone). A more detailed discussion of how the project was transitioned from in-person to online formats using inclusive principles is described in Miller & van Heumen, 2021. Six participants were recruited for observation of their participation in online programming; four 30-minute interviews; two 1-hour art-based focus groups; and one 1-hour, member-checking focus group. Participants' ages ranged from 25-62 years and included four women and two men. One participant identified as being Black, two identified as White, one identified as Latino, and two participants did not disclose their racial or ethnic identities. The aims of the project were two-

fold: 1) To learn what artists think is important about their studio and what they want to change in the future; and 2) to explore the use of arts-based appreciative inquiry to engage artists labeled/with IDD in evaluation of their studio programming.

Appreciative inquiry (AI) was used as an evaluation framework. AI is a participatory approach to organizational and community evaluation and change (Cooperrider et al., 2008). In AI, community members are engaged in a four-phase, structured process. The phases include: 1) *Discovery*- identifying the strengths of the organization or community; 2) *Dreaming*- imagining what the community could be in an ideal world; 3) *Designing*- hypothesizing about how the ideal can be achieved; and 4) *Delivery/Destiny*- creating a plan for how the community can achieve the ideal (Whitney & Cooperrider, 2005).

Using appreciative inquiry supported the artists to describe their own strengths, the strengths of their community, and the strengths of other community members. Further, because AI is grounded in “the artful creation of positive imagery” (Cooperrider, 2001, p. 32), AI leans heavily on individual and group interviews where people provide personal narratives of their accomplishments. These narratives can be depicted using the arts (Graham-Pole & Lander, 2009). This approach supported the artists to both verbally describe *and* create images that illustrate what is most important to them and what they want in the future at the studio.

C. **Studios for Artists labeled/with Intellectual and Developmental Disabilities**⁷

People labeled/with IDD are engaged in studio-based artistic practices across the United States (Sellen, 2008). A number of studio frameworks guide practice in studios. A discussion of frameworks is important because most studio-based practices of people labeled/with IDD include some level of collaboration with non-disabled helpers (Perring, 2005). The way non-disabled

⁷ Portions of this section describing disability theory and disability studies scholars are taken from Chapter III: Methods

helpers support and engage with people labeled/with IDD in the arts, and the assumptions they make about art and disability, flow from the general philosophy or framework of the studio (Lige, 2011), and therefore have bearing on how much subjectivity is present in the work of artists labeled/with IDD (Perring, 2005). Evaluating the strength and limitations of these frameworks supports practitioners to interrogate assumptions embedded in these frameworks and to engage in informed studio practice.

A series of scholars have attempted to name these frameworks and discourses surrounding the creative practices of artists labeled/with IDD. Perring (2005) identified three major modes of engagement based on interviews with non-disabled arts facilitators in London: normalizing, post-therapeutic, and counter cultural. Solvang (2018) identified four “discourses” around studios: art therapy, outsider art, disability art, and disability aesthetics. Finley (2013) identified five types of art programming in the US: art as recreation, independent and creative art centers, art for employment, art therapy, and arts education. In practice, these categories are flexible, ideas and influences overlap (Perring, 2005; Solvang, 2018). The studio where this study took place, like many studios, is a combination of multiple and intersecting frameworks. It supports the participation of art therapy interns, receives federal and state funding through Medicaid, participates in disability art and culture events and Outsider Art festivals and fairs. What follows is an examination of the intersection between the most prominent frameworks present in the studio under study: Creative Art Centers; Normalization; Outsider Art; Art Therapy; and Disability Art. The underlying assumptions and contradictions within these frameworks will be explored with an emphasis on how they intertwine, as well as how they have historically positioned the art of people labeled/with IDD. Understanding these frameworks in

the context of the artists stories helps to evaluate the strengths and limitations of these frameworks in studio practice.

1. **Studio frameworks**

Florence Ludins Katz and Elias Katz were at the forefront of the studio movement in the United States in the 1970s. They published their seminal work, *Art & disabilities: Establishing the creative art center for people with disabilities*, in 1989. They advocated for community involvement in the establishment of “creative art centers,” with the purpose of reducing the exclusion of people with disabilities in society at large (Ludins-Katz & Katz, 1989). Methods established by the Katz’s to connect the artists to the community are still used today by creative art centers, and their methods inspire “progressive studios” that support artist-led creative practices (Ortiz & Donahue, 2015). These studios are characterized by large, communal spaces filled with “cross talk and laughter” (The Creative Growth Book, 2015).

Some of the earliest Creative Art centers established by the Katz’s -- Creative Growth, Creativity Explored, and the National Institute on Art and Disability -- were established to support the needs of adults with disabilities who were leaving institutions in the 1970’s (Vick, 2016). The turn towards deinstitutionalization was a key moment in the emergence of studios for artists labeled/with IDD and was spurred by “normalization,” a concept developed in Sweden by Dr. Bengt Njire and championed in the US by Wolfensberger and Koch (Carey, 2009). Normalization and Wolfensberger’s *Social Role Theory* asserted that people labeled/with IDD should live in an environment, “as close as possible to the norms and patterns of the mainstream of society” (Carey, 2009, p. 141). This includes employment, education, and recreation. In normalizing-oriented studios, people labeled/with IDD are referred to as “artists,” or “students” and are encouraged to think of artmaking as a profession available to them that “normal people”

also might pursue (Ludins-Katz & Katz, 1989). Exhibition is used as a key strategy to reduce stigma and change societal attitudes about people labeled/with IDD (Ludins-Katz & Katz, 1989; Ortiz & Donahue, 2015). Their employment in the arts, the exhibition of their work, and the sale of their art demonstrate that “disabled people are a positive force and have much to contribute and share with their society” (Ludins-Katz & Katz, 1989, p. 95).

Despite its role in deinstitutionalization, normalization has been critiqued for reinforcing the role of professionals and professional systems in the lives of people with disabilities (Carey, 2009). Perring describes normalization in studios as an approach that brings artists labeled/with IDD into “mainstream performance discourse, often through the application of mainstream production values and aesthetic criteria” (Perring, 2005, p. 185). It says, “Bring people inside the existing margins!” in affect *centralizing mainstream aesthetics* instead of *challenging them* (Perring, 2005, p. 186).

Studios influenced by normalization and the goal of including people labeled/with IDD in the norms of society, including gainful employment, often pursue these goals through the Outsider art genre. Some studio artists labeled/with IDD have achieved international acclaim and financial success as Outsider artists, including Judith Scott, Dan Miller, and Marlon Mullen (Ortiz & Donahue, 2015). It is with some irony that “outsider artist” status can bring artists labeled/with IDD into societal recognition because early proponents of Outsider art and its European predecessor Art Brut emphasized the cultural isolation of artists and their distance from formalized art practices (Peiry, 2001). In contradiction to the creative art center framing, these artists would not be considered “students” because lack of training is part of the description of Outsider artists. Nevertheless, Outsider art has brought artists on the margins into public view in a way that might otherwise have been impossible. Even today, the art-world, which is

typically sealed off from people without the proper training has opened to the work of outsider artists. “Artists who were once hidden from view because of disability or disadvantage are now actively sought” (Prinz, 2017, p. 270); however, critics questions who has/should have the power and privilege to label, profit, and promote outsider art.⁸

Art therapy, another common studio framework, is most prominently known today as a component of treatment towards the remission of diagnosable symptoms of mental or physical illness or disease (Solvang, 2018). This framing is partly due to the history of art therapy and its connection with the art of institutionalized psychiatric patients, which began in the early 1900’s. Hans Prinzhorn, the historian and psychiatrist who collected one of the earliest and most influential collections of *Bildnerei des Geisteskranken* (Artistry of the Mentally Ill), has been called the “uncle of art therapy;” in fact, Prinzhorn’s collections were later sought after by collectors in search of Art Brut (Cohen, 2017, p 41). He and many of his colleagues were interested in how making artwork impacted the psychological health of patients receiving treatment in asylums (Cohen, 2017).

Some art therapists argue that this medicalized focus too narrowly defines the field (Cohen, 2017; Vick, 2016). Not every art therapist has “treatment in mind” (Cohen, 2017, p. 17). Art therapists too have used principles of normalization to make art a *normalizing* social practice (Solvang, 2018) in which people with disabilities are not seen as “sick” or “disabled” but as “socially devalued” (Vick & Sexton-Radek, 2008, p. 4). While this approach may make art therapy more accessible and less clinical, the downside is that people labeled/with IDD are sometimes placed in therapy they do not need. This occurs in day centers where people labeled/with IDD often have their time managed, and “art therapy” becomes a practice that

⁸ For examples of critical analysis of outsider art see Fine (2003) and Prinz (2017).

occurs on a specific day at a specific time without any real meaningful connection to the needs or wants of people labeled/with IDD (Swain & French, 2008, p. 96). Prevailing assumptions that all services for people living with IDD need to be therapeutic is related to a stigma about sickness and cure assigned to all people labeled/with IDD (Cohen, 2017).

To distance themselves from medicalized narratives associated with institutionalization, many studios claim, “we do not do art therapy!” (Vick & Sexton-Radek, 2008, p. 4). While not overtly in alignment with medicalization, many studios still operate as state and federally funded rehabilitation and developmental training centers funded by Medicaid. Artists who attend art centers often live in institutional or institutional-like settings like nursing homes and group homes. This means that artists are sometimes subject to institutional practices such as ongoing clinical evaluation, restrictive rules around physical contact and limited personal space and property.

Studios that espouse a “progressive practice” (Ortiz & Donahue, 2015) or “socially engaged” or “inclusive practice” (Fox & Macpherson, 2015) have an inherently social or political impact. Progressive studios, which link themselves directly to the inclusionary methodology initially proposed by Katz and Ludins-Katz, support people labeled/with IDD to have ownership over the studio space and their creative practice, to participate and be included in their community, and to collaborate as equals with others (Ortiz & Donahue, 2015). These practices run contrary to and challenge the way that people labeled/with IDD are typically engaged: as recipients of services and care delineated by others.

Disability art elevates the lived experiences of artists with disabilities for the purposes of articulating a disability culture and identity (Solvang, 2018). The development of disability identity and disability culture is seen as an important component of disability rights activism

(Longmore, 2003; Swain & French, 2008). While seemingly in line with disability art, the relationship between what artists labeled/with IDD *do* and disability art often remains unclear (Fox & Macpherson, 2015; French, 2017). Aspects of the disability art paradigm rely on separation from the non-disabled mainstream to generate and transmit disability culture and values (Kuppers & Wakefield, 2009). This prescribed freedom from non-disabled professional oversight is complicated for artists labeled/with IDD who are often supported by non-disabled helpers, “muddying the waters around autonomy and authorship” (French, 2017, p. 25).

D. Artists’ Stories

What follows are personal accounts of four artists labeled/with IDD, C, W, B, and T, (Letters used as pseudonyms) about their experiences as artists. This study acknowledges what Natalie Spagnuolo calls “limited knowledge claims” (2016). As a researcher without a label of IDD, I cannot know or communicate the direct experience of living with/being an artist with IDD. I can only communicate what I understand from my experience of being in relationship, albeit briefly, with the artists labeled/with IDD who participated in the study. Inclusive and participatory research methods and interview techniques were used to shift from speaking *for* to speaking *with* people labeled/with IDD. Some of these techniques are apparent in the text below when the artist’s statement was rephrased or repeated back to them, “so you are saying -----.”

The artists’ personal accounts emerge from their experience in studio practice. As mentioned above, this studio is situated in the suburbs of a large metropolitan center in the United States. The frameworks described above assert an influence over the studio, its staff, and the artists. The artist's stories at times reinforce frameworks, for example when they describe the social connection they experience through public exhibition; at other times, their stories refute assumptions within frameworks, for example when they challenge notions embedded in the Outsider art genre. The stories further serve to call into question the concept of people

labeled/with IDD as perpetual recipients of care and control from others. The artists' stories describe experiences of both receiving and providing help and support in their studio community and in their lives, expanding an understanding of cognitive impairment past the boundaries of the individual, labeled person. Impairment, which in the studio appears to translate to the need for varying degrees of assistance, is described as something that emerges in the relationship between people. Importantly, assistance is described as something that every studio member *including staff, volunteers, and artists labeled/with IDD requires*.

1. **Stories from C**

C and I met for the first time over Zoom. C was sitting at the kitchen table at his family's home. C was temporarily staying there after having had a shoulder injury. His permanent residence was a group home, a shared residence with other men with disabilities. Using the screen sharing tool on Zoom, I pulled up C's online portfolio available through the studio's website. It is notable that C's name, his photograph and about a dozen examples of his artwork are available online. This points to the studio's connection with normalization and creative practices that emphasize exhibition and selling work, but C directed my attention almost immediately towards a piece of personal significance that he has not sold, a clay sculpture of his late father. C told me that the sculpture was a great source of pride.

Sara: Can you tell me about a time that you felt really proud at the studio?

C: When I made my dad's face in clay.

Sara: Your dad's face?

C: I was crying.

I asked C about the construction of the piece. He said it was both easy and frustrating.

Sara: What was frustrating about it?

C: The eyes.

Sara: The eyes?

C: Yeah

Sara: They were hard to do?

C: Yes, they were.
 Sara: How did you do them?
 C: I made them in clay.
 Sara: You made them in clay?
 C: Yeah.
 Sara: But they were hard to do?
 C: Yes. They were.
 Sara: I wonder if you got some advice about doing them.
 C: Yes, I did.
 Sara: From who?
 C: M.
 Sara: Who is M.?
 C: He's a volunteer at the studio.

I begin with this story from C because on the surface, C's account aligns with assumptions about people labeled/with IDD needing help. That C has a label of IDD and that his work emerges from a studio for people so labeled conjures the easy and automatic assumption that *C depends on M for support*. An art therapist working from a medicalized perspective might even read a therapeutic value into the scene: *M is helping C with grief through art*. Take IDD out of the narrative and it reads quite differently. C is an artist asking for advice, not an uncommon practice of *many* artists when they get stuck. An artist's "stuckness" is also not uncommon but it might be pathologized or medicalized where C is concerned, bringing the weight of the label of IDD into focus.

Further, the quick assumption that M is helping C denies the obvious way that C is helping M, by supporting his volunteer experience. Many volunteers in the studio where C makes art are there because they need a certain number of service hours to finish a degree or certification; therefore, C and the other artists support the volunteers' professional and academical advancement. Non-disabled artists and facilitators working with people labeled/with IDD might also glean creative rewards from their work with the artists, an opening of their own aesthetic horizons (Perring, 2005). Paid staff and administrators benefit in these ways and more

because they also make money. This is an important but often unrecognized aspect of human service organizations, that they play a role in *producing* and then *profiting from* disability (Albrecht, 1992).

Later in our interviews, C further disrupts assumptions about who receives help from whom by critiquing the level of support provided at the studio. He describes a desire to have *less assistance* and provides some practical advice on how the studio could reduce support, *even as he reflects on his own physical needs for support*.

Sara: If you could change anything about the studio, what would you change?

B: The way the studio is set up

Sara: The way the studio is set up? So, what is it about now that you don't like?

B: Move supplies...I'd move it to the front of the studio. It would be easier to get.

Sara: So, it almost sounds like you'd like if the supplies were more accessible to the artists to get themselves.

B: Yes

Sara: Do you, do think there might be any problems or challenges with making supplies more accessible?

B: Kind of. Yeah.

Sara: What kind of problems do you think might come up?

B: Getting clay. I'd have to walk up and grab the clay.

Sara: You'd have to walk up and grab the clay?

B: [and] Bring it back

Sara: So that would be one problem with everyone getting their own supplies?

B: Uh huh

Sara: Yeah. How would you solve that problem?

B: I'd put something on my walker.

Sara: Put something on your walker?

B: Yeah

Sara: Like uh, something that would help you carry the clay?

B: Yes

C's insider knowledge produced insight that is, in my view, invaluable for guiding artist-led practice in the studio, but people labeled/with IDD are often left out of the assessment and evaluation of services they receive (Robinson et al., 2014). Notably, supporting C to speak up for himself, to self-advocate for *less* assistance, creates a dilemma for paid staff whose jobs are dependent on C's *need* for their assistance (a dynamic noted by Goodley, 1998).

2. Stories from W

W participated in all interviews and focus groups via Zoom from his bedroom at his group home. Due to his group home's COVID-19 quarantine policy, W had not been able to return to the studio since its initial closure in March 2020, a fact which caused W great concern and frustration. W expressed to me and to the other artists in the study that he missed the staff and his friends.

While W also makes art, he told me that he primarily focuses on curatorial practices at the studio. He takes part in organizing shows and exhibitions and frequently emcees these events, speaking directly to the public about the work through what the studio calls *art talks*. W describes exhibitions as “helpful when I have to go and meet people,” again pointing towards the studio's value of community inclusion and its alignment with the Creative Art Center framework.

I asked W what curating an exhibition was like at the studio. W's answer points to both how he is helped to be successful in this role, as well as how his contribution to the curatorial process is unique and important to the success of the exhibitions.

W: What we do is they discuss, we discussed what happened last [exhibition]. We chose, last time we talked about exhibitions and coming up events that we can always have a talk about it. Then we both plan it out so that people can, people know what the date is.
 Sara: What is there to talk about? What do you have to go over in terms of exhibitions?
 W: We have to go over the things that they, that they explain to me. They'll say, okay, this is an exhibition that we're having...I was helping staff set up the exhibition, and I discussed at the meeting last time we had it, [there should be] a mention of every artist (*raises arm to show how the artists name should be high on the wall*) and they [could] see what artists, you know the name of the artist (*raises arm again to show how the artists names would be high on the wall*) I did great. That's a very good thing to do...She [staff] thinks I can do another art sale with her... I can help her set up the paintings and then people can come and look at them.
 Sara: So, you may help her set that up?
 W: Yeah, I've done it already. Yeah, she thinks I'm, she'll say, come here and help me out. And I do.

W described how his input influenced the placement of artists' names in the gallery. W recommended that the artists' names were placed high, which would have had an aesthetic impact in the gallery, perhaps emphasizing an acknowledgement of the individual artists for their work. W brought a unique vision for the exhibition, a distinct viewpoint that emerged from some aspect of his life experience. W offered a viewpoint to support the exhibition process, something he describes as a recurring event, an example of the way that he routinely helps the studio and staff run successful exhibitions.

W's story illustrates his unique and valuable viewpoint, and throughout our interviews W recognized his own value noting, "No, they're happy with me there. They're happy because they need me to come back. I don't know when but soon enough," and later, "I hope they realize that they need me." His story also points to the ways that power and control move between the artists and the staff at the studio. He ends by saying, in effect, that he helps when he is told to help, but from his story there also seems to be evidence that at least sometimes, staff also do what W tells them to do.

As Kupperts (2012) notes in her analysis of representation of artists labeled/ with IDD, people labeled/with IDD "often have to struggle to find voice and accurate representation, to escape the heavy burden of stereotypes and medical imagery that surround them." Curatorial practices offer people labeled/with IDD the rare opportunity to represent themselves, to *curate* the way they are presented and perceived. The ability of W and other artists labeled/with IDD to contribute to their own representation and the representation of their peers brings curation into the realm of self-advocacy, people labeled/with IDD speaking up for themselves (French, 2017). Further, the inclusion of people labeled/with IDD in the curatorial process brings insight that

elevates new aesthetic perspectives and potentially increases the accessibility of exhibitions, perhaps another aim of W's suggestion to post names high overhead (French, 2017).

3. **Stories from B**

B was the only artist that I interviewed who did not have a legal guardian. While the other artists needed their guardian's permission and signature to participate in the study with me, B could have signed for herself. Still, B asked that one of her sisters be involved in the consent process and be invited to the phone call when I talked with B about the study and what it would entail. It seemed that B wanted a second pair of eyes and ears to size up the potential benefits and risks of participating in the project.

B's relationship to her two sisters seemed characterized by a respect for what B could do for herself and for others, with the right kinds of support. This sentiment was captured in B's description of the collaborative art practice she developed with one of her sisters.

B: My sister said you do good art, why don't you, you do good art, and I did people. You do good, so why don't you teach me?

Sara: She said you do good art and then what?

B: She said you do good art, so why don't you teach me how to draw, when it comes to art?

Sara: She's said you're good at art. Why don't you teach me to do art?

B: Uh huh

Sara: So, you taught your sister?

B: Yes, and sometimes I can't think of what to make so she comes up with idea. And if I don't know how to do something, If I don't know how to do it, sometimes she helps me out too.

Sara: You help each other?

B: Yep

In addition to not having a guardian, B was the only artist I interviewed who lived alone in the community. With the help of her sisters, weekly visits from a personal aid and personal trainer, and the diligent use of a personal planner, B cares for herself and her cat.

4. Stories from T

T's love for Japanese art and culture is matched perhaps only by her love for pop icons. Her creative process involves carefully drawing and then painting representations of her favorite pop star and manga characters, often set in Japanese locales. T is so committed to her work that she told me she rarely takes a break during the day at the studio. Every other artist I interviewed described taking a walk daily at the studio with staff and peers, but T prefers to keep working.

Sara: What do staff do after lunch?

T: Oh, they are walking with the artists

Sara: Oh, they walk. Do you walk?

T: No, because I had too busy

Sara: Oh, so you could walk, but you choose to keep working?

T: Yes.

T's deep curiosity about a singular topic and her skillfulness in rendering that topic, *coupled with her label of IDD*, can potentially lead to troublesome interpretations of her story. For example, aspects of the Outsider Art genre rely on the notion of artists with socially isolated temperaments who produce stylistically labor-intensive and repetitive work (Prinz, 2017). Stuart Murray also brings attention to public fascination with the notion of the savant which has “increasingly become accepted as a common face of autism” (2008, p. 97), a figure that relieves public anxiety by compensating for disability with special abilities. Adding to complexity, these traits, “repetitive patterns of behavior” and “lack of social-emotional reciprocity,” are also used in medical frameworks for diagnostic purposes, for example in the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013). The DSM names and describes the conditions which receive Medicaid funding, funding that at least partially supports T's studio programming.

Lack of interest or inability to engage with others socially is a deeply rooted and damaging assumption about people labeled/with IDD (Kliewer et al., 2015), one that can be read into T's choice not to take walks with others at the studio only if we ignore the fact that *many* people choose to not to take breaks while at work. T's artwork further diminished projections of social disconnection. T brought my attention to a painting she created in response to the Kyoto Animation Studio arson attack in 2019 in Japan. The tragedy led to the deaths of 36 people.

T: I paint HelpKyoAni Heal.

Sara: You painted this?

T: Yes.

Sara: Oh, cool what's this about?

T: Yes, it was a tragic on July, July 18.

Sara: There was a tragedy?

T: Yes.

Sara: What happened?

T: 36 people died in Japan.

Sara: Wow.

T: It was a studio.

Sara: And that's why you made this art?

T: Yes.

Sara: [reads name of art] *Help KyoAni Heal*. So, you made this art to help, Help KyoAni heal?

T: Yes.

Sara: Sounds like you wanted to help?

T: Yes, I want to help. I want to help about survivors.

Sara: Do you think you did help?

T: Not yet.

I was not aware of the KyoAni tragedy before T brought it to my attention, perhaps because I do not think of myself as an animator the way T does. Despite the great geographic distance between them, T clearly considered this group part of her community. T's statement at the end "not yet," led me to question how assumptions about people labeled/with IDD as recipients of care limit their capacity to offer care to others. How often are opportunities to support and care for others foreclosed for people labeled/with IDD? How often too do presumptions of incapacity limit what people labeled/with IDD *think* they can do for themselves?

Another perspective might see that T's work is not just about care and concern for others but is a response to our collective exposure to acts of violence. Either way, it invites a recognition that people labeled/with IDD are aware of the world around them and that their art deals with social and political issues that extend well beyond their individual experiences.

E. **Conclusion**

To advance the participation and visibility of people labeled/with IDD in disability studies and in society, greater attention to the social construction of IDD *and* the social construction of cognitive impairment is needed. This paper examines the stories and creative practices of artists labeled/with IDD to illuminate the ways they receive and provide support to others in their studio community. Their stories reveal resilience and engagement which counter assumptions of people labeled/with IDD as passive and without culture (Goodley, 2001). Situating these stories within studio frameworks reveals the ways that people labeled/with IDD challenge misrepresentation and false narratives of individual tragedy, disconnection, and dependency attached to IDD.

Expressive art forms are potential avenues for people labeled/with IDD to engage in choice making, self-determination (Finley, 2013), and political empowerment (Goodley & Moore, 2002). But, while according to Hayden and Nelis (2002, p. 221) everyone has the potential for self-advocacy and resilience, it is also true that, as Goodley asserts (2004, p. 344), self-advocacy is a "product of the contexts in which it can emerge." Historically rooted studio frameworks influence studio practices. The artists' stories reveal the ways the artists are impacted by frameworks *and* the ways they challenge frameworks. For example, the artists described collaboration with non-disabled helpers that invites a reconsideration in disability art for the ways that some people value structures of support, such as the story of B and her sister and the help that C sought from the studio volunteer. This raises important questions about how

disability-led partnerships fit into the disability art paradigm. Similarly, C 's attention to receiving the *right level* of support, invites art therapists and other historically medically oriented practitioners to challenge assumptions about dependency, and to ask themselves exactly *who is helping whom* and *who is benefiting from what* in relationships with artists in studio settings. Further, the artists stories of social connection challenge assumptions at the heart of Outsider Art which profits from positioning artists as separate from society. By contrast, these artists seem to deeply connect and care for not only members of their own studio community, but in T's case, even a much wider network of people that spans the globe.

Thinking of IDD and impairment in terms of collaboration and interdependence does not foreclose or deny ongoing efforts to increase the autonomy of people labeled/with IDD. It continues to be important to ask why artists with physical disabilities may have *access* to the choice of working without non-disabled helpers and why people labeled/with IDD seemingly do not? People labeled/with IDD have a long history of being over-controlled. Medicalized definitions have justified the perpetual placement of control figures in the lives of people labeled/with IDD. Historically, these control figures have been practitioners, providers, and sometimes family members. Although in studios they may have different names (i.e., studio manager, artist mentors or volunteers), their function in some studios may be essentially the same: oversight, observation, and management. It is important to continue to question when any form of "help" is just another form of control. People labeled/with IDD are clearly critical voices in the advancement of adequate and respectful support and recognition as whole persons in society. Art alone cannot support this advancement, but artists labeled/with IDD and their creative practices may be the one piece of the puzzle needed to move forward toward these goals (Fox & Macpherson, 2015, p. 19).

VII. DISCUSSION

This chapter begins with a reflection from the researcher. It continues with a review of the aims of the study and the research questions posed by the study. Finally, this chapter evaluates methodological approaches used in the study, discusses limitations of the study, and suggests directions for future research.

A. **Researcher Reflection**

The artists at the Chicago Arts of Life studio used to have an inside joke about “wooden shoes.” I was never “insider” enough to be let in on the joke, but throughout my time volunteering there in 2017-2018, I witnessed this joke being told between artists at least 20 times. The artists would just say “wooden shoes” to each other, and everyone would crack up laughing. When the artists at Arts of Life Glenview started laughing in that *insider* way about “pom pom juice,” I started reflecting more on the role of insiderness/outsiderness and belonging in the studio. Hall (2010) described studios for artists labeled/with intellectual and developmental disabilities (IDD) as “spaces of social inclusion and belonging” (p. 48). In many ways, this study has reflected that assertion. While a group of artists were wishing another artist a happy birthday, I wrote in my Zoom studio observation notes *“A place to feel valued. A place to feel that your work, ideas, interests, life events are important. A community that you are a part of, that will mourn you, that will listen to you, that will celebrate you.”* In response to his own observation of the belonging of artists labeled/with IDD in art making spaces, Hall argues that only through people labeled/with IDD continually feeling valued and taking part in “continuous active processes of insiderness and proximity” will structures of exclusion and marginalization be dismantled (Hall, 2010, p. 56).

There is no guarantee that studio spaces for artists labeled/with IDD will foster feelings of belonging. Given the wide range of practices within studios, it seems likely that many studios

do not create environments of acceptance and connection. Perhaps that is one of the reasons why the artists in this study named *the people* at this studio as important. Together artists, staff, and volunteers created an environment capable of supporting deep personal connection, and maintained it, even in the face of great difficulty brought by the pandemic.

During the study, the artists' contrasted the belonging and inclusion they felt in the studio with experiences of being perceived as "different" outside the studio. During one of our focus groups, I asked the artists "Do you think there's anything special about Arts of Life that you can't get anywhere else, but you can only get at Arts of Life?" M said, "We have good friends...And you can feel free." I questioned further, "And you can't feel free outside of Arts of Life?" M said, "Sometimes it's hard." I asked the rest of the group to weigh in. "Do you guys think that's true, sometimes it's hard to feel free outside of Arts of Life?" W chimed in, "Mostly it is yeah. When you go outside of Arts of Life, I think people think you're doing something different." M agreed, "You're right W, and so they ask you right W?" M and W draw attention how feeling looked, perhaps *stared at*, inhibits their freedom outside of the studio.

Their observations raise important questions about how studios like Arts of Life can expand a culture of acceptance, felt in the studio, into broader society. Hall (2013) argues that making art with "known others" *coupled with* sharing artwork with "unknown" others does just that (p. 245). In other words, spaces of belonging are created by making art in community with people the artists know. Spaces of belonging are expanded outside the studio by the artists' willingness to share their work with people they do not know, people like me, for example. M reflected this when she told me that her wish for the studio is that her art, "will open their eyes to see how I feel and let the art show how I feel around my environment...What I mean when I say, 'open their eyes' what I mean is let them see the art between my eyes." I asked M "Who is

‘they’? Who is your audience?” She said, “The people outside of Arts of Life.” M’s vision for her work, to be a vehicle to share her knowledge and perspective with others, speaks directly to the heart of this study and to its aims.

B. **Research Questions**

1. **What do the artists value about and want for the future of their studio community?**

The artists engaged in this study identified people as the most important aspect of the studio, specifically the staff and their friends; they also expressed the importance of being able to make *their* own art, art that is self-directed. The importance of people at the studio was a prominent and repeated theme throughout the study. The artists both described and made art about the people they value and why they are valued. For example, one artist said during an interview that the people were the most important thing about the studio and then drew representations of a friend and a staff member at the studio during the focus group. Another artist drew a purple flower, a color and object he said he loved, to represent his love for the people at the studio. A third artist drew people at the studio going for a walk, opening the focus group up to discussion about why people are important at the studio -- what they do that makes them important. The artists identified that one of the most important things that people do at the studio is to talk with them about their lives, their families, and their interests. Talking and sharing their lives with each other was valued. One artist explained this by describing himself as “a people person” who always talks with friends while he works at the studio. In response to the prompt, “What do you want for the future at the studio?” This artist illustrated his love for talking and laughing with friends by drawing a party with people talking and laughing.

The people at the studio, both their friends and the staff, were a source of pride for the artists. In addition to talking with them, the artists described specific actions and qualities of staff

members that made them important in the studio. Key qualities of staff members were respect and patience. The artists also described the important things that staff do in the studio: the staff help the artists generate ideas for their work, retrieve materials to make art, problem-solve the construction of art, and problem-solve challenges that come up in the studio, such as interpersonal conflict.

The artists' value of people connects to their desire for more opportunities to be social and to make new social connections through parties and exhibitions. Exhibitions were valued by the artists in multiple ways. They see exhibitions as an opportunity to show their artwork to others, to take on leadership roles (curation and public speaking), to meet new people, and to make more money. The desire for more money and/or fame was described by multiple artists. One artist drew money when asked what she wanted for the future of the studio. She clarified that this was money for the artists, not for the studio itself.

Some of the artists reported a sense of belonging in the studio, described by one artist as feeling like “family.” Feeling a sense of belonging in the studio was juxtaposed with a comment from one artist (confirmed by others) that they feel they are looked at differently outside the studio. Despite this, the artists reported a desire for more access to the community. The desire for increased community access was illustrated in the second focus group by a drawing of an accessible van, a desire for the studio in the future. In response to this drawing, the artists discussed where they would like to go in their local community and where they dream of going nationally and internationally.

The artists' desire to make *their* art was accompanied by one artist's articulation of the importance of having a designated space to create her work, illustrated in a drawing of her studio worktable. The illustration reflects the artist's desire to have choice and control not only over her

creative practice but also over the space in which she creates. Choice and control were further emphasized by the artists' desires for specific materials and types of instruction at the studio, including more clay, a kiln, and tattoo and sewing lessons. Further, one artist described his desire to change the way materials are set-up in the studio to make them more accessible for the artists to retrieve independently.

The artists' expressed values and desires point to a community culture which could be described as collaborative, social, and creative. Stories from the artists that reflect these collaborative, social and creative practices challenge epistemological assumptions about people labeled/with IDD and about the relationship between IDD and impairment. In their stories about their experiences in the studio, the artists articulate social connection and mutual support that complicates and resists stereotypical negative social constructions of IDD as "deculturized, or without culture" (Goodley, 2001). Their values and desires also point to their capacity for insight and awareness. Despite people labeled/with IDD being frequently positioned as *unknowing* (Carlson, 2010b), these artists described what they know, *establishing themselves* as knowing.

2. **Is arts-based appreciative inquiry an effective method to include artists labeled/with intellectual and developmental disabilities in evaluation of their studio programming?**

Arts-based appreciative inquiry proved to be an effective method to engage artists labeled/with IDD in evaluation of their studio. Even when shifted unexpectedly online, the method provided a solid framework for the artists to talk about and make art about what they value and want for the future. The questions imbedded in the framework-- *what is most important or 'best' about the studio? what do you want in the future at the studio? And how do you think you can make your wishes/desires happen?* --were accessible to most research

participants and accessible to all participants with some rephrasing. Participants responses to these questions reveal their deep level of insight into their studio community. This itself is a key finding of the study because it positions the artists as having knowledge and the capacity to share that knowledge. It serves as evidence that people labeled/with IDD can and should be included in evaluation about the services and supports they receive. Despite increased efforts to include service users and their experiences in evaluation, people labeled/with IDD are rarely engaged in evaluation (Robinson et al., 2014).

The exclusion of people labeled/with IDD in evaluation research and in research generally can be at least partially attributed to methodological and ethical challenges. Some people labeled/with IDD have difficulty engaging in research projects that rely solely on language-based data collection methods. Art-based approaches like photovoice and the use of image-based research materials have been employed to increase inclusion of people labeled/with IDD (Kidney & McDonald, 2014). This study attempted to build on the effectiveness of these approaches in data collection by including both talk-based interviews and artmaking focus groups, both with positive results.

Art making is a strength of the research participants. The artists reported that their artistic practice is a source of pride and enjoyment; therefore, including artmaking in the study may have resulted in better participation and improved outcomes. All participants engaged in art making during the study, and their images contributed to study findings in important ways. For example, the artists' images were used as visual aids in participatory analysis. Using the artists' own images as visual aids to illustrate a theme helped them understand and evaluate the accuracy of the theme.

In most cases, the participants' artwork supported the themes they discussed during individual interviews. For example, the participants talked about the importance of people at the studio. This was reflected in drawings of people or representations of people during the focus groups. In some cases, the art created by participants pointed towards themes not included in talk-based interviews and focus groups. For example, as discussed in Chapter IV, one of the artists drew her studio space in response to the question "what is most important to you about the studio." The image led to the development of the theme, *it is important to the artists to make their art*, to have choice and control about what kind of art they make, and in the space where they make it. This finding may have been missed without the inclusion of art in analysis. It is also a theme that may not have been generated if art making was not a component of data collection, supporting the claim asserted by Nissley (2004) that art making may be is a way of knowing that reveals tacit or implicit knowledge not easily accessed through words alone. In arts-based research, sensory perception and bodily experience are understood as ways of knowing (Blumenfeld-Jones, 2016). Psychotherapist Eugene Gendlin called this phenomenon 'felt sense,' which he described as internalized awareness within the body that is preverbal but holds experiential knowledge (1978). The concepts are also supported by Tobin Siebers' concept of "complex embodiment," which asserts that bodies hold important situated knowledges (Siebers, 2008).

In addition to an evaluation of appreciative inquiry and art-based methods, the project had to address whether online methods could be used in inclusive evaluation research. Beginning with an assumption of the capacity of people labeled/with IDD to be creative and adaptive and a recognition of the flexibility of qualitative methods, this project transitioned from in-person to online methods with interesting and promising process findings outlined in Chapter

IV, Inclusive online research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: Technological adaptations. Just as the pandemic highlighted previously existing problems in services for people labeled/with IDD, for example, limited pool of caregivers (Consantino, 2020) and lack of medical professionals trained to meet their needs (Krahn et al., 2006), the use of online research methods highlighted pre-existing exclusion of people labeled/with IDD in online environments (Chadwick et al., 2013). Despite barriers, benefits to inclusive online research emerged during the study including allowing for participation when in-person methods were not safe, allowing for more participant choice and control of the research environment, and the use of online research to support people labeled/with IDD to gain online skills.

Supporting the artists' articulation of their values and desires has the potential to impact studio practice. In this study, the artists shared their desires for the studio with the studio manager. Five study participants participated in a studio meeting that was observed by the researcher. During this meeting, the artists talked about their desires for the future of Arts of Life and made actionable plans with the staff and other artists to enact change at the studio. In addition to this direct impact, the artists' accounts have implications for studio practice more broadly. The artists' stories challenge frameworks established in studios for artists labeled/with IDD and the epistemological assumptions on which the frameworks are built. Further, the artists' needs and wants in the studio reveal some aspects of their experiences outside the studio. For example, the desire for an accessible van reveals limitation in transportation options available to the artists, and the desire for more opportunities for social connection relates to experiences of social disconnection and isolation experienced outside the studio.

C. **Methodological Discussion**

This study explored the use of art-based appreciative inquiry to include artists labeled/with IDD in evaluation of their studio programming. The appreciative inquiry four-stage model supported the artists to first identify their strengths (Discovery), imagine possible futures (Dreaming) and explore strategies for achieving their collective goals (Designing and Delivery/Destiny). Talking with the artists about their artwork was a wonderful way to start this process because it validated their sense of accomplishment and pride in their work and community. Supporting the artists to respond to prompts and questions both verbally and through art during focus groups enhanced the artists' engagement and enjoyment in the process and led to positive outcomes. This method shows promise to increase inclusion of artists labeled/with IDD in both in-person and online research.

While art-based researchers have written about the potential of art to increase participation of marginalized groups in research because it does not rely on verbal expressions or language (Coemans & Hannes, 2017; Sinding et al., 2008), researchers should be cautioned not to assume that all people labeled/with IDD like making art or would be able to engage in artmaking in research. Not all people labeled/with IDD want to or are comfortable making art, just as not all people without IDD are comfortable making art. Assuming that this group would somehow naturally be comfortable or willing to make art as part of research relies on false assumptions of heterogeneity. It may be that artists labeled/with IDD are uniquely skilled to use art as a tool to communicate their community values.

In addition to the use of art to increase participation and inclusion of the artists, inclusive principles were utilized in the study design. The inclusion of marginalized voices in evaluation and evaluation research is seen both as a social justice endeavor and as a process that improves evaluation (Mertens, 1999). Participatory program evaluation that includes the perspectives of

people with disabilities can increase the quality of data that is obtained and the relevance and utility of the evaluation (Robinson et al., 2014; Gill, 1999). TABLE II, outlines how some of the inclusive approaches used in this study align with core inclusive research practices identified by Nind (2014).

This project utilized a collaborative approach to inclusive research in which the researcher and research participants took on different tasks based on skills and interests (Bigby et al., 2014; Walmsley et al., 2018). For example, the researcher developed the initial protocol and applied for Institutional Review Board (IRB) approval for the project. The researcher also completed a verbatim transcription of interviews and focus groups and developed initial themes. In addition, the study participants provided analysis of their own images and reviewed the researcher's initial themes for accuracy. The artists also took a leading role in the dissemination of findings. In addition to this written dissertation, which includes three papers intended for publication in peer-reviewed journals, the artists were provided with the list of the most important things in the studio (the people, making their own art) and desires for the future of the studio (more opportunities for social, to make more money, to get out in the community more, and have more materials, equipment and types of instruction) generated in the study. To protect privacy, the researcher included no identifying information and reminded the artists to keep each other's identity and contributions to the list confidential. Although the group discussed who they thought should see the list, and although the researcher later learned that the artists shared the report with their studio manager, the researcher did not have control over whom else the artists shared the list with.

TABLE II
CORE IDEAS IN INCLUSIVE RESEARCH APPLIED TO THIS STUDY

Disrupting the hierarchy	<ul style="list-style-type: none"> • The artists were positioned as experts with valuable insight into the research topic. • Consent was ongoing, revisited at each interview and focus group and reviewed at decision points during the study
Maximizing participation and competence	<ul style="list-style-type: none"> • Plain language and image-based research materials were developed for the study. • Image-based tools available on the online platform were used (screen sharing) to increase participation and understanding. • The study engaged the artists in an activity they identified as enjoyable and felt skillful doing (art making) to increase their participation.
Enhancing authenticity	<ul style="list-style-type: none"> • The study was grounded in the experiences of people labeled/with IDD. • The study included the artists with IDD in analysis of findings written in plain language and accompanied by the artists own images.
Empowerment	<ul style="list-style-type: none"> • Through the appreciative inquiry process, participants articulated their values, imagined possible futures, and discussed strategies to achieve collective goals increasing their capacity to identify and make changes in their community.
Accessibility, authorship, and readership	<ul style="list-style-type: none"> • Participants had a leading role in dissemination of findings.
Ethical considerations	<ul style="list-style-type: none"> • Throughout the study, the researcher engaged in critical reflexivity, keeping a reflective journal, and consulting more experienced inclusive researchers about ethical concerns.

These types of inclusive approaches should be expanded in future studies. For example, future arts-based appreciative inquiry should involve artists more in the study design, especially the art-based aspects of the study protocol. A preliminary planning meeting could be held prior to the study or early in the study to talk with the artists about the primary questions asked in the study, how long the artists think they would need to complete artwork in response to those questions, and what kinds of materials and supports they would need. Under such circumstances, the artists in this study would likely have been able to describe their process and predict many of their needs, but it would still be beneficial to establish check-ins as artmaking progressed to ensure that artists had the supports, materials, and time they needed. This would likely extend the length of the project but may ultimately make the project more enjoyable and more satisfying for the artists.

This study draws from established inclusive research practices and explores the innovative use of inclusive principles in online environments. Chapter IV highlights the benefits and potentials of inclusive online methods which include increasing the access to online tools for people labeled/with IDD. During the study, the artists emphasized the importance of connection through the online Zoom studio programming. None of the artists in the study reported having used Zoom before the pandemic, but three said that they would like to continue using the platform even after the pandemic ended. The artists' growing familiarity and comfort with the online platform opens doors for the research participants' future connection with others through online platforms, potentially reducing experiences of social isolation.

D. **Limitations**

The methodological components of the study, coupled with the impact of COVID-19 on the studio and on in-person research, limited the size of the study. Interviews and focus groups can already be time-intensive; adding art making and analysis of the art into the study design *and*

then moving the study online required the researcher to limit the study size to a small number of participants. The small number of participants significantly limits the generalizability of findings across people or groups. Additionally, while the demographic make-up of the group was somewhat broad (broad age range and diverse racial and ethnic identities), identity groups with which artists labeled/with IDD identify were missing. These study findings should be viewed not as a representation of what all artists in studio practice want for their studio, but rather as a *strategy* that practitioners can use with a diverse group of artists in studio practice to learn what they want in their studio community.

Another limitation of this study is that online methods were added late in the study. While significant attention was paid to ethical and methodological considerations for moving this inclusive study online, some aspects of the procedure proved awkward or ill-fitting after the shift to the Zoom platform. For example, the third focus group was planned to include food to create a celebratory atmosphere. Because the third focus group was held virtually, it was difficult to create an event that felt as rewarding as an in-person gathering would have been. While it would be impossible to predict a pandemic, it might behoove future inclusive researchers to at least consider early in the planning process how in-person research projects might translate to online formats, whether those plans are ever implemented.

Finally, this study was conducted during an unusual time. The pandemic impacted every aspect of this study including not only the artists and the studio, but this researcher as well. From the beginning of data collection until the final focus group, everyone involved was being impacted by a global catastrophe that threatened not only our safety but also our ability to meet our own and each other's personal and social needs. There is little doubt that this situation had an impact on what the artists told me was important to them at the studio: *the people*. In fact, many

of the artists reflected on the importance of people at the studio by reflecting on what they missed about the studio when it was closed. The pandemic might also have a limiting impact on how quickly changes recommended by the artists can be implemented. During the studio meeting, when the desire to purchase an accessible van was discussed, the studio manager reminded the group that trips into the community as a group were on hold due to COVID-19. The purchase of an accessible van was put on the backburner. Hopefully, the shelving of the idea will not lead to its demise.

E. **Future Directions for Research**

Despite its emphasis on “positive imagery,” very little research using the appreciative inquiry process actually includes art making (Nissley, 2004). Researchers need to investigate more how art making can be built into the research model. Further, researchers should examine how artmaking is prompted and supported in inclusive research. In this study, images were completed in a short time frame, in one-hour focus groups. This time frame may have been limiting to the artists, impacting the quality of the work and the artists’ ability to effectively communicate their meaning through art. Future art-based inclusive work with artists should involve the artists in planning the art making protocol in the study.

Supporting artists to more purposefully dictate the conditions in which they create art invites researchers to move away from what Wang, Coemans, Siegesmund, & Hannes (2017) call *art in research*, research that is situated in the social sciences and uses art as a methodology or a means to an end; toward *art as research*, research that is practitioner or artist led. In *art as research*, research is situated in arts-practice, thereby framing the artistic process as a form of inquiry that can lead to a better understanding of experiences, concepts, or environments (Wang et. al. 2017). For example, Fox and Macpherson (2015) define *inclusive arts practice and research* as creative practice between artists labeled/with IDD and artists without IDD, an

exchange that is mutual and collaborative. Artists with and without disabilities “learn (and unlearn) from each other,” shifting away from the roles of ‘helper’ and ‘helped’ (Fox & Macpherson, 2015, p. 2). Moving away from these roles is a way of re-envisioning the world and results in both high-quality art and cultural products that can affect social change (Fox & Macpherson, 2015).

Art as research could expand on insights gleaned from the artists’ stories of collaboration shared in Chapter VI of this dissertation. Future researchers may use art making to look at the difference between the way artists labeled/with IDD work collaboratively with each other versus how artists labeled/with IDD work collaboratively with non-disabled helpers. Future studies may also examine how different mediums or environments impact collaboration. The COVID-19 pandemic has shown us that online and remote collaboration are meaningful tools for artists labeled/with IDD. Researchers should study how online or remote collaboration differs from in-person collaboration. Another future direction that has been promoted by Fraser (2018), is research that turns a humanities lens to focus on the established portfolios of artists labeled/with IDD. With this lens, *research about art* investigates art-related topics or art objects to understand how art and aesthetics impacts both individuals and society (Wang et. al., 2017).

F. **Policy Implications**

Organizations supporting people labeled/with IDD funded by state and federal entities, like Arts of Life, are routinely subject to auditing and program monitoring by funding bodies. In Medicaid funded day programming in Illinois, this program monitoring includes review of provider quality assurance and on-site interviews with clients, guardians, and agency staff (IDHS, 2020). These reviews necessitate that organizations develop a plan for program evaluation. This study asserts the potential value of emphasizing participatory and participant-focused program evaluation.

Program evaluators engaged in evaluation research and Disability Studies scholars have articulated the importance of including people with disabilities meaningfully in the evaluation of programs that serve them (Gill, 1999; Schlosnagle, McBean, Cutlip, & Panzironi, 2014). Not only are people with disabilities the experts on their own experiences, but people with disabilities bring unique strengths and insights into evaluation including “a matter-of-fact orientation toward helping; acceptance of human interdependence over individualism,” “highly developed skills at managing multiple problems, systems, and helpers”, “creativity, lack of rigidity, ability to use traditional elements in new ways to solve problems,” and “sophisticated future orientation and planning around anticipated obstacles” (Gill 1999). Further, Gill asserts that there are limits to the understanding of disability as a phenomenon without the lived experience of disability (1999).

G. **Conclusion**

This study’s findings support the inclusion of artists labeled/with IDD, their stories and their art, in evaluation of the studios in which they participate. The implications of these findings have bearing not only on this studio, but on the assumptions that underpin studio facilitation more broadly. For example, the artists’ stories, art, and artistic processes draw attention to and challenge assumptions in art therapy that art making is necessarily therapeutic, and assumptions imbedded in outsider art that artists labeled/with IDD have stereotypical qualities such as lack of social connection. The artists’ work also challenges broader assumptions about people labeled/with IDD as perpetually in need of professional support and control. The artists instead articulate a studio community that is mutually supportive across members with labels and those without labels. Finally, the artists themselves reflect on their own strengths and support needs in insightful ways. The artists insight and insider knowledge about barriers to participation and

access brings them into disability studies discourse that articulates the social construction of intellectual and developmental disability, an important and perhaps still under recognized aspect of IDD. Further, with this work, these artists contribute to an understanding of how people labeled/with IDD seek and receive and how they provide support to others, complicating assumptions about impairment with stories of collaboration and social connection.

APPENDICES

APPENDIX A



Research means to look carefully at something in order to learn about it. Would you like to be a part of research at Arts of life? **It is your choice. You can say no or stop at any time.**



Sara Miller is a student at the University of Illinois at Chicago. She would like to do a research project with the artists at the Glenview Arts of Life Studio called Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD.

Sara would like to visit the studio 1 x per week for 2-3 months:

Right now the studio is closed due to COVID 19 safety measures. Until the studio re-opens and it's safe for Sara to visit in person, Sara will participate in the online Zoom studio programming at Arts of Life.



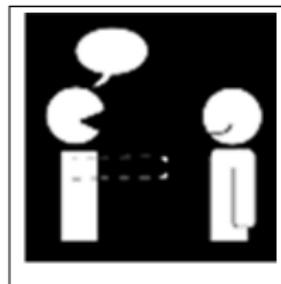
You may be asked to allow Sara to observe you in the studio or in online programming going about your day-to-day activities. Sara will be trying to learn about the most important parts of the studio.



APPENDIX A (continued)

You may also be asked for individual interviews (up to four interviews for no more than 30 minutes each). You may be asked questions like:

1. What are you good at?
2. What do you like about the studio?
3. What do you do at the studio?



If the studio re-opens and interviews can happen in person, the interview will be audio recorded and some of your artwork will be photographed with your permission. If the interviews take place by phone or using Zoom, the interview will be video recorded.

You may also be asked to participate in two, 1 hour art-based focus groups where you may be asked to make art and talk about:

1. What are the best parts of the studio?
2. What you want the studio to be like?



At the end of the project, you may also be asked to participate in one last 1 hour focus group where Sara will share what she has learned about the studio and you can tell her what you think.

If the studio re-opens and focus groups can happen in person, the groups will also be audio recorded and your artwork photographed with your permission. If the interviews take place by phone or using Zoom, the interview will be video recorded.

APPENDIX A (continued)

It is your choice. You can say no or stop at any time. Your information is kept private.

Contact Sara at (317) 938-2992 or 4734 N. Kenmore, Chicago, IL 60640 with any questions.

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APPENDIX B

Protocol: The studio manager will identify artists who meet the eligibility criteria for the project:

Primary research participants who will be engaged in participant observation, individual interviews and focus groups (up to 6 subjects) will meet the following inclusion criteria: 1) Attendance at the studio at least two days per week for at least four months prior to COVID 19 outbreak or attendance in virtual programming since COVID 19 outbreak at least one day per week, 2) the ability to respond to both verbal and art-based interview and focus groups prompts, 3) placement in a "leadership track" within the arts of life studio model (curator or educator).

Secondary research participants who will be engaged only in participant observation (up to 25 subjects).
1) Attendance at the studio for at least one day per week for at least 1 month prior to COVID 19 outbreak or attendance in virtual programming since COVID 19 outbreak at least one day per week.

Once identified, the studio manager and/or staff member will show the flyer to the participant and read the following script.

*Script: You are being invited to be a part of research project. The project will take place using Zoom and by phone, these are virtual/remote formats, until the studio re-opens. Research means to look carefully at something, to learn about it. Would you like to be a part of research at Arts of Life? Remember, it is your choice. **You can say no or stop at any time.** Sara (pictured here), is a student at the University of Illinois. She would like to come to "research" or learn more about the studio and the artists at the studio. As an artist at Arts of Life, Glenview studio, you may be asked or observed to find out:*

What do you do in the studio?

What are the best things about the studio?

What do you want the studio to be like in the future?

If you are an artist in the Educator, Career or Curator track, Sara might also ask for individual interviews (up to 4, no more than 30 minutes each). An interview is a one-to-one meeting with Sara. Sara might also ask for you to join three focus groups with up to 5 other artists. A focus group is a group meeting. The first two focus groups will include art making about what you like about the studio and what you want in the studio. At the final focus group, Sara will share with you what she has learned about the studio and you can tell her what you think.



APPENDIX B (continued)

It is your choice if you want to participate. You can say no or stop at any time! Your information is kept private.

Are you interested to learn more? If so, we will invite Sara to call you (or visit the studio if it reopens) and give you more information. If you have a guardian, Sara will ask them first to make sure it's okay.

In person recruitment/consent process steps are as follows: The artist evidences interest after seeing the flyer, then the PI contacts any guardians to inform them of the study and the participant's interest, then guardians are sent the consent form to sign and return to the PI, then the PI meets with artists to obtain assent (consent if no guardian). Guardians will receive the consent form in the mail with a stamped addressed envelope to return the form to the primary investigator.

Virtual/remote recruitment/consent process steps are as follows: The artist evidences interest after seeing the flyer, the PI will be informed by the staff and will be provided with contact information for the participant. If the participant has a guardian, the PI will be provided with the guardian's contact information. Individual consent/assent meetings will be schedule (by phone or Zoom) with participants without guardians. Multi-person consent/assent meetings will be schedule with participants with guardians. Consent/assent materials will be sent ahead of consent/assent meetings with stamped addressed envelopes to return to the PI.

APPENDIX C

Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD

1

Participant eligibility checklist

Primary research participant eligibility checklist:

Participants must be at least 18 years old



____ 1) Attendance at the studio at least two days per week for at least four months prior to COVID 19 outbreak or attendance in virtual programming since COVID 19 outbreak at least one day per week (information provided by studio manager)

____ 2) Able to respond to verbal prompts (evaluated based on responsiveness to consent questions)

1) Please tell me, in your own words, what is this study about?

Participant response:

2) What will you be doing if you take part in this study?

Participant response:

3) What are the risk of being in this study?

Participant response:

4) When I say your taking part is your choice, what does that mean?

Participant response:

5) When I say that your information will be kept confidential, what does that mean?

Participant response:

6) What can you do if you start the study, but don't want to finish it?

Participant response:

____ 3) Placement in a "leadership track" within the arts of life studio model (curator, career or educator).

____ 5) Consent of guardian/LAR if applicable

APPENDIX C (continued)**Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD 2**

Secondary research participant eligibility checklist:

____ **1) Attendance at the studio for at least one day per week for at least 1 month prior to COIVD 19 outbreak or attendance in virtual programming since COIVD 19 outbreak at least one day per week (information provided by studio manager)**

____ **3) Consent of guardian/LAR if applicable**

APPENDIX D

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PROTOCOL #:	2020-0393
DATE:	07/20/2020
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**University of Illinois at Chicago (UIC) Research Information and Consent/Assent for
Participation in Social, Behavioral, or Educational Research
Arts-based Appreciative Inquiry with Studio Artists Labeled/with Intellectual and Developmental
Disabilities**

Principal Investigator/Researcher Name and Title: Sara Miller Faculty **Advisor Name and
Title:** Carrie Sandahl, Associate Professor UIC
Department and Institution: Disability and Human Development, University of Illinois at
Chicago
Address and Contact Information: 4734 N. Kenmore Chicago, IL 317-938-2992

Note: This research includes subjects who are adults who are not able to consent for themselves. If you are a parent, guardian, or legal representative, the terms “you” or “you” refer to the research subject for whom you are responsible. At the end of this document both the research participant and guardian/LAR will sign indicating their consent/assent for participation in this study.

About this research study

You are being asked to participate in a research study. Research studies answer important questions that might help change or improve the way we do things in the future.

Taking part in this study is voluntary

Your participation in this research study is voluntary. You may choose to not take part in this study or may choose to leave the study at any time. Deciding not to participate, or deciding to leave the study later, will not result in any penalty or loss of benefits to which you are entitled and will not affect your relationship with the University of Illinois Hospital and Health Sciences System (UI Health) and/or University of Illinois at Chicago (UIC). Deciding not to participate, or deciding to leave the study later, will not impact your relationship with Arts of Life.

This consent form will give you information about the research study to help you decide whether you want to participate. Please read this form and ask any questions you have before agreeing to be in the study.

UIC IRB Social, Behavioral, and Educational
Research Informed Consent Template: 11/01/19
Do NOT Change This Field – IRB Use ONLY

AI with Artists Labeled/with
IDD
Page 1 of 9

[Version 9, 7/17/2020]

APPENDIX D (continued)

You are being asked to participate in this research study because you are an artist at Arts of Life. This study will invite the artists at Arts of Life to talk about and create art about what they like about the studio, what is important to them about the studio and what they want the studio to be like in the future. Up to 31 artists at Arts of Life will be enrolled in this research study.

Important Information

This information gives you an overview of the research. More information about these topics may be found in the pages that follow.

WHY IS THIS STUDY BEING DONE?	This research will help support Arts of Life to meet the wants and needs of the artists.
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APPENDIX D (continued)

<p>WHAT WILL I BE ASKED TO DO DURING THE STUDY?</p>	<p>With current COVID 19 safety measures in place, all aspects of this study will be conducted using virtual or remote formats at this time, Zoom or phone. If COVID 19 measures are lifted this research project will move from virtual/remote formats to in-person formats. Both in-person and remote/virtual formats are described below:</p> <p>Participant observation:</p> <p>Virtual/remote format: You will participate in virtual programming on the Zoom platform facilitated by Arts of Life along with the primary investigator (PI) of this research (Sara Miller). Sara will engage in virtual programming for 6 hours per week for 2-3 months. Sara will observe the day-to-day activities of the online programming <u>in order to</u> learn what the most important/best parts of the studio are from the artists perspective. Sara's observation will include: How the research participants spend their time, what the research participants say about their thoughts, feelings and experiences in the studio, the content of research participants artwork, and how research participants make and share their artwork with others.</p> <p>In-person format: You will participate in programming at the studio as usual along with the primary investigator (PI) of this research (Sara Miller). One time per week for up to 6 hours for 2-3 months, Sara will observe the day-to-day activities of the studio <u>in order to</u> learn what the most important/best parts of the studio are from the artists perspective. Sara's observation will include: How the research participants spend their time, how the studio space is utilized, navigated and negotiated by research participants, what the research participants say about their thoughts, feelings and experiences in the studio, the content of research participants artwork, and how research participants make and share their artwork with others.</p> <p>Individual Interviews at the studio:</p>
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APPENDIX D (continued)

	<p>Virtual/remote format: If you are in the Educator, Career or Curator track at Arts of Life, you may also be asked to participate in individual interviews by phone or using the Zoom platform during normal studio hours. To protect your privacy, individual meetings conducted via Zoom will require a password to join. You will be supported to find a private location where other people that you live with will not be recorded captured by the camera without their knowledge. During individual interviews, participants will be asked to share their feelings and thoughts about themselves and the studio and potentially show artwork they have made about themselves or being a part of the studio. If they choose, participants may also create artwork during the individual interviews. Individual interviews will be video recorded.</p> <p>In person format: If you are in the Educator, Career or Curator track at Arts of Life, you may also be asked to participate in individual interviews at the Arts of Life Glenview studio during normal studio hours. Individual interviews will occur at the studio in a space selected by you (could be in a private room, a semi-private where people come in and out or in the main studio area where someone is always close by). During individual interviews, participants will be asked to share their feelings and thoughts about themselves and the studio and potentially show artwork they have made about themselves or being a part of the studio. If they choose, participants may also create artwork during the individual interviews. Individual interviews will be audio recorded and some of the artists artwork will be photographed with their permission.</p> <p>Focus groups at the studio:</p> <p>Virtual/remote format: If you are in the Educator or Curator track at Arts of Life, you may also be asked to participate in two small artbased focus groups at the Arts of Life Glenview studio during normal studio hours. Focus groups will last no more than 1 hour each. During focus groups, you will be asked to make art and talk <u>about</u>: 1) The best parts of the studio and 2) What they would like the studio to be like in the future. You may also be asked to participate in a third and final focus group (one hour) where Sara will share what she has learned about the studio and you can tell her what you think. Focus groups will be conducted using the UIC Zoom platform. Focus groups will be video recorded. Focus groups will invitation only, password protected meetings for primary research participants. Participants will be reminded about choosing</p>
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APPENDIX D (continued)

	<p>a location for their participation in the focus group that is private, where non-research participants residing with the participant are not likely to be captured by the camera without their knowledge, for example choosing a room with a door or sitting against a wall.</p> <p>In person format: If you are in the Educator or Curator track at Arts of Life, you may also be asked to participate in two small art-based focus groups at the Arts of Life Glenview studio during normal studio hours. Focus groups will last no more than 1 hour each. During focus groups, you will be asked to make art and talk <u>about</u>: 1) The best parts of the studio and 2) What they would like the studio to be like in the future. You may also be asked to participate in a third and final focus group (one hour) where Sara will share what she has learned about the studio and you can tell her what you think.</p>
HOW MUCH TIME WILL I SPEND ON THE STUDY?	<p>Participant observation: In the beginning, Sara will visit the studio to observe the studio activities 6 hours per week for 2-3 months. You can go about your normal activities when Sara is in the studio or visiting the Arts of Life virtual Zoom platform. The total amount of observation may be as many as (but not more than) 72 hours.</p> <p>Individual Interviews at the studio: If you are in the Educator or Curator track at Arts of Life, you may be asked for up to for individual interviews. Individual interviews will last no more than 30 minutes each. The total amount of time requested for individual interviews for each participant is 2 hours.</p> <p>Focus groups at the studio: If you are in the Educator or Curator track at Arts of Life, you may be invited to participate in <u>three focus</u> groups which will last no more than one hour each. The total amount of time requested for focus group participation is 3 hours.</p>
ARE THERE ANY BENEFITS TO TAKING PART IN THE STUDY?	There are no direct benefits to research participants for participating in this study.
WHAT ARE THE MAIN RISKS OF THE STUDY?	The primary risks presented by this research study are breaches of privacy (others outside of the study may find out you are a subject) and/or confidentiality (others outside of the study may find out what you did, said, or information that was collected about you during the study). Sara may share with others what you said or images of the

APPENDIX D (continued)

	<p>artwork you made during individual interviews or focus groups, but your name will be removed so that no one knows who you are.</p> <p>If you are the focus group, Sara will ask that the focus group members respect each other's privacy, and not repeat what is said to others outside of the group, this confidentiality cannot be guaranteed.</p> <p>Talking about thoughts and feelings can cause distress for some people. If you become upset or distressed, Sara will support you to talk about and use art to cope with those feelings. Sara may also help you to talk with a "key support person" that you identify ahead of time. You can also skip and/or not respond to any questions that may make you uncomfortable. You can also take a break at any time.</p> <p>There may also be risks from the study that are not known at this time.</p>
DO I HAVE OTHER OPTIONS BESIDES TAKING PART IN THE STUDY?	This research study is not designed to provide treatment or therapy, and you have the option to decide not to take part at all or you may stop your participation at any time without any consequences.
QUESTIONS ABOUT THE STUDY?	<p>For questions, concerns, or complaints about the study, please contact Sara Miller at 317-938-2992 or email at smille61@uic.edu or Carrie Sandahl at csandahl@uic.edu (faculty advisor)</p> <p>If you have questions about your rights as a study subject; including questions, concerns, complaints, or if you feel you have not been treated according to the description in this form; or to offer input you may call the UIC Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.</p> <p>If you have questions or concerns regarding your privacy rights under HIPAA, you should contact the University of Illinois HIPAA Privacy Office at (844) 341-2201 or hipaa@uillinois.edu.</p>

Please review the rest of this document for details about these topics and additional things you should know before making a decision about whether to participate in this research. Please also feel free to ask the researchers questions at any time.

What procedures are involved?

This research will be performed at Arts of Life, Glenview, Illinois

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IDD
Page 6 of 9

[Version 9, 7/17//2020]

APPENDIX D (continued)

During this study, Sara will collect information about you for the purposes of this research. Sara will collect notes about her time in the studio, audio recordings or video recordings of individual interviews and focus group meetings and photographs of your artwork. This data will all be collected in order to better understand what is most important or “best” about the studio and what you would like to change to make the studio even better.

What will happen with my information used in this study?

Your identifiable private information collected for this research study will not be used for future research studies or shared with other researchers for future research.

What about privacy and confidentiality?

Efforts will be made to keep your personal information confidential; however, we cannot guarantee absolute confidentiality. In general, information about you, or provided by you, during the research study, will not be disclosed to others without your written permission. However, laws and state university rules might require us to tell certain people about you. For example, study information which identifies you and the consent form signed by you may be looked at and/or copied for quality assurance and data analysis by:

- Representatives of the university committee and office that reviews and approves research studies, the Institutional Review Board (IRB) and Office for the Protection of Research Subjects.
- Other representatives of the State and University responsible for ethical, regulatory, or financial oversight of research.
- Government Regulatory Agencies, such as the Office for Human Research Protections (OHRP).

A possible risk of the study is that your participation in the study or information about you might become known to individuals outside the study. Your data will be kept confidential until the master list/identifiers are destroyed. Your demographic information, including address and phone number will be stored in a locked location and destroyed at the end of the final focus group.

To minimize these risks, the researchers will ask all members of the group to respect each other’s privacy and confidentiality, and not identify anyone in the group or repeat what was said during the group discussion, but other members of the group may accidentally disclose this information.

When the results of the study are published or discussed in conferences, no one will know that you were in the study. During the study, photographs, and/or audio recordings will be collected. Your identity will be protected or disguised by de-identifying your data and storing data in a password protected computer. All identifiable data will be destroyed at the after the completion of data analysis.

Please remember that there is an exception to protecting subject privacy and confidentiality if child, elder, and/or disabled adult abuse or neglect of an identifiable individual, or the threat of imminent self-harm or harm to others is disclosed. If such information is disclosed, the researchers may be obligated to inform the appropriate authorities.

APPENDIX D (continued)

What are the costs for participating in this research?

There are no costs to you for participating in this research

Will I be reimbursed for any of my expenses or paid for my participation in this research?

You will receive \$5 for your participation in the participant observation portion of the study. If you do not finish the study, you will be compensated \$5 for any amount of participation in the participant observation portion of the studio. If you are in the Educator or Curator track at Arts of Life and you complete at least one interview and one focus group you will receive \$50, totaling \$55 dollars if you have also participated in participant observation. This money will be dispersed after the final focus group.

Can I withdraw or be removed from the study?

If you decide to participate, you have the right to withdraw your consent and leave the study at any time without penalty.

The researchers also have the right to stop your participation in this study without your consent if they believe it is in your best interests.

Remember:

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Signature of Subject

I have read the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this form.

Your signature below indicates that you are providing both consent/assent to participate in the research study in both virtual/remote and in-person formats described above.

Signature

Date

Printed Name

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IDD
Page 8 of 9

[Version 9, 7/17/2020]

APPENDIX D (continued)

Signature of Parent, Guardian, Legal Representative	Date of Signature
Printed Name of Parent, Guardian, Legal Representative	
Describe relationship to subject including the legal authority this individual <u>has to</u> act on behalf of the subject. (Check one below)	
<input type="checkbox"/> Parent <input type="checkbox"/> Legal guardian <input type="checkbox"/> Other; specify	

[Required]

Signature of Person Obtaining Consent

Date (must be same as subject's)

Printed Name of Person Obtaining Consent

APPENDIX E

You are being asked to be a part of a research project.

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PROTOCOL #: _____ 2020-

DATE: _____ 07/20/2020



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You can say no. You can stop at any time.

What will happen if you agree to be in the project?



Sara Miller will participate in studio programming for up to 6 hours per week for 2-3 months. If the studio is closed, Sara will participate in online studio programming on Zoom. If the studio is open, Sara will participate in the day-to-day activities at Arts of Life Glenview in the studio with you. Sara will be trying to learn what the most important/best parts of the studio are.

If you are in the Curator, Career or Educator studio track, Sara may also:



Meet with you one-on-one to interview you at the Glenview studio (up to four interviews for no more than 30 minutes each). If the studio is closed, Sara will schedule individual interviews by phone or using Zoom.

There are no right or wrong answers.

The interview will be audio or video recorded and some of your artwork will be photographed with your permission.

APPENDIX E (continued)



Meet with you two times in a small focus group (you and up to 5 other artists from the studio) for up to 1 hour each time. If the studio is open these groups will happen in the studio. If the studio is closed, these groups will happen using Zoom

You will make art and talk about your feelings about the studio!

The focus groups will be audio or video recorded and your artwork photographed with your permission.

What will happen when?

Step 1: You are asked if you consent (agree) to be a part of the research project



Sara will talk to you about the research project

You will learn about the benefits and risks of the project

You can ask any questions you have

Step 2: Sara will participate in the studio



Sara will attend studio programming (in person or using Zoom) for up to six hours for 23 months.

Sara will participate in the day-to-day activities of the studio with you such as making art.

Later, Sara will write about the things you show and tell her are important to you in the studio.

Step 3: Get paid! All artists who participate in Steps 1 and 2 get \$5.00!



Step 4: Individual interviews

APPENDIX E (continued)



If the studio is open, Sara will meet with you individually at the studio (up to four times for no more than 30 minutes each time) to talk about yourself and the studio. If the studio is closed, Sara will call you or schedule a Zoom meeting for individual interviews.

This interview will be audio or video recorded and some of your artwork will be photographed with your permission.

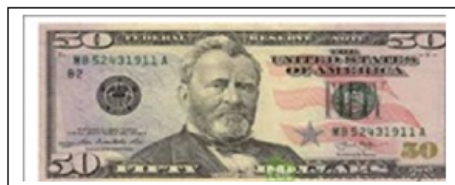
Step 5: Focus Groups



Sara will meet two times with you and a small group of artists from the studio for up to 1 hour each time for an art-based focus group. If the studio is open these groups will happen in the studio. If the studio is closed, these groups will happen on Zoom.

You will make art and talk about your feelings and thoughts about the studio.

Step 5: Get paid again! All artists who participate in Step 1, Step 2, Step 3, Step 4 and 5 get \$50.00 dollars!



At the end of the project, Sara will invite you to participate in a final 1 hour focus group where she will share with you what she has learned about the studio and you can tell her what you think. If the studio is open this final group will happen in the studio. If the studio is closed, this final group will happen on Zoom.

Remember, it is your choice if you want to participate.

You can say no or stop at any time!

Benefits

APPENDIX E (continued)



There are no direct benefits to research participants.

Risks



Talking about your feelings may cause you to feel upset. Who can you talk to when you feel upset?

Support _____ person's _____ name:



Sara will write about what you show and tell her, and may share your art with others, but your name is kept private. Sara will keep your personal information safe on a computer with a password.



If you are in the focus group, Sara will ask that other group members keep what you share private, but that can't be guaranteed (promised).

APPENDIX E (continued)

Also, if a child, elder, or person with a disability is being abused or neglected, or if there is a threat of harm to you or someone else, Sara may have to tell the authorities.

Do you want to be a part of the research? If so, please review and sign the behavioral consent form provided by Sara.

You can change your mind anytime.

APPENDIX F

Daily Observation Scale

Date:	Time observation started:	Time observation ended:

Research participants present during observation (use coded identifiers):		

*Note any significant deviations from daily routine (i.e. Participant X arrived late at around ____, or participant X left early around ____.)

Other notes about attendance:

How research participants spend their time in the studio:					
Coded identifier	Time spent socializing with other artists	Time spent engaging in art making on their own	Time spent engaging in art making with the support of someone else	Time spent engaging in collaborative art making with others	Other (describe):

Note the posted daily schedule of activities:

Note quality and characterization of time spent (i.e. frequently interrupted, uninterrupted, frequent breaks, frequent prompts etc.):

APPENDIX F (continued)

Describe interactions with others and support received from others:

How research participants use space in the studio:			
Coded identifier	Areas of the studio used	How is that area used by the participant?	length of time

Note how are participants supported/prompted to go to or leave certain areas in the studio? What areas are restricted or off limits in the studio (include areas that are off limits for certain periods of time).

Note if artists have free access to art materials?

Other observations about how space is used in the studio by research participants:

What artists think, feel about experiences in the studio:			
Coded identifier	Comment about the studio itself or experience in the studio (describe mode of communication, affect/voice inflection)	Comment made to who? Where?	Other notes about the situation:

Note what research participants complain about in the studio and what do research participants express pride about in the studio.

APPENDIX F (continued)

Note when challenges/problems emerge in the studio. What do research participants do when challenges emerge in their art making? What do research participants do when challenges emerge in their socialization with others? How do research participants respond to other kinds of challenges/problems?

Note how research participants talk about/address challenges that happen outside of the studio (personal or larger societal challenges).

Note topics discussed by research participants that are not about the studio.

What do participants report wanting or needing?

Note requests that artists make in the studio.

Other observations of participants sharing thoughts and feelings about experiences in the studio:

Content of art:			
Coded identifier	What is the content/subject of the artwork	How is this content/subject matter generated (did the artists choose this subject)?	What materials are used (note how materials are chosen and used)?

APPENDIX F (continued)

Note and describe research participant work that is directly about themselves or about the studio or an experience in the studio.

Note what kinds of supply/material requests artists make.

Note what kinds of support/assistance artists request.

Other observations impacting the content/construction of artwork:

Exhibition/showing others artwork:		
Coded identifier	Description of artwork	Description of how the artists was observed showing/talking about their work with someone else (specifically state whether it is a peer, the PI, staff member/volunteer or other).

Note how do the artists observed participate in decisions about exhibition/public display of the work.?

Note how do the artists observed talk about experiences with exhibition/public display of their work.

Other observations about showing work to others:

APPENDIX F (continued)

Other notes:

APPENDIX G

Virtual/Remote Individual Interview guide 1 of 4

This interview guide will be used to facilitate the first section of a four-part interview. It is divided into four sections to support the artists to take a break between sections. The interviewee will be asked if they would like to take a break at the end of this section. If they do not want a break, and the interview has not lasted more than 30 minutes, the interview will proceed to the next section. Participants are encouraged to indicate if they would like a break at any time.

Name of artist: _____

Date: _____

Time started: _____

Time ended: _____

Script: I am interviewing you because you are in the Educator, Career or Curator track at Arts of Life in Glenview. This interview will last no more than 30 minutes. Because there are a lot of questions, if we don't get to all the questions now, we can meet again up to three more times. You can stop or take a break at any time. You just need to say: "I want to stop," or "I want a break." I will prompt you a few times throughout the interview to ask you if you would like a break.

To protect the privacy of other people that live with you or are in the room with you, I want to make sure you are in a private space where other people are not likely to walk by the camera or interrupt our interview. Are you in a private space?

Since we are meeting by phone or by Zoom, internet and technology problem may come up. If that happens and we aren't able to talk easily, we can stop the interview temporarily and work together to solve the problem. If we can't solve the problem now, we can also reschedule our meeting and get some help to solve the problem.

I will be asking you to tell me about your feelings and thoughts about being an artist at the studio. I will be audio recording our talk (if by phone) OR I will be recording the video of our Zoom (if using Zoom). Is that okay? I may also write down some notes as we talk so that I don't forget important things you share with me. I will keep everything you share private and confidential.

Remember, you can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break." Do you have any questions before we start?

Okay Let's get started:

(Questions about the artist)

1. What is your name?
 - a. What do you like to be called?
2. What kind of art do you like to make?
 - a. What kinds of art materials do you use?

APPENDIX G (continued)

Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD

2

- b. What do you make art about?
 - c. What kinds of pictures do you draw/paint?
 - d. What kinds of objects or people are in your drawings/paintings?
- 3. What are you good at?
 - a. What are your strengths?
 - b. What do other people give you compliments for?
 - c. What do you like about yourself?
 - d. What makes you feel proud?
- 4. What do you like about being an artist at Arts of Life?
 - a. What do you like about your art?
 - b. Do you have a favorite piece of art that you have made?
 - c. Can you show me?
 - d. What do you like about this piece of art?
 - e. How do you feel when you make art?
- 5. Is any of your art about you?
 - a. Is any of your art a self-portrait?
 - b. Is any of your art a picture of you?
 - c. Which one(s)?
 - d. What does it show about you?
- 6. Is there anything else about you that I should know?

“Do you want to take a break or stop for today or keep going?”

Notes:

APPENDIX H

Individual Interview guide 2 of 4

This interview guide will be used to facilitate the second section of a four-part interview. It is divided into four sections to support the artists to take a break between sections. The interviewee will be asked if they would like to take a break at the end of this section. If they do not want a break, and the interview has not lasted more than 30 minutes, the interview will proceed to the next section. Participants are encouraged to indicate if they would like a break at any time.

Name of artist: _____

Date: _____

Time started: _____

Time ended: _____

Script: We are meeting to continue our interview. I am interviewing you because you are in the Educator, Career or Curator track at Arts of Life in Glenview. This interview will last no more than 30 minutes. Because there are a lot of questions, if we don't get to all the questions now, we can meet again up to two more times. You can stop or take a break at any time. You just need to say: "I want to stop," or "I want a break." I will prompt you a few times throughout the interview to ask you if you would like a break.

To protect the privacy of other people that live with you or are in the room with you, I want to make sure you are in a private space where other people are not likely to walk by the camera or interrupt our interview. Are you in a private space?

Since we are meeting by phone or by Zoom, internet and technology problem may come up. If that happens and we aren't able to talk easily, we can stop the interview temporarily and work together to solve the problem. If we can't solve the problem now, we can also reschedule our meeting and get some help to solve the problem.

I will be asking you to tell me about your feelings and thoughts about being an artist at the studio. I will be audio recording our talk (if by phone) OR I will be recording the video of our Zoom (if using Zoom). Is that okay? I may also write down some notes as we talk so that I don't forget important things you share with me. I will keep everything you share private and confidential.

Remember, you can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break." Do you have any questions before we start?

Okay Let's get started:

(Questions about the studio)

1. What do you like about the studio?
 - a. What is your favorite thing about the studio?
 - b. What do you look forward to doing every day at the studio?
 - c. What are the best things about/parts of the studio?

APPENDIX H (continued)

Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD

2

2. Have you ever felt proud of the studio?
 - a. What made you feel proud?
 - b. Can you tell me about a time you felt proud in the studio?
3. Have you ever felt excited in the studio?
 - a. What were you excited about?
 - b. Can you tell about a time you felt excited in the studio?
 - c. Can you tell me about a time you felt happy in the studio?

"Do you want to take a break or stop for today or keep going?"

Notes:

The interview location selected by the interview was:

Additional observations during the interview:

APPENDIX I

Individual Interview guide 3 of 4

This interview guide will be used to facilitate the third section of a four-part interview. It is divided into four sections to support the artists to take a break between sections. The interviewee will be asked if they would like to take a break at the end of this section. If they do not want a break, and the interview has not lasted more than 30 minutes, the interview will proceed to the next section. Participants are encouraged to indicate if they would like a break at any time.

Name of artist: _____

Date: _____

Time started: _____

Time ended: _____

Script: We are meeting to continue our interview. I am interviewing you because you are in the Educator, Career or Curator track at Arts of Life in Glenview. This interview will last no more than 30 minutes. Because there are a lot of questions, if we don't get to all the questions now, we can meet again one more time. You can stop or take a break at any time. You just need to say: "I want to stop," or "I want a break." I will prompt you a few times throughout the interview to ask you if you would like a break.

To protect the privacy of other people that live with you or are in the room with you, I want to make sure you are in a private space where other people are not likely to walk by the camera or interrupt our interview. Are you in a private space?

Since we are meeting by phone or by Zoom, internet and technology problem may come up. If that happens and we aren't able to talk easily, we can stop the interview temporarily and work together to solve the problem. If we can't solve the problem now, we can also reschedule our meeting and get some help to solve the problem.

I will be asking you to tell me about your feelings and thoughts about being an artist at the studio. I will be audio recording our talk (if by phone) OR I will be recording the video of our Zoom (if using Zoom). Is that okay? I may also write down some notes as we talk so that I don't forget important things you share with me. I will keep everything you share private and confidential.

Remember, you can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break." Do you have any questions before we start?

Okay Let's get started:

1. What do you do at the studio?
 - a. What do you when you first get here in the morning?
 - b. What do you do in the afternoon?
2. What do the other artists do at the studio?
 - a. What are the artists doing in the studio now?
 - b. What do the artists do when the come in in the morning?

APPENDIX I (continued)

Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD

2

- c. What do the other artists do in the afternoon?
- 3. What do the staff do at the studio?
 - a. What are the staff doing in the studio now?
 - b. What do the staff doing when they come in in the afternoon?
 - c. What do the staff do in the afternoon?
- 4. If you have a problem at the studio, what do you do?
 - a. Who do you tell if you have a problem in the studio?
 - b. What does that person do if you tell them you have a problem?

"Do you want to take a break or stop for today or keep going?"

Notes:

The interview location selected by the interview was:

Additional observations during the interview:

APPENDIX J

Individual Interview guide 4 of 4

This interview guide will be used to facilitate the last section of a four-part interview. It is divided into four sections to support the artists to take a break between sections. The interviewee will be asked if they would like to take a break at the end of this section. If they do not want a break, and the interview has not lasted more than 30 minutes, the interview will proceed to the next section. Participants are encouraged to indicate if they would like a break at any time.

Name of artist: _____

Date: _____

Time started: _____

Time ended: _____

Script: We are meeting to continue our interview. I am interviewing you because you are in the Educator or Curator track at Arts of Life in Glenview. This interview will last no more than 30 minutes. This is our last individual interview. You can stop or take a break at any time. You just need to say: "I want to stop," or "I want a break." I will prompt you a few times throughout the interview to ask you if you would like a break.

To protect the privacy of other people that live with you or are in the room with you, I want to make sure you are in a private space where other people are not likely to walk by the camera or interrupt our interview. Are you in a private space?

Since we are meeting by phone or by Zoom, internet and technology problem may come up. If that happens and we aren't able to talk easily, we can stop the interview temporarily and work together to solve the problem. If we can't solve the problem now, we can also reschedule our meeting and get some help to solve the problem.

I will be asking you to tell me about your feelings and thoughts about being an artist at the studio. I will be audio recording our talk (if by phone) OR I will be recording the video of our Zoom (if using Zoom). Is that okay? I may also write down some notes as we talk so that I don't forget important things you share with me. I will keep everything you share private and confidential.

Remember, you can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break." Do you have any questions before we start?

Okay Let's get started:

1. If you were granted three wishes to use at the studio, what would you wish for?
 - a. If you could change anything about the studio, what would you change?
 - b. What would you like the studio to be like in the future?
2. Have you ever created a picture of the studio? Have drawn or painted a picture of the studio or anyone in the studio?
 - a. Which one(s)?
 - b. What does it show about the studio?

APPENDIX J (continued)

Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD

2

c. What is happening in this picture?

3. Is there anything else about the studio that you want me to know?

18. We are going to have a group meeting called a focus group, and you're invited. We will make art about the studio in the focus group. What art supplies do you want to use to make art in the focus group?

Notes:

The interview location selected by the interview was:

Additional observations during the interview:

APPENDIX K

Arts of Life

The most important parts of the studio today **and** wishes for the future

1

What are the most important or *best* parts of Arts of Life Glenview?

2



APPENDIX K (continued)

The people

- They are patient
- They are kind
- Artists said they feel important
- They are respectful- *"The studio makes me proud because they treat me with respect"*
- Staff
 - help when someone is stressed or upset
 - help solve problems at the studio
 - help the artists with making art and set goals

3

The people at Arts of Life are important

4


APPENDIX K (continued)

Selling artwork

- Making money is important (3 out of 5 said this was the **number 1** reason they make art)
- Selling artwork makes the artists feel excited and proud
- Some of the artists said that they need money, and that is what makes it important

5

Making money at Arts of Life is important



6

APPENDIX K (continued)

Having fun

Having fun is important! (2 out of 5 said this was the **number 1** reason they make art)

Arts of Life is *"a fun place to go"*

Art Making is fun

Having and preparing for exhibitions is fun

Parties at Arts of Life are fun

7

Having choice

- It's important to some of the artists to be make art about what they like and are interested in

- The artists can choose what they want to do:

- Have an art or fashion career
- be an art teacher/educator
- organize exhibitions and shows

8

APPENDIX K (continued)

It's important to some artists to have their own space to work



9

Expressing
thoughts and
feelings

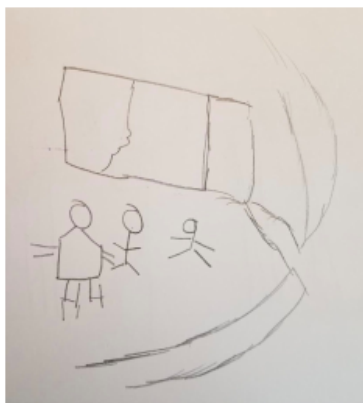
- It's important to some artists to express thoughts and feelings through art
- It's important to some artists to share their thoughts and feelings with others - *"It will open their [people outside of arts of life] eyes to see how I feel and let the art show how I feel around my environment."*

10

APPENDIX K (continued)

Other important things

- Having artwork on the walls at the studio
- Going on walks with friends at Arts of Life



11

What would do wish
for or want for the
future at Arts of
Life?

12

APPENDIX K (continued)

Have more
parties

- Two artists said that if they could wish for *anything* at Arts of Life, they would wish for a party
- Laughing and talking at parties with friends makes the artists happy
- Meeting new people from outside of Arts of Life at parties also makes the artists happy

13

A party where people are talking and laughing



14

APPENDIX K (continued)

Have more shows and exhibitions

- Artists can make more money
- The artists can meet more people – *"They [Exhibitions] are very helpful when I have to go and meet people."*
- Some artists would like more exhibitions that focus on their interests
 - Japanese art
 - Fashion show

15

A runway fashion show



16

APPENDIX K (continued)

3/15/2021

Changes to the studio

- Move art supplies to the front of the studio so the artists can get them by themselves (this is a wish for after COVID)
 - Some artists may still need help
 - Some artists may need something to help them pick up and carry art supplies on their own (like a tray or basket attached to their walker)
- Freshen up the walls with new paint or wallpaper

17

Getting out into the community more

- Some of the artists said that it's hard for them to get out in the community very often
- One artist wished for a wheelchair accessible van at Arts of Life so that the artists could go out into the community more often at Arts of Life

18

APPENDIX K (continued)

2/20/2022

An Arts of Life wheelchair accessible van



19

More travel around the US and the world

- Many artists would like to travel around the US and the world
- Some artists would like to travel so that they can learn about art and fashion around the world
- Some artists would like to travel for vacation with friends and family

20


APPENDIX K (continued)

Other important wishes for the studio

- Sewing lessons
- A visiting tattoo artist
- Braille lessons
- A kiln and more clay

21

How can we make
our wishes and
dreams come true?



22

APPENDIX K (continued)

Wish for the studio	Ideas to make this wish come true
Have more parties	Talk to the party planning committee about our ideas
Have more exhibitions	Ask staff; Talk to the curatorial committee about our ideas
Get an Arts of Life van	Bring it up at the studio meeting; Have a fundraiser to raise money
Travel around the US & World	Save money; Go to Disney world and start to have a fashion show to raise money at Cinderella's castle (Use camera to film fashion show and photo shoots); Use zoom to visit studios around the world
Move art supplies to the front of the studio	Ask staff; Get some training on how to use art supplies by ourselves (for example how to make sure not to waste paint and clean brushes)

25

Wish for the studio	Ideas to make this wish come true
Paint/wallpaper the studio	Ask staff to buy paint and wallpaper; Ask if we can get paint or wallpaper donated; ask paint supply store if they could donate; ask volunteers to come and paint
Get a kiln/more clay	Go to a store to ask how much they are and then save up money; Ask a local studio if we can use their kiln sometimes; Ask staff and family for help
Sewing lessons	See if a sewing teacher can come to Arts of Life; Ask a volunteer that knows how to sew
Braille lessons	Talk with someone from a Braille school or Lighthouse in Chicago to see if they could come to Arts of Life
Get a tattoo artist to visit the studio	Save money; find someone who does tattooing that could visit Arts of Life

26

APPENDIX L

Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD

1

Focus group 1 protocol

Script: You are in this focus group because you are in the Educator, Career or Curator track at Arts of Life in Glenview. We will meet three times. Our meetings will last no more than 1 hour. You can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break."

I will be asking you to tell me about your feelings and thoughts about being an artist at the studio. I will be recording the video. Is that okay? I may also write down some notes as we talk so that I don't forget important things you share with me.

I will keep everything you share private, and I ask that you respect each other and not repeat what other people in the group say outside of the group.

To protect the privacy of other people that live with you or are in the room with you, I want to make sure you are in a private space where other people are not likely to walk by the camera or interrupt our group. Are you in a private space?

Since we are meeting by Zoom, internet and technology problems may come up. If that happens and we aren't able to talk easily, we can stop the group temporarily and work together to solve the problem. If we can't solve the problem in 15 minutes, we may have to go ahead with the group meeting. We will not continue with the meeting if more than one person is having problems with internet or technology.

Remember, you can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break." Do you have any questions before we start?

(pause)

Okay Let's get started. Today I would like you to create a piece of art about the best parts of the studio. What is the best thing about the studio? What makes you happy, proud or excited to be in the studio?

You can draw/paint a day when you were happy in the studio.

You can draw or paint about something that happened in the studio that made you feel excited, happy or proud,

You can draw specific part of the studio, object or person in the studio that is important to you.

You will have 40 minutes.

Members will be prompted to show finished images to the group. One at a time, each artist will be invited to give their art piece a label or title and will be asked to offer context about the piece using a simplified version of the SHOWed method used by Hefron, Spassiani, Angell & Hammel (2018) in a participatory photovoice project with people labeled/with IDD. The method includes asking people to describe what they see, what's happening, how it relates to their lives,

APPENDIX L (continued)**Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD**

2

why the problem or strength exists, and what they can do about it (Hefron, Spassiani, Angell & Hammel, 2018).

*Thank you for participating in the group. Remember we will meet one more time on (date, time).
See you then!*

Observations during the interview:

APPENDIX M

Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD

1

Focus group 2 protocol:

Script: You are in this focus group because you are in the Educator or Curator track at Arts of Life in Glenview. This is our second of three group meetings. It will last no more than 1 hour. You can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break."

I will be asking you to tell me about your feelings and thoughts about being an artist at the studio. I will be recording the video Is that okay? I may also write down some notes as we talk so that I don't forget important things you share with me.

To protect the privacy of other people that live with you or are in the room with you, I want to make sure you are in a private space where other people are not likely to walk by the camera or interrupt our group. Are you in a private space?

Since we are meeting by Zoom, internet and technology problems may come up. If that happens and we aren't able to talk easily, we can stop the group temporarily and work together to solve the problem. If we can't solve the problem in 15 minutes, we may have to go ahead with the group meeting. We will not continue with the meeting if more than one person is having problems with internet or technology.

Remember, you can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break." Do you have any questions before we start?

(pause)

Okay Let's get started. Today I would like you to create a piece of art about what could be possible in the studio. If you were granted three wishes to use at the studio, what would you wish for? If all your dreams came true, what would the studio be like in the future? If you could change anything about the studio, what would you change?

You will have 40 minutes.

Members will be prompted to show finished images to the group. One at a time, each artist will be invited to give their art piece a label or title and will be asked to offer context about the piece using a simplified version of the SHOWed method used by Hefron, Spassiani, Angell & Hammel (2018) in a participatory photovoice project with people labeled/with IDD. The method includes asking people to describe what they see, what's happening, how it relates to their lives, why the problem or strength exists, and what they can do about it (Hefron, Spassiani, Angell & Hammel, 2018).

Thank you for sharing such wonderful thoughts and ideas. Now, do you think there is anybody who needs to see your artwork about the studio and hear your ideas? Who should we share your artwork and stories with? Who needs to know about how you feel about the studio? How could we show or tell these people about what's important to you in the studio?

Great ideas!

APPENDIX M (continued)**Arts-based Appreciative Inquiry with Studio Artists Labeled/with IDD**

2

Thank you for participating in the group.

Observations during the interview:

APPENDIX N

|

Focus group 3 protocol:

Script: You are in this focus group because you are in the Educator, Career or Curator track at Arts of Life in Glenview. This is our third and last group meeting. It will last no more than 1 hour. You can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break."

I will be sharing with you what I have learned in my time at Arts of Life and asking you to tell me if I have gotten it right. I will be recording the video. Is that okay? I may also write down some notes as we talk so that I don't forget important things you share with me.

I will keep everything you share private, and I ask that you respect each other and not repeat what other people in the group say outside of the group.

To protect the privacy of other people that live with you or are in the room with you, I want to make sure you are in a private space where other people are not likely to walk by the camera or interrupt our group. Are you in a private space?

Since we are meeting by Zoom, internet and technology problems may come up. If that happens and we aren't able to talk easily, we can stop the group temporarily and work together to solve the problem. If we can't solve the problem in 15 minutes, we may have to go ahead with the group meeting. We will not continue with the meeting if more than one person is having problems with internet or technology.

Remember, you can stop or take a break at any time. You just need to say, "I want to stop," or "I want a break." Do you have any questions before we start?

(pause)

Okay Let's get started. These are the things I have learned about you and about Arts of Life (point to list on accessible handout page 2).

Let's go through them one at a time. (State item 1).

Prompt 1: *Is this true? Is this true of you or of the studio?*

Prompt 2: *Did I understand what you said or what I saw correctly? Or did I miss something?*

Prompt 3: *Would you change what I have said or written? How?*

Prompt 4: *Is there anything else that is important to say or add to this?*

Repeat questions for each theme/statement:

Thank you for sharing such wonderful thoughts and ideas and thank you for participating in the group.

Observations during the interview:

APPENDIX N (continued)

APPENDIX O

University of Illinois at Chicago Department of Disability and Human Development

3/14/2021

Christophe Preissing

Estate of Charles Steffen

I am writing to request permission to use the image of artwork by Charles Steffen (show below) of which you hold the copyright. This image will be cited as Steffen, Charles P. *Portrait of My Mother and Myself*. 1991. The Estate of Charles Steffen. Digital copy provided courtesy of Christophe Preissing. [Received March 16, 2021]



Thank you for your kind consideration of this request.

Sara Miller, 3553 Forest Cove Lane, Lexington KY 40515.

The above request is approved. Approved by:

Christophe Preissing

Printed name :

Signature: 

Date: March 17, 2021

APPENDIX P

University of Illinois at Chicago Department of Disability and Human Development

3/17/2021

Alan Foley

The Center on Human Policy, Syracuse University

I am writing to request permission to use an image from Blatt, B. & Kaplan F. (1974). Christmas in Purgatory, Page 20. This image will appear as originally shown in the Disability History Museum archive available at

<https://www.disabilitymuseum.org/dhm/lib/catcard.html?id=1804>

Unless you request otherwise, I will use the following as acknowledgment:

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Thank you for your kind consideration of this request.

Sara Miller, 3553 Forest Cove Lane, Lexington KY 40515.

The above request is approved. Approved by:

Alan Foley



Printed name:

Signature:

Date: **3/19/21**

APPENDIX Q

3/10/2021

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'Weightless?': disrupting relations of power in/through photographic imagery of persons with intellectual disabilities

Author: Ann Fudge Schormans

Publication: Disability & Society

Publisher: Taylor & Francis

Date: May 28, 2014

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APPENDIX R (continued)

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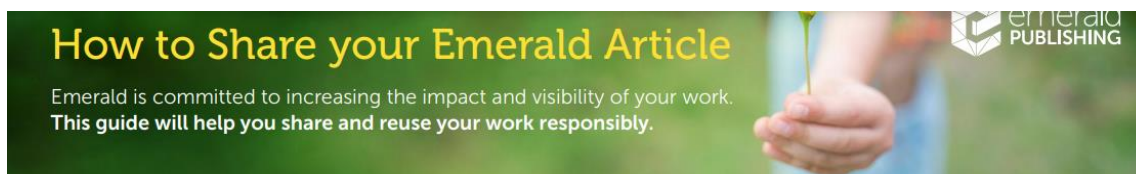
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











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APPENDIX S

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APPENDIX T



**Approval Notice
Initial Review – Expedited Review**

May 12, 2020
Sara Miller
Disability and Human Development

RE: **Protocol # 2020-0393**
“Arts-based Appreciative Inquiry with Studio Artists Labeled/with Intellectual and Developmental Disabilities (IDD)”

Dear Ms. Miller:

Members of Institutional Review Board (IRB) #2 reviewed and approved your research protocol under expedited review procedures [45 CFR 46.110(b)(1)] on May 11, 2020. You may now begin your research.

Your research meets the criteria for approval under the following categories:
Protocol reviewed under expedited review procedures [45 CFR 46.110] **Category: 5, 6, 7**

Please remember to submit Appendix Z for funding, via an Amendment, when available.

Please note that the Initial Review Application will serve as the Research Protocol of record for future submissions.

Consistent with institutional mandates regarding COVID-19 precautions, an administrative hold has been placed on all UIC human subjects research meeting the following criteria:

1. The research is not designed for therapeutic benefit; and,
2. The research involves in-person interactions with investigators or the public.

If your research meets the criteria for an administrative hold, no in-person research activities may take place until normal operations resume at UIC. Investigators may still conduct activities that can be completed remotely (i.e., by phone or online), as appropriate to the research.

For further updates, please refer to the following sources:

UIC Coronavirus Update page:

https://today.uic.edu/coronavirus?utm_source=homepage&utm_medium=website&utm_campaign=covid-19

UIC OPRS Homepage: <https://research.uic.edu/human-subjects-irbs>

Please direct questions regarding the administrative hold to OPRS: uicirb@uic.edu

APPENDIX T (continued)



Please note the following information about your approved research protocol:

<u>Protocol Approval Date:</u>	May 11, 2020
<u>Approved Subject Enrollment #:</u>	31
<u>Performance Sites:</u>	UIC, Arts of Life
<u>Sponsor:</u>	Not Available
<u>Institutional Proposal (IP)#:</u>	Not Available
<u>Grant/Contract No:</u>	Not Available
<u>Grant/Contract Title:</u>	Not Available
<u>Research Protocol(s):</u>	
a)	Arts-based Appreciative Inquiry with Studio Artists Labeled/with Intellectual and Developmental Disabilities (IDD) (IR Application); Version 5; 05/12/2020
b)	Arts-based Appreciative Inquiry with Studio Artists Labeled/with Intellectual and Developmental Disabilities (IDD) (RP); Version 4; 05/11/2020

Documents that require an approval stamp or separate signature can be accessed via [OPRS Live](#). The documents will be located in the specific protocol workspace. You must access and use only the approved documents to recruit and enroll subjects into this research project.

Recruitment Material(s):

- a) Participant Eligibility Checklist; Version 2; 04/17/2020
- b) Accessible Focus Group 3 Handout; Version 1, 04/30/2020
- c) Accessible Recruitment Flyer; Version 3; 04/30/2020
- d) Recruitment Flyer Script; Version 3; 04/30/2020
- e) Script for call with guardians; Version 3; 04/30/2020

Informed Consent(s):

- a) Accessible consent/assent information (addendum); Version 3; 04/30/2020
- b) Script for Accessible Video About Consent (addendum); Version 2; 04/30/2020
- c) Research involves activities related to screening, recruitment, or determining eligibility per 45 CFR 46.116(g).
- d) An alteration of consent/assent has been granted under 45 CFR 46.116(f) for the use of accessible format consent/assent materials; minimal risk; subjects will be provided with accessible consent/assent addendum materials.

Parental Permission(s):

- a) AI with Artists Labeled/with IDD; Version 5; 05/12/2020

Additional Determinations for Research Involving Minors:

These determinations have not been made for this study since it has not been approved for enrollment of minors.

APPENDIX T (continued)



Please remember to:

- Use only the IRB-approved and stamped consent document(s) when enrolling new subjects.
- Use your **research protocol number** (2020-0393) on any documents or correspondence with the IRB concerning your research protocol.
- Review and comply with the [policies](#) of the UIC Human Subjects Protection Program (HSPP) and the guidance [Investigator Responsibilities](#).

Please note that the UIC IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the [scope of work](#) in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS office at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS via [OPRS Live](#).

Sincerely,

Allison Brown, PhD
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

cc: Carrie Sandahl (Faculty Sponsor), Disability and Human Development, M/C 626
Tamar Heller, Disability and Human Development, M/C 626

APPENDIX U



**Approval Notice
Amendment – Expedited Review
UIC Amendment # 1**

July 20, 2020

Sara Miller
Disability and Human Development

RE: **Protocol # 2020-0393**
“Arts-based Appreciative Inquiry with Studio Artists Labeled/with Intellectual and Developmental Disabilities (IDD)”

Dear Ms. Miller:

Your application was reviewed and approved on July 20, 2020. The amendment to your research may now be implemented.

Please note the following information about your approved amendment:

Please remember to submit Appendix Z for funding, via an Amendment, when available.

Please note that the Initial Review Application will serve as the Research Protocol of record for future submissions and the submitted Research Protocol has been deactivated.

Please note that minor administrative revisions were made to the documents by OPRS staff to bring the documents in compliance with UIC IRB Board determination(s). Please remember to use only those approved documents to recruit and enroll subjects into this research project.

PIs who wish to begin or resume research involving activities that have been placed on temporary hold by the University due to the COVID-19 pandemic (i.e., non-therapeutic, in-person research) must complete a COVID-19 Human Subjects Research Restart Worksheet for an assessment of their studies prior to resuming or initiating the research.

<https://uic.infoready4.com/#applicationForms/1817478>

Please refer to the Human Subjects Research Restart page on the OVCR website for additional information.□

<https://research.uic.edu/news-stories/human-subjects-research-restart>

The research restart is being managed by the Office of the Vice Chancellor for

Page 1 of 3

UNIVERSITY OF ILLINOIS AT CHICAGO
Office for the Protection of Research Subjects

201 AOB (MC 672)
1737 West Polk Street
Chicago, Illinois 60612

Phone (312) 996-1711

APPENDIX U (continued)



Research (OVCR) and the UIC Center for Clinical and Translational Sciences (CCTS).
 Questions about the campus research restart may be directed to research@uic.edu.

Amendment Approval Date:

July 20, 2020

Amendment:

Summary: UIC Amendment # 1 (Response to Conditions) dated and received via OPRSLive on July 07, 2020, is an investigator-initiated amendment to:

- a) Move study participant recruitment, consent/assent procedures, individual interviews and focus groups to remote/virtual formats (phone, Zoom) until COVID 19 restrictions are lifted and in-person programming at the studio and in-person human Subjects research at UIC resumes. In-person procedures and protocol remain in place. This amendment outlines Virtual/remote procedures that will be added to the research protocol and utilized until in-person research procedures are safe to implement. No study subjects have been previously enrolled to this amendment (IR, v9, 7/17/2020; RP, v5, 6/12/20; Revised Appendix V; Arts of Life letter of support, 05/29/20; Virtual/Remote Individual Interview Protocol Part 1, v1, 6/15/20; Virtual/Remote Individual Interview Protocol Part 2, v1, 6/15/20; Virtual/Remote Individual Interview Protocol Part 3, v1, 6/15/2020, Individual Interview Protocol Part 4, v1, 6/15/20; Virtual/Remote Focus Group 1 Script and Protocol, v1, 6/15/20; Focus Group Two Script and Protocol, v2, 07/17/20; Focus group 3 script and protocol, v2, 07/07/20;), and ,
 b) Submit recruitment and consent materials reflecting the changes above (Recruitment Flyer Script, v4, 07/07/2020; Accessible Recruitment Flyer, v5, 07/07/2020; Demographic form, v2, 07/17/2020; Participant Eligibility Checklist, v3, 07/07/20; Accessible consent/assent information (addendum); v5; 07/07/2020; AI with Artists Labeled/with IDD; v8; 07/17/2020).

Approved Subject Enrollment #:

31

Performance Sites:

UIC, Arts of Life

Sponsor:

None

Research Protocol(s):

- a) Arts-based Appreciative Inquiry with Studio Artists Labeled/with Intellectual and Developmental Disabilities (IDD) (IR); Version 9; 07/17/2020

Documents that require an approval stamp or separate signature can be accessed via [OPRS Live](#). The documents will be located in the specific protocol workspace. You must access and use only the approved documents to recruit and enroll subjects into this research project.

Recruiting Material(s):

- a) Recruitment Flyer Script; Version 4; 07/07/2020
 b) Accessible Recruitment Flyer; Version 5; 07/07/2020
 c) Demographic form; Version 2; 07/17/2020
 d) Participant Eligibility Checklist, Version 3, 07/07/2020

Informed Consent(s):

- a) Accessible consent/assent information (addendum); Version 5; 07/07/2020

Page 2 of 3

APPENDIX U (continued)

**Parental Permission(s):**

a) AI with Artists Labeled/with IDD; Version 8; 07/17/2020

Please be sure to:

- Use only the IRB-approved and stamped consent document(s) and/or HIPAA Authorization form(s) when enrolling subjects.
- Use your research protocol number (2020-0393) on any documents or correspondence with the IRB concerning your research protocol.
- Review and comply with the [policies](#) of the UIC Human Subjects Protection Program (HSPP) and the guidance [Investigator Responsibilities](#).

Please note that the IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the [scope of work](#) in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS via [OPRS Live](#).

Sincerely,

Allison Brown, PhD
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

cc: Carrie Sandahl (Faculty Sponsor), Disability and Human Development, M/C 626
Tamar Heller, Disability and Human Development, M/C 626

Page 3 of 3

UNIVERSITY OF ILLINOIS AT CHICAGO
Office for the Protection of Research Subjects

201 AOB (MC 672)
1737 West Polk Street
Chicago, Illinois 60612

Phone (312) 996-1711

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VITA

NAME: Sara M. Miller

EDUCATION: B.S., Psychology/Fine Arts, University of Evansville, IN, 2004
M.A., Art Therapy/Counseling, Southern Illinois University, IL 2006
PhD., Disability Studies, University of Illinois at Chicago, IL, *current*

TRAINING: UIC Certificate in Foundations of College Teaching Completed May 2020
Illinois LEND Training Program (leadership education in neurodevelopmental and related disabilities) Completed May 2018

CREDENTIALS: Art Therapy Certified Supervisor (ATCS) #10-264
Licensed Clinical Professional Counselor (LCPC) 180.007473

HONORS: 2020 Rawley Silver Research- American Art Therapy Association
Spring 2020 UIC Student Travel Award
Spring 2020 UIC Graduate Student Travel Award
Spring 2020 UIC Department of Disability and Human Development Ann & Edward Page-El Scholarship

PROFESSIONAL EXPERIENCE:

Research Specialist, University of Illinois at Chicago Dec 2019-present
Clinical Art Therapist/Counselor, Ability Arts Counseling Inc., Chicago Aug2011-Oct2020
Teaching Assistant, University of Illinois at Chicago Sept 2018-Dec 2019
Research Assistant, University of Illinois at Chicago Sept 2017-Dec 2019

PROFESSIONAL MEMBERSHIP.LEADERSHIP:

Jan 2009-present Member American Art Therapy Association
Jan 2010-present Member Illinois Art Therapy Association
Sept 2009- Sept 2019 Member Illinois Imagines Committee
Jan 2011 – Jan 2013 Director of Membership Illinois Art Therapy Association
2005-2006 Co-President Student Art Therapy Association (SATA)

PUBLICATIONS:

Miller, S. (2020). Disability art: Potential intersections in studio practice with artists labeled/with intellectual and developmental disabilities, *Art Therapy*, 37(2), 93-96.

Miller, S., Ludwick, J., & Colucy, C. (2020). Professional considerations for art therapists supporting the work of people with intellectual disabilities. *Journal of the American Art Therapy Association*, 37(2), 83-87.

Miller, S., & van Heumen, L. (2021). Inclusive research with people labeled with intellectual and developmental disabilities during the COVID-19 pandemic: Technological adaptations. *Journal of Enabling Technologies*, 15(2), 122-135. <https://doi.org/10.1108/JET-12-2020-0051>