

**Adults with Intellectual Disabilities and the Visual Arts:
“It’s NOT Art Therapy!”**

by

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ABSTRACT

This thesis examines the emerging discourse concerning adults with intellectual disabilities and their agency as visual artists. People with intellectual or developmental disabilities are arguably the most marginalized members of our society and have historically suffered oppression. They have not experienced the same access to the arts as non-disabled people; artists with intellectual disabilities are typically situated within a therapeutic paradigm and excluded from institutional structures of contemporary art. This thesis raises issues of access and identity and problematizes the hegemonic structures and boundaries faced by artists with intellectual disabilities within the field of contemporary art. This interdisciplinary project evolves from a Disability Studies perspective and is heavily influenced by Emancipatory Methodology. A brief overview of Disability Theory is provided including a discussion concerning 'cognitive ableism'. I propose a theoretical framework that supports artists with intellectual disabilities as legitimate artists. Issues of 'Outsider Art' and art therapy are addressed.

A key component is a discussion of Cool Arts and the exhibition "We Are Artists", which I curated. The exhibition worked to counter stereotypes and included an exhibition catalogue written in Plain Language. The qualitative research component to this thesis examines the art-making practices of three participants. Data collection methods included participant observation, semi-structured interviews and video-elicitation; documentation of the art-making process served to validate and recognize the participants as legitimate artists.

I argue that artists with intellectual disabilities are legitimate artists and must have the same access to the arts as non-disabled people. This research makes a significant contribution to an emerging discourse which, to date, has had little scholarly literature devoted to it. This thesis counters misconceptions, and brings attention to issues of access and the lack of research in this interdisciplinary field.

PREFACE

Ethics approval was obtained from The University of British Columbia Office of Research Services Behavioural Research Ethics Board. Certificate Number is HO8-01747.

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DEDICATION

*I would like to dedicate this thesis to artists everywhere
who happen to live with an intellectual disability.*

1 INTRODUCTION

This enterprise has been a labor of love as well as an arduous undertaking. Integrating my experiences as a family member, a community activist and an artist, this project has become a statement of who I am and what is important to me in this life; what more could one really ask for in a project? This interdisciplinary thesis with its multi-layered approach is a reflection of these varied experiences. Entering into research with people living with intellectual disabilities necessitated the study of qualitative research and disability studies; both areas of study were new to me. Addressing the topic of artists with intellectual disabilities also required research within the scope of creative studies, which was more familiar territory. Study of theory, both within Disability Studies and beyond, was also an unfamiliar and challenging task, although ultimately a satisfying one. I was determined to both approach and deal with my topic from a holistic point of view. This introduction will frame the project as well as offer a literature review that indicates the diversity of my research.

1.1 Background

My vocational background until recently has been concerned with design and fine arts. After graduating from a college program in interior design as a young adult, I worked as a kitchen designer off and on between having my four children. As a mature student I returned to school and graduated with a BFA in 2000, and for seven years maintained a studio practice and taught adult education art classes. Printmaking, collage, drawing and painting were my chosen media.

At the same time, I was involved in the world of disability. Our second child was diagnosed with a mild intellectual disability when he was a preschooler; school integration and support, and, later on, adult services, became an ongoing reality. As described in Chapter Five, in 2002 I founded an arts group called Cool Arts for local adults living with developmental disabilities. I had many questions when the group began and my questions multiplied as time went by. What should I expect from these individuals in terms of creativity and ability? Should I expect others to regard them as legitimate artists? Was there a proper protocol for structuring a group like this? What about the question of inclusion? Were there other groups like this? I did not know of any. Looking online helped to locate groups located in various countries, but still left me with unanswered questions. Why wasn't there a guide book for this? There were social workers I could ask questions of concerning developmental disabilities, and I knew lots of artists and art teachers to speak to about artistic concerns, but I knew of no one with real expertise in the area of fine arts and intellectual disabilities. A few years later a friend told me about the new Interdisciplinary Graduate program at the University of British Columbia Okanagan (UBCO), and I was intrigued. Presumably I could actually tailor a program of study to reflect what I was really interested in, which was visual arts and adults with intellectual disabilities as artists, not as participants in a recreational program or therapy. My graduate studies began.

1.2 Terminology

At this point clarification is necessary in regards to the often-problematic aspect of terminology. After beginning to search for relevant literature, it did not take me long to discover that a variety of terms are used to label people living with intellectual or developmental disabilities. In Canada, the Canadian Association of Community Living prefers the term 'intellectual disabilities' and will also accept 'developmental disabilities'. In BC, Community Living British Columbia (CLBC), the Crown Corporation that delivers services to this group, uses the term 'developmental disabilities'. A developmental disability is described on the Statistics Canada website (dated 2001) as "cognitive limitations due to the presence of a developmental disability or disorder, such as Down syndrome, autism or mental impairment caused by a lack of oxygen at birth".¹ Terms used in Canada are common in the US as well, but unfortunately, so is 'mental retardation'.

In the UK, considered the most forward thinking locale when it comes to disabilities, 'learning disabilities' and also 'learning difficulties' are the accepted terms. In medically related literature, as well as books and articles dated before 1985 or thereabouts, 'mental retardation' is commonly used. Some scholars use the term 'cognitive disability', which can be potentially confusing as it can often include conditions of dementia and brain injuries, for example, whereas the other terms used generally apply to individuals born with a developmental disability or acquired as the result of an illness or accident before adulthood. I have decided to use both the terms of intellectual disability and developmental disability; for the sake of

¹ Statistics Canada. Statistics of Disability 2001. 10/11/2007.

<<http://www.statscan.ca/english/freepub/89-577-XIE/tables/table7.htm>>

brevity the acronym 'IDD' will be used to stand for either 'intellectual or developmental disabilities' or 'intellectually or developmentally disabled'.²

1.3 Interdisciplinary Aspect

As mentioned, this project is interdisciplinary in nature; I would go as far as to say that the interdisciplinary scope of this thesis extends beyond what the majority of 'interdisciplinary' projects demonstrate. I have not observed any other similar graduate projects at UBCO that integrate Social Sciences with Creative Studies and Critical Studies. As unexplored territory this has been exciting; however, there have been some pitfalls. The relatively new Graduate Studies department still has some logistical issues to resolve concerning projects with so broad an orientation; I believe that UBCO will work to make adjustments to support and encourage true interdisciplinary scholarship. More importantly, I recently realized that in all likelihood I had done too much research as a result of drawing from different disciplines, and consequently had difficulties in managing the amount of accumulated literature. In an effort to illustrate the span of my research, I constructed a visual representation, which, although not perfect, helps to identify the areas of study my research draws from (Figure 1.1).

This is a Humanities project that includes a chapter concerning Qualitative Research. Also formatted in MLA as is rest of the thesis, the content in these sections is more typically found in works more oriented to the Social Sciences

² I first noted the use of 'IDD' as an identifier in the article "Introduction: Rethinking Philosophical Presumptions in Light of Cognitive Disability" by Licia Carlson and Eva Feder Kittay in *Metaphilosophy* 40:3-4, 2009, 307-330.

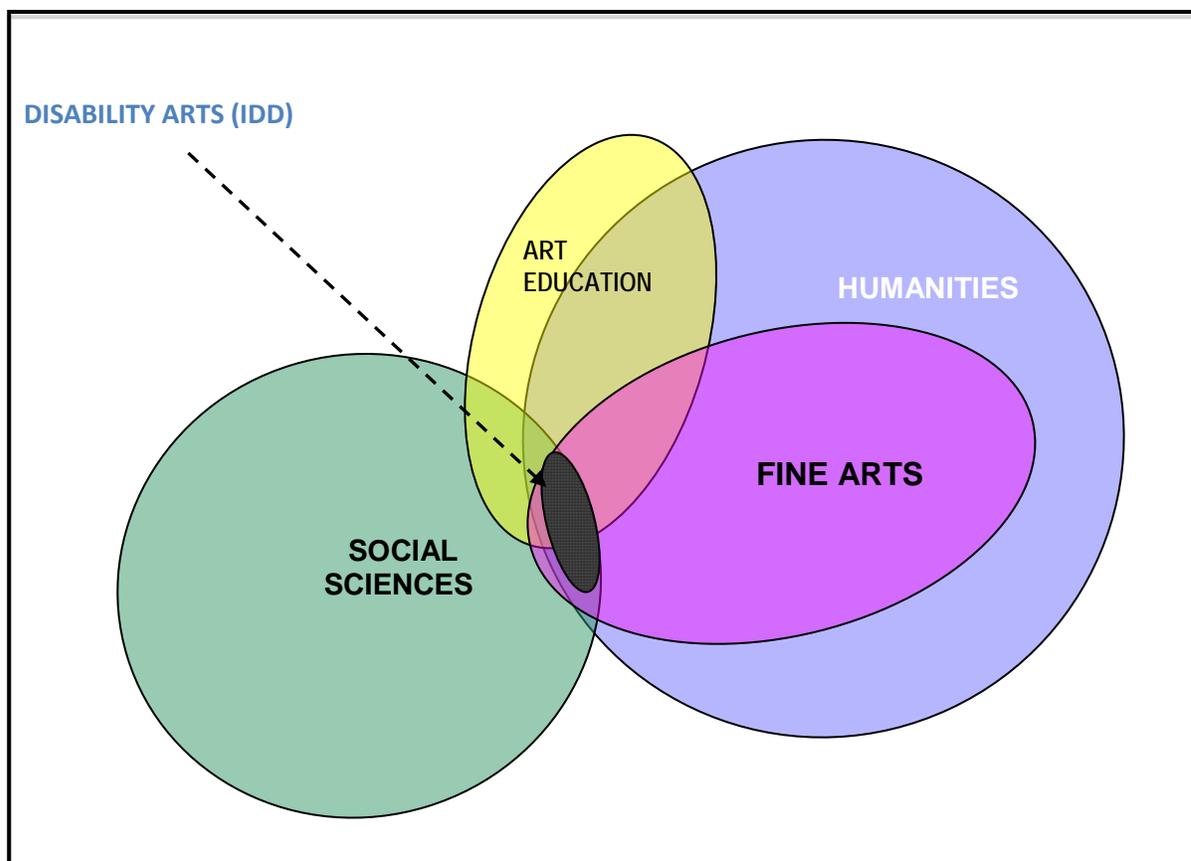


Figure 1.1 Disability Arts (IDD) and Interdisciplinary Studies. Diagram by Sara Lige

than the Humanities. Carrying out research with the artists was important as a way to respect and to validate their experience. It was also an opportunity to conduct research on a subject that I had yet to see documented anywhere else in the same way, even with such a basic premise as I put forth. The paradigmatic aspect of ‘blurred genres’ applies to my project as it employs various perspectives as needed (Brantlinger, Klinger and Richardson; Kinchloe and McLaren). Utilizing an approach that passes through disciplinary boundaries helps to produce a uniquely positioned research project. This interdisciplinary way of addressing disability is a relatively new one. Prior to the 1980s, academic engagement with the subject of disability

was limited almost completely to the fields of medicine and education. The first scholars to address disability in another way were British writers who used a political perspective in their writing, which worked to ignite the Disability Rights movement. At UBC, Disability Studies is still offered within the context of Health; hopefully in the not too distant future Disability Studies will be a separate interdisciplinary program.

1.4 Goals of Thesis

My aim for this thesis is to meet the following goals:

- 1) Research as much existing literature as possible concerning visual arts and IDD. This has resulted in a heavily documented project, but due to the embryonic nature of the field and corresponding lack of literature, my intent is to provide both a thorough examination and comprehensive resource on the subject.
- 2) Identify specific characteristics associated with artists living with IDD, as well as negative and positive factors affecting their experiences as artists.
- 3) Conduct qualitative research with three local artists living with IDD concerning their working process as artists, thereby documenting and validating their experience.
- 4) Discuss Cool Arts Society and the “We Are Artists” exhibition within the context of this project.³

³ The “We Are Artists” exhibition took place during the period of my MA studies, but was not research in the sense that it required an ethics review.

In doing the above, this thesis will add to the existing knowledge base and contribute in a practical sense to the well being and support of people living with IDD, and in particular, artists with IDD. To sum up, I want my research to have practical implications. The intent for this thesis is that it be part of a building process in the emerging field of visual arts and IDD in accord with this description of emancipatory research put forth by Colin Barnes:

. . . the emancipatory research paradigm must be seen not in terms of one single project or projects but as a process. Each piece of research must build on and develop what has gone before. It must seek to make a further contribution to our understanding and ability to erode the various forces: economic, political and cultural, which continue to create and sustain disability at both the macro and micro levels (emphasis added). (“Emancipatory” 16)

It should be emphasized that the text in this project is the experience of the art-making process of artists with IDD and not the end product or finished artwork. The subject of this thesis is this process and any discussion or description of artwork is given only as supports to the main text.

1.5 Literature Review

The quantity of literature concerning Disability Studies is a reflection of its status as an emerging discipline. As noted throughout this thesis, there is a general lack of research concerned with intellectual disabilities and a number of scholars have complained about the lack of literature. Siebers suggests that a “caste system” exists that ranks people with physical disabilities as higher than those with intellectual disabilities, adding that this can be seen in “models of political citizenship, the history of civil and human rights, structures of legal practice, and the

politics of institutionalization, employment history and the organization of the disability community itself” (*Disability Theory* 78).

1.5.1 Chapter Two: Examining Disability

Any discussion concerning the **social model of disability** would be incomplete without referencing the work of Michael Oliver and his article, “Changing the Social Relations of Research Production?”, which is supported by numerous scholars (Boxall, Carson and Docherty; Humphrey). Explanations concerning the medical model are offered (Hughes and Paterson; Linton; Schriempf), as well as the more contemporary affirmative model (Hughes; Truchan-Tataryn; Wendell). Another important writer is Disability Arts scholar Petra Kuppers who draws from both Butler and Foucault to break down nondisabled hegemony, thus offering an example of how these theorists have influenced Disability Theory (*Disability*). In noting the influence of feminism on Disability Theory, Rosemarie Garland Thomson is particularly helpful, while Samuels and Rose identify the influence of gender studies, including Butler and Foucault, as do Carlson, Mitchell, Taylor and Yates.

Early writers were instrumental in bringing disability to the attention of academia and questioning the status quo. As noted by Trent, the issues of stigma and discrimination as concerning people with IDD has been a theme since early works by Goffman and Edgerton, while Wolfensberger was notably influential for his concept of normalization. Among **current theorists**, Rosemarie Garland Thomson is recognized as a leading Disability Studies scholar; her discussions concerning ‘normate’ as constructed identity, as well as ‘able-bodiedness’, are particularly

useful here (*Extraordinary*), as is Robert McRuer's work concerning 'compulsory ablebodiedness' within the scope of Crip Theory.

From the field of education, scholars offer definitions to help provide a more complete understanding of the term '**ableism**' (Griffin, Peters and Smith; Hehir; Komesaroff and McLean). Educational theorists, while acknowledging the uneven history of services to students with profound/severe impairments, frequently cite current special education practices as still based on ableist structures (Ferguson and Ferguson; Hehir; Komesaroff and McLean; Ward).

Inventing the Feeble Mind by James Trent is an invaluable text dealing with the **historical context** of IDD, while Oullette-Kutz et al provide a more contemporary societal positioning. The ever-present and ubiquitous IQ test has had wide ranging implications for people living with IDD (Ferguson and Ferguson; Philip Harris). Explorations relating to **typology** and the categorization of people with IDD become a critical way to understand the impact of 'naming' (Danforth and Navarro; Gelb; Patterson and Satz; J. David Smith; Smith and Mitchell).

Scholarship concerning disability in general has often not included or has overshadowed the unique characteristics and particularities of IDD; the lack of attention paid to this population by scholars can be seen as a reflection of their societal status. Philosopher Licia Carlson has written extensively about the concept of '**cognitive ableism**' and poses "critical questions regarding the multiple positions that philosophers can and do occupy in relation to intellectual disabilities " (Philosophers" 552). Carlson's texts are a main source for this project. Her identification of a particular kind of inequity works to support my position concerning

IDD and the arts. A number of scholars cite IDD within the context of Disability Studies (Burke; Danforth and Navarro; Goodley, “Learning”: Mahowald); some provide useful insights regarding the social model as applied to this group (Chappell, “Still Out”; Humphrey). The newer area of genetic technology as related to IDD raises contemporary concerns that expose existing societal values and assumptions (Kafer; Patterson and Satz: Ward). Goodley notes the emerging status of people living with IDD as within research in the UK (“Editorial”; “Who Is”).

1.5.2 Chapter Three: Intellectual Disabilities and the Arts

Traditionally, most literature concerning the arts and disability reference physical disability, chronic illness, or mental illness. A number of academics and leaders in the disability world have lamented the dearth of research concerning IDD, and it should be noted that literature concerning IDD and the arts *from other than a therapeutic or rehabilitative viewpoint* is even more limited (Moussouri 91).

MacGregor asserts that “the study of art and [IDD] is still an unexplored area” (*Metamorphosis* 17).⁴ Art educator Blandy states that although his discipline pays attention to the art educational needs of children and adults, little has been done to support lifelong learning opportunities in the arts for individuals with disabilities (“Conceptions” 181). This scarcity of literature necessitates ‘borrowing’ from disciplines that ordinarily would not fall into the scope of this project, such as art therapy, education, mental health, quality of life studies and leisure studies, as well as ‘grey literature’ – reports, exhibition catalogues and websites. Reports offer

⁴ The number of writers in agreement regarding the issue of insufficient research on this topic is numerous (Abbas et al; Blandy, “Assuming Responsibility”; Carlson; Rapaport; Warne).

excellent information regarding practical applications and contemporary delivery models (Carnegie; Earncliffe; Masefield; Mencap; Verrent, Flood and Garside).⁵

Literature used in discussing the establishment of a theoretical framework for IDD and visual arts comes from a variety of sources. Such work tends to be situated in an indirect manner within larger works about disability arts in general (Kuppers; Sandahl and Auslander), theory (Siebers); special education (Blandy; Lubet; Wooster), research methods (Leighton; Price and Barron) or embedded within specific concerns like organizational theory (Ineland).

It must be acknowledged that within this range of perspectives, as noted above and throughout this work, notions concerning the nature of art itself are exceedingly diverse. The purpose of this thesis is not to enter into a theoretical discourse concerning the definition of art; rather than attempt to define the term, I propose that here it shall be understood to be the end product of the art-making process. For the purposes of this project, I also propose that the 'contemporary art world' be understood to be the site of public cultural institutions, curated exhibitions, biennales, and art criticism.

Tobin Siebers is one of the few scholars that addresses this subject of artists living with IDD in a specific fashion, albeit as a way to illustrate his arguments within a broader context. The emphasis on linguistics within both our society and in visual arts, and its implications for people with IDD is discussed by Kuppers ("Disability"), Swineburne and Nash. MacGregor and Lakin both draw attention to Gardner's

⁵ The *Attenborough Report* is seen as a historical document that opened the door to advocacy and activism regarding disability arts in the UK. Although the document is known as such, it is cited as "Carnegie United Kingdom Trust. *Attenborough Report*. London: Author. 1995".

concept of multiple intelligences as an influence on their own work and as a worthwhile theory in regards to IDD and the arts.

UK scholars provide politically oriented points of view that claim equal rights for people living with disabilities in general (Abbas et al; Casling; Finklestein) and more specifically, for people living with IDD (Earnscliffe; Mencap). The Disability Equality Scheme (DES) in the UK and the United Nations Convention on the Rights of Persons With Disabilities are indispensable documents for discussions supporting IDD and equal rights in the arts. Differing perspectives concerning artists with IDD and whether or not such artists should be positioned within the genre of Outsider Art or Art Brut are offered by a number of writers (Cardinal; MacGregor, "Creativity"; MacAuliffe; Rivers, "Working Process"). Art journal *Raw Vision* is an invaluable source for bringing to light various artists living with IDD (Heidenwag; Koide; Rivers, "Right Here"; Telsnig). Although some might argue with the journal's broad parameters concerning Outsider Art, it nevertheless offers a look at artists seldom written about or shown in other publications. MacGregor's excellent documentation of Judith Scott and Dwight Mackintosh is simply unparalleled as documentation of artists living with IDD (*Dwight Mackintosh; Metamorphosis*). MacGregor is both an art historian and a psychiatrist and has written extensively concerning Outsider Art and artists with psychiatric disorders; hence, he does write from a more traditional 'medical model' perspective and without reference to the orientation of Disability Studies or Disability Arts as a movement. Artist Scott has been discussed by a number of other writers as well (Fraser; Peiry; Sedgwick; Siebers; Velasco).

German academic Kläger and the Canadian report by Abbas et al provide validation of the sole Canadian artist living with IDD noted in literature, Jane Cameron.⁶

It should be mentioned that I have made certain assumptions concerning the issue of whether or not the arts should be an important part of the lives of individuals living with IDD. I believe that the question of whether members of this population are capable of creativity and whether they should be able to enjoy the same benefits of creative expression as do the non-disabled has been long settled. Several authors have affirmed that the arts benefit individuals with IDD in a variety of ways, only a few of whom are mentioned here (Carnegie; Edelson; Katz; Kläger; Malley et al; Price and Barron; Stamatelos and Mott; Taylor; Warne; Winner). Some writers have even asserted “that the art of [people with IDD] can be more aesthetic, more creative than work by ordinary nonretarded people” (Winner 91).

Psychotherapists Stamelotos and Mott’s assertions lend credence to my research and have acted as a building block for many writers who advocate for arts opportunities for this population; use of this article is an example of why an interdisciplinary approach to this subject is a valid and beneficial way of doing research. As previously mentioned, openness in approach to study can yield a richer analysis of the subject than restricting oneself to a specific discipline.

Articles by Ineland, as well as Ineland and Sauer, clearly articulate the tensions existing in disability arts organizations that must exist within both therapeutic and arts-oriented models. Two directors of existing disability groups, Cheryl Daye of Arts Project Australia (APA) and Tom DiMaria of Creative Growth Art Centre (CGAC), also comment on this topic (Daye, “Studio”; Fraser). It also should be noted that

⁶ To clarify, I should add that Cameron is the only Canadian artist living with IDD that I have found.

some articles discussing people with IDD and the arts refer to drama rather than the visual arts (Ineland; Wooster; Leighton). In the UK and Sweden in particular, drama groups for this population have become numerous; although some aspects differ, the majority of the content is very relevant to this discussion.

1.5.3 Chapter Four: Unique Barriers and Benefits

This chapter takes a pragmatic approach in identifying characteristics specific to artists living with IDD and helps to provide as complete an analysis of my topic as possible. These observations correspond to emerging themes within the literature and are intended to be further developed; I have not observed any similar approach in any other source, thus these points could be considered preliminary in their conclusions. A number of scholars write that there are certain advantages and challenges when individuals with IDD engage with the visual arts. The barriers I have identified here are intervention, accessibility, stereotypes and financial matters; established benefits are social acceptance, self-esteem, choice making, self determination and establishing identity.

Discussing the issue of intervention and influence within the studio are Daye (“Studio”) and Boulangé. Other writers consider the topic while discussing the working process of individual artists (Bridie; Rivers, “Working Process”), while Leighton explores the subject from within the context of a drama group. Groups from the UK are able to use the DES as a way to evaluate accessibility and make recommendations (Mencap; Verrent, Flood and Garside). Both Lefens and Lee deal with accessibility in regards to multiple disabilities, particularly physical impairments.

There is no shortage of writers who discuss IDD and stereotypes within the arts (Blandy, "Conceptions"; Cocks; Katz; Lakin; Mencap). Earlier writer Edelson has been much cited and asserts that association with the arts can challenge stereotypes. Koppers discusses audience reaction to a performance of a French drama group (*Disability*), while Leighton addresses the topic from a background of drama as well. In an effort to confront long held assumptions, Borenzstein discusses his approach in his book of photographic portraits of artists living with IDD. Karafistan and Fraser both address finances and potential problems that are specific to people with disabilities.

The issue of identity is central to people living with IDD and the arts have been very beneficial in enhancing and realizing identity (Edelson; Ineland and Sauer; Lee; Rix; Watts and Ridley). Participation in the arts can also work to improve status (Blandy, "Community"; Boulangé; Cocks, Nash). It is well documented that people with IDD experience limited opportunities to exercise choice and subsequent self-determination (Cavet; Malley, Dattilo and Gast; Perring, "Facilitation"; Wall and Dattilo); however, involvement in the arts can greatly increase potential for choice making (Daye, "Studio"; Timmerman; Wall and Dattilo). Opportunity for personal expression has also been somewhat limited for this population although such activity carries significant benefits (Daye, *Inner*, Mencap; Malley et al). Of critical importance are the benefits of the visual arts to people who have communication impairments (Cocks; Daye, "Introduction"; Perring, "Making"). A benefit not always recognized is that of the potential of the visual arts as a vocation, or an emphasis

“on art as work, rather than on art as therapy or hobby” (Edelson 85). Fraser explores this at length and uses the example of Judith Scott in his discussion.

This chapter provides some links to the following two chapters in regards to some of my own experiences with Cool Arts and qualitative research conducted for this project.

1.5.4 Chapter Five: Cool Arts and “We Are Artists”

My own experience in founding a disability arts group was the catalyst for this project; discussion here examines Cool Arts within a larger context. The “We Are Artists” exhibition provided an opportunity to describe and evaluate the experience of curating such an event, as well as operating to disseminate my research.

Much of the literature in this section comes from essays within exhibition catalogues published by art centres in other countries that provide services to people with IDD. In particular, the catalogues published by Arts Project Australia (APA) were very valuable (Boulangé; Bridie; Cocks; Daye, “Studio”, Introduction”). From Finland, the catalogue from the Kirsikoti group also contained essays that were relevant (Kalha; Kaitavuori; Puhakka). The UK has many excellent examples of arts groups dedicated to supporting IDD arts practitioners. It must be noted that these aforementioned catalogues and reports fall under the category of ‘grey literature’. There is simply not a great deal of ‘academic’ literature to support research, although I would argue that the essayists in the APA publications are scholars and experts in their fields. It appears that there have simply not been other arenas for such articles. Also of use are websites from various disability arts groups

(APA; CGAC; Project Ability/PA), as well as a personal interview with the director of PA.

Within my discussion concerning Cool Arts, Dusenberry and MacDonald, as well as Watts and Ridley, work to support statements concerning identity. The “We Are Artists” exhibition necessarily entailed planning around accessibility (Earnscliffe) and evaluation of various aspects including media involvement (Ineland, “Logics”). In citing goals for museum accessibility, Museum Studies scholar Heather Hollins offers four stages of progressive inclusivity that illustrate shifts of power from museum staff to shared authority.

1.5.5 Chapter Six: Qualitative Research

Qualitative research was conducted within a vulnerable population, therefore, my fine arts question was answered from within a Social Science context, utilizing established social science strategies in regards to research and ethics. A thorough REB ethics review process was completed prior to the onset of the research. Primary texts for planning my research were Denzin and Lincoln, Oliver, “Changing” and Mercer; important adaptations are necessary when conducting emancipatory research with participants who are living with IDD (Walmsley). I see my research as part of building of an ever-expanding base of knowledge (Barnes, “Emancipatory”; Knox, Mok and Parmenter). Asserting that there is a ‘gap in the literature’ in this subject,⁷ my aim is to add to the knowledge base and to empower artists with IDD by documenting and therefore validating their artistic processes.

⁷ I use the term “gap in the literature” with trepidation; however, I believe that I am justified in doing so.

As noted by Kinchloe and McLaren, assumptions must be made clear from the start of research (265). Thus my assumptions are situated and framed by various scholars (Denzin and Lincoln; Mercer; Moosa-Mitha; Roets and Goedgeluck). Specific challenges posed by conducting research with individuals with IDD are discussed and supported by Liamputtong, and Lloyd, Gatherer and Kalsey. The paradigm of emancipatory research was influenced by feminist research (Morris; Moosa-Mitha) and postmodern/postructuralist perspectives (Lather; Liamputtong; Richardson).

Participants were selected using a 'typical case sampling' strategy (Miles and Hubberman). The concept of 'doubly vulnerable' was considered as put forth by Liamputtong. Data collection methods were those of participant observation, video documentation, unstructured interviews and video elicitation. Attention was paid to characteristics of participants with IDD as described by Booth and Booth ("Against") and Taylor and Bogdan. Video elicitation is a newer strategy that was utilized in the second interview sessions (Boxall and Ralph; Rose). In descriptions of data, particular attention was paid to the participant with communication challenges (Brodin and Renblad). Thematic analysis was employed to discover emergent themes (Braun and Clarke) and the analysis process was started during transcription (Lapadat and Lindsay).

1.6 Family Matters

In an effort to be transparent, I have disclosed that I am a family member of an individual living with IDD and that this project is of a personal nature, meaning that it

is motivated and fuelled by a personal interest and investment. My motivation for being involved in disability arts, starting a non-profit group and even entering grad school is intrinsically tied to this aspect of my life. As a researcher who identifies with an emancipatory stance, I do not believe that this position as a family member presents a conflict concerning validity or objectivity; the traditional perspective of the scholar and researcher mythologized by academia as a thoroughly impartial and neutral party is, I believe, flawed. It speaks to an old paradigm and fails to recognize the reality of identity and experience as being an intrinsic factor in one's work. As expressed by Kittay, "it is this personal experience that has informed my study and writing "(606). This is not to say that I have not made every effort to pursue this study with every intention of being as objective as possible, but it is also an acknowledgement that admits a subjective attachment to my subject. I have no reservations in positioning myself in this way. Scholars like Kittay (*Love's Labour*; "Personal") and Michael Bérubé (*Life*) also situate themselves as family members.

I would like my research to be assessed as a contribution to an emerging field and evaluated as to whether it contributes in a practical sense to correcting inequities in the arts for people with IDD. My hope is that this work will be of some benefit outside academia; perhaps the "We Are Artists" exhibition and catalogue will have the greatest impact outside the university.

Although my project represents a relatively small 'slice' of the world of IDD, it is representative of the greater disability sphere and speaks to issues of value, ability, voice and identity. To reiterate, this project is intended to contribute to the knowledge base regarding not only IDD and visual arts, but also IDD and the arts in

general, as well as IDD and emancipatory research. My hope is that this addition of knowledge will counter misconceptions, bring attention to access issues, and lack of research, consequently giving my research an underlying theme of social justice.

The study of visual arts and adults with IDD may seem to be a subject with a narrow focus, however, like most specific areas of research, this narrow focus serves to illuminate a wider scope: both within the arts and disability. The broader application within the arts community is, of course, a reflection of the attitudes towards IDD within society at large.

2 EXAMINING DISABILITY

The area of inquiry known as Disability Studies has been influenced by a number of academic disciplines. Gender and queer theory, for example, have been frequently referred to as disability scholars have sought to build a theory of disability identity, whereas post-colonial studies have been helpful in examinations of the disabled 'other' in the context of the broader community. The work of certain theorists has been extensively used or 'borrowed' to build a framework for disability theory. As Koppers notes, although disability as a social category is different than race or gender, it does share some critical elements: all share a distinctive binary construction and all 'structure' people into separate categories (*Disability 5*).

The moniker TAB, or 'Temporarily Abled Bodied', reminds us all that we are subject to that most unfixing of designations; indeed, as our baby boomer population ages, more and more of our society will enter TAB territory. According to Statistics Canada, 12.4% of Canadians have a disability⁸ and some other countries, especially in Europe, report this figure as much higher; considering this significant and increasing demographic, one wonders why more scholars and universities are not addressing the topic of disability in greater numbers.

It is necessary to recognize that within Disability Studies, IDD holds a unique position. Individuals living with IDD are often not perceived as equal within communities, within the medical system and within the realm of disability itself (Edgerton, *Foreword* vii). This inequality extends to scholarship where IDD

⁸ Statistics Canada. *Prevalence of Disability in Canada*. The Participation and Activity Limitation Survey (PALS), 2001. <<http://www.statcan.gc.ca/pub/89-577-x/4151361-eng.htm>> Google. Web. 22 Feb 2011.

continues to be under-researched in general and where the unique characteristics and challenges of this population are largely unaddressed, particularly in the Humanities.

2.1 Perspectives on Disability

The question of how to classify or identify disability appears to not have a definitive answer. The definition of disability as put forth by the United Nations is widely used and often preferred by disability activists and is as follows:

Impairment: Any loss or abnormality of psychological, physiological, or anatomical structure or function. *Disability:* Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being”.⁹

Disability is frequently cited as an essentially unstable category that is constantly shifting (Bérubé, “Foreword” xi; Davis, “Crips” 502; Kafer 78). Disability scholars examine constructed concepts like normalcy, and then challenge or destabilize those meanings. If one is to ask “What is disability?”, the answer may be to ask “What is normal?”, and thus, “not normal”. In an attempt to effect a reexamination of the word ‘normal’, Rosemarie Garland Thomson suggests the term ‘normate’ instead, which she describes as “the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them”; normates enforce a standard of normality by holding up an unachievable standard to which all others must adhere (*Extraordinary* 8). The human body is never simply a material vessel; the body is more than a single presence, rather it is a succession of opinions towards it. This is

⁹ United Nations *Enable: Rights and Dignity of Persons With Disabilities*.
<http://www.un.org/disabilities/default.asp?id=23> Google. Web. 22 Feb 2011.

a “most labile and pliable of categories”, that encompass[es] a myriad of conditions of the body, and shift[s] within changes of geography, history and culture (Bérubé, “Foreword” vii).

2.1.1 Models of Disability

Medical Model

The traditional paradigm within both society and the field of medicine is that of the medical model, also known as the personal tragedy, deficit, individual or biology model. The issue here is one of natural science as defined by a medical diagnosis that pathologizes disability, characterized by the belief that “social restrictions for a disabled person [are] a consequence of physical dysfunctions” (Hughes and Paterson 328), and accordingly subject to treatment or rehabilitation. The inherent distinctive within this model is a focus on the person or the problem and consequent treatment as belonging to an individual.

This perspective conceptualizes disability as a “deviance from an able-bodied norm” and unrelated to social and cultural contexts (Schriempf 58). In *Claiming Disability: Knowledge and Identity*, Simi Linton describes the medical model this way:

The medicalization of disability casts human variation ... as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy. Society, in agreeing to assign the medical meaning to disability, colludes to keep the issue within the purview of the medical establishment, to keep it a personal matter and ‘treat’ the condition and the person with the condition rather than “treating” the social process and policies that constrict disabled people’s lives (11).

In practical terms, the medical model has resulted in individuals being segregated

and placed outside society; it has been associated with the idea that “biology is destiny”, and in its darkest form, this model has led to infant euthanasia, institutionalization, sterilization and eugenics.¹⁰

Social Model

Largely formulated by UK scholar Michael Oliver in the early 1990s, the ‘social model’ situates society as a hegemonic able-bodied norm and as the source of disabling social, environmental and attitudinal barriers. Disability is seen as a social construct, located in the environment instead of in the body. Disabled people “are ipso facto in a privileged ontological and epistemological position in relation to disability...”; it is their experiences and knowledge that should guide the agenda of disability policy and politics (Humphrey 65). From a social model position, disability is not the result of a person’s impairments, rather, it is caused by “the failures of society to accommodate people with impairments and the barriers presented by such failures of accommodation that cause disability (Boxall, Carson and Docherty 101).

As suggested by Schriempf, one way to further understand the significance of the social model is to describe it in terms of feminism because without feminism patriarchy remains unidentified as oppressive. Similarly, the social model framework provides the necessary structures and standpoints from which to identify and locate the medical model of disability as a system of values (ableism) that oppress disabled people (59).

¹⁰ For further discussion regarding infant euthanasia, sterilization, adult euthanasia and eugenics see writing by Lennard Davis, Rosemarie Garland Thomson, Paul Longmore, and Fred Pelka.

Affirmative Model

The body itself is effectively removed from the definition of the social model, which sees disability as being embedded within barriers that ask for a complete reorientation of society in regards to perceived hostile physical and social environments (Hughes 68). Some feminist proponents of the social model have argued that in attributing all of the problem to society, people with disabilities are being deprived of expressing the reality of their lived experience (including the truth of their impaired body), and therefore are not being fully heard or understood in a complete way (68). These writers suggest a 'return to impairment' or a 'returning to the body' within a renewed social model.¹¹

Truchan-Tataryn asserts that the "failure to acknowledge and interrogate issues of human variation has seriously distorted our collective knowledge base not only by rejecting the voice and experience of a significant segment of human populations, but also by denying the integrity of corporeal diversity to our human condition" (207). As discussed by Wendell, if the social constructionist aspect of the social model is overemphasized, it will be to the detriment of the complex lived experience of those who have disabilities (45). I am in agreement with the idea that an understanding of IDD disability experience is complete only with both the personal/biological and social/constructive aspects intact. For an individual with IDD, the removal of societal barriers, as beneficial as that would be, would still not remove all areas of difficulty from that person's life. For example, a person with IDD who is uncommunicative will still have great difficulty in expressing him or herself

¹¹ Feminist/disability writers Mairian Corker, Liz Crow, Rosemarie Garland Thomson, Jenny Morris and Susan Wendell all subscribe to this view.

through language, and to identify language as a constructed societal barrier is unrealistic. Thus, it is with this determining perspective that I align myself in regards to this research concerning visual arts and intellectual disabilities.

2.2 Major Influences

Feminism

Disability theory is indebted to feminism; as feminists separated sex from gender, disability writers separated impairment from disability or difference from social reactions to that difference. Many of the issues that feminism faced in the 1970s parallel today's concerns in disability study. Garland Thomson states that feminist theory cannot be applied in its entirety to Disability Studies, but suggests that "feminist theory can offer profound insights, methods, and perspectives that would deepen disability studies" ("Integrating" 257). Feminism has in recent years acknowledged disability as a critical area of difference within its own boundaries (Kuppers, *Disability* 50).

Gender Studies and Queer Studies

Disability studies are seen as having shared experiences with gender studies and/or queer theory; both "problematize the public and the private, the social and the biological, difference, stigma and deviance, and the construction of identities" (Sherry 769). In the same way that Michel Foucault's writings have been appropriated as part of the groundwork in disability studies in general, the writings

of gender theorist Judith Butler are also referenced.¹² Her notion of performativity, which suggests that gender is enacted, offers a natural link to disability identity theory and is useful in explaining situational identification¹³ (Samuels 59). Repeated acts establish the performance of normative power; norms must be performed repeatedly because their constituting reference of the subject and non-subject is never assured. Rose notes “discursive power performs its productive effect through its reiteration of naturalizing norms; it enacts what it names” (58). This idea harkens back to the previously discussed concept of normate as being a constructed identity.

Although Butler does not strictly engage with Disability Studies, precipitating some confusion around applying her work in regards to how to distinguish between whether she intends ‘impairment’ or ‘disability’, some of her writings do provide a straightforward link. *In Undoing Gender*, she writes:

The terms by which we are recognized as human are socially articulated and changeable. And sometimes the very terms that confer ‘humanness’ on some individuals are those that deprive certain other individuals of the possibility of achieving that status, producing a differential between the human and the less-than-human. These norms have far-reaching consequences for how we understand the model of the human entitled to rights or included in the participatory sphere of political deliberation. ... Certain humans are recognized as less than human, and that form of qualified recognition does not lead to a viable life. Certain humans are not recognized as human at all... (2).

¹² See *Gender Trouble* (New York: Routledge, 1990) and *Bodies That Matter* (New York: Routledge, 1993).

¹³ For writers discussing performativity in relation to disability, see Alison Kafer, Robert McRuer, Ellen Samuels and Rosemarie Garland Thomson.

Certainly the phrase “less than human” produces thoughts of perceived lesser members of our society; reflect on those common words used to describe individuals that suggest ‘other than human’, like ‘vegetable’, for example.

Foucault

Foucault’s writings are enormously helpful concerning the complex conditions relating to power relations and IDD (Barnes, “Disability” 29; Goodley, “Who Is” 121). If one acknowledges that people with IDD typically hold a level of societal power that exists on a continuum between little and none (Aspis 176), one must also acknowledge that power relations are a critical issue. In particular, Foucault discussed how certain knowledge systems “are dynamically linked to power and the formation of subject positions through which people become tied to a certain identity” (Yates 65).

Foucault argued that excessive diagnosis and assessment of bodies within types of pathology is the typical form of oppression in modern times (Mitchell 1). This concept, referred to as ‘bio-power’ or ‘bio-politics’, characteristically classifies, sorts, distributes and identifies subjects or members of society, consequently attaching them to an identity. The concept of biopower can be explained as two interlocking systems which concentrate on knowledge gathering, first by surveillance that creates ‘data’ about ‘normal’ bodies and, second, by individuals ‘disciplining’ themselves to give attention to being ‘normal’ (Kuppers, *Disability* 5). Foucault’s theories are critical to any discussion concerning how people with IDD have been essentialized to a single factor. Scholars addressing the issue of classification and

typology within IDD make frequent reference to Foucault's work regarding power-knowledge structures; Licia Carlson joins other disability scholars like Shelley Tremain and Scott Yates, who build their work on the foundations built by Foucault.

The concept of the panopticon has a connection to the overly regulated lives of people with disabilities that echoes the reality of many lives; the experience of being classified, as well as being under continuous surveillance is an experience familiar to many disabled people (Taylor 771). Foucault described the jailer and the offender as formed by each other; in the same way, institutions for people with IDD created a new professional space that fashioned new typologies and experts (Carlson, "Philosophers" 553).

2.3 Disability Theory

Disability Studies is a relatively young discipline. The work of Erving Goffman and Robert Edgerton could be considered precursors of contemporary thought around disability. Goffman's writing on stigma and "spoiled identity" occurred during the 1960s, and although it can be difficult at times to connect to what can appear to be dated material, his 'stigma theory' is significant because of the way it repositions disability from the body to the social construction of the body.

The concept of 'normalization' is of importance because of its enormous impact and long reaching influence. As put forth by Wolfensberger in the 1970s, supports and services for people with IDD have often served only to draw attention to the "uniquely devalued qualities of retarded people", who consequently absorbed these devalued qualities (Trent 262). Of critical importance is Wolfensberger's insistence

that work with persons with IDD must “help them to assume socially valued behaviors and integrate them into culturally normative settings”, thus instigating the enormous move to ‘integration’ within the field of IDD (263). This emphasis on ‘normal’ gave a framework to and prompted the early stages of deinstitutionalization. Normalization was extremely significant within the evolution of modern disability rights and practice for individuals with IDD. This concept, currently known as ‘social role valorization’, now appears to many as suspect in its emphasis on goals of supporting people with IDD to appear or become more ‘normal’.

Current Theorists

Disability Studies in general questions the hegemony of ‘normal’ and works to place the body as a changing and chaotic presence. Leading Disability Studies scholar Rosemarie Garland Thomson clearly presents disability and ‘ablebodiedness’ as other than physical conditions and defamiliarizes identity categories. She also employs the idea of performativity to assert that disability is, in fact, understood as dangerous by non-disabled people, because persons with disabilities are perceived as being uncontrollable, or not being in control of their bodies, and therefore, “not only do they violate physical norms, but by looking and acting unpredictable they threaten to disrupt the ritualized behavior upon which social relations turn” (*Extraordinary* 37). This danger that people with disabilities seemingly project has at times resulted in physical violence against individuals with disabilities themselves,

for example, in the form of forced institutionalization and sterilization.¹⁴ As noted, Garland Thomson introduced the term ‘normate’, a powerful descriptive of the constructed identity of non-disabled individuals (8).

Within the field of Crip Theory (loosely defined as an intersection between disability studies and queer theory), Robert McRuer argues that the structure of “compulsory able-bodiedness, which in a sense produces disability, is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness” (2).¹⁵ Compulsory able-bodiedness implies and recommends that a disabled identity must be prevented and avoided at all costs, thus each of these frameworks depends on the other for continued existence. Current pre-natal genetic screening for Down Syndrome and consequent termination rates of 88% and over aptly illustrate the point. According to a systematic literature review conducted by Mansfield and her colleagues, average termination rates for Down Syndrome were 92%¹⁶; the authors cited “negative attitudes towards giving birth to a child with serious cognitive impairments” as a factor (810). A scholarly survey of eighteen western countries established an average termination rate of 88% related to prenatal detection of Down Syndrome; rates varied between countries and demonstrated a range of between 73% to 100 % (Boyd et al 693).

McRuer explains compulsory ablebodiedness as follows:

¹⁴ Several writers have discussed the perceptions of intellectually disabled persons being labeled as deviant and dangerous to the general public, for example, works by Licia Carlson and Rosemarie Garland Thomson. Also see *The Disability Rights Movement* by Fred Pelka, Santa Barbara: ABC-CLIO, 1997.

¹⁵ The term “compulsory able-bodiedness” is a term borrowed from Adrienne Rich’s writings on heteronormativity, and ‘cripped’ by McRuer to provide a name for the theory he puts forth.

¹⁶ Literature review included sources from five countries and dated 1990 – 1999.

Culture ... assumes in advance that we all agree: able-bodied identities, able-bodied perspectives are preferable and what we all, collectively, are aiming for. A system of compulsory able-bodiedness repeatedly demands that people with disabilities embody for others an affirmative answer to the unspoken question, "Yes, but in the end, wouldn't you rather be more like me? (9).

Maintaining that performativity is even more critical to compulsory able-bodiedness than to gender studies, McRuer reminds us of "how many institutions in our culture are showcases for able-bodied performance"; this performativity as applying to disability is doomed to failure. The ideal body can never be completely achieved; is not the endless quest for a perfect physique or even perfect bodily health (or even perfect emotional health, for that matter), in the end, unsatisfied and never entirely complete? (9).

Ableism

The term 'ableism' would seem to be straightforward and simple to understand as parallel to the common terms sexism and racism, however, despite this relationship to everyday descriptors, ableism is not a familiar word or concept. Komesaroff and McLean characterize ableism as being "based on the perception that being able-bodied is superior to being disabled, the latter being associated with ill-health, incapacity, and dependence" (88). As defined by Hehir, ableism is "devaluation and disregard of people with disabilities" (3). Other scholars describe ableist assumptions as those that operate "on individual, institutional and cultural levels to privilege temporarily able-bodied people and disadvantage people with disabilities" (Griffin, Peters and Smith 335).

2.4 Contextualizing Intellectual Disabilities

2.4.1 Historical Context

In his comprehensive work, *Inventing the Feeble Mind*, James Trent sums up the evolution of ‘mental retardation’ in his introduction:

Since ... the second quarter of the nineteenth century, educators, social reformers, physicians, psychologists, sociologists, and social workers have viewed mental retardation in diverse ways: as a disorder of the senses, a moral flaw, a medical disease, a mental deficiency, a menace to the social fabric, and finally as mental retardation. Constructed sometimes in the name of science, sometimes in the name of care and sometimes in the name of social control, these views have accompanied and reflected shifts in the social, political, economic and cultural order in the United States. ... I have concentrated my study on the fabrications and the gazes – pitying, fearful, knowing, controlling – of those in control of mental retardation... (2).

I put forth that this population is the most marginalized group in western culture with a history that encompasses institutionalization, sterilization, and euthanasia.¹⁷ In a national context, Oullette-Kuntz et al. situate this group as the most vulnerable sector of Canadian society (8).

From the mid 1800’s until the later part of the twentieth century, attitudes towards people with IDD were based on damaging beliefs that effectively excluded them from being typical citizens of society and formed social and physical barriers that prevented interaction between people with IDD and others. Individuals with IDD were commonly and stereotypically “perceived to be sick, less than fully human, menaces, objects of pity, burdens of charity and holy innocents” (Cocks 20).

In 1910, the American Association on Mental Retardation (AAMR) established four divisions for people with IDD; ‘feeble-minded’ signified a mental age of twelve or less, followed by ‘moron’, ‘imbecile’ and, lastly, ‘idiot’ (Figure 2.1).

¹⁷ I am not able to comment on non-western cultures in regards to their actions and attitudes towards people with IDD.

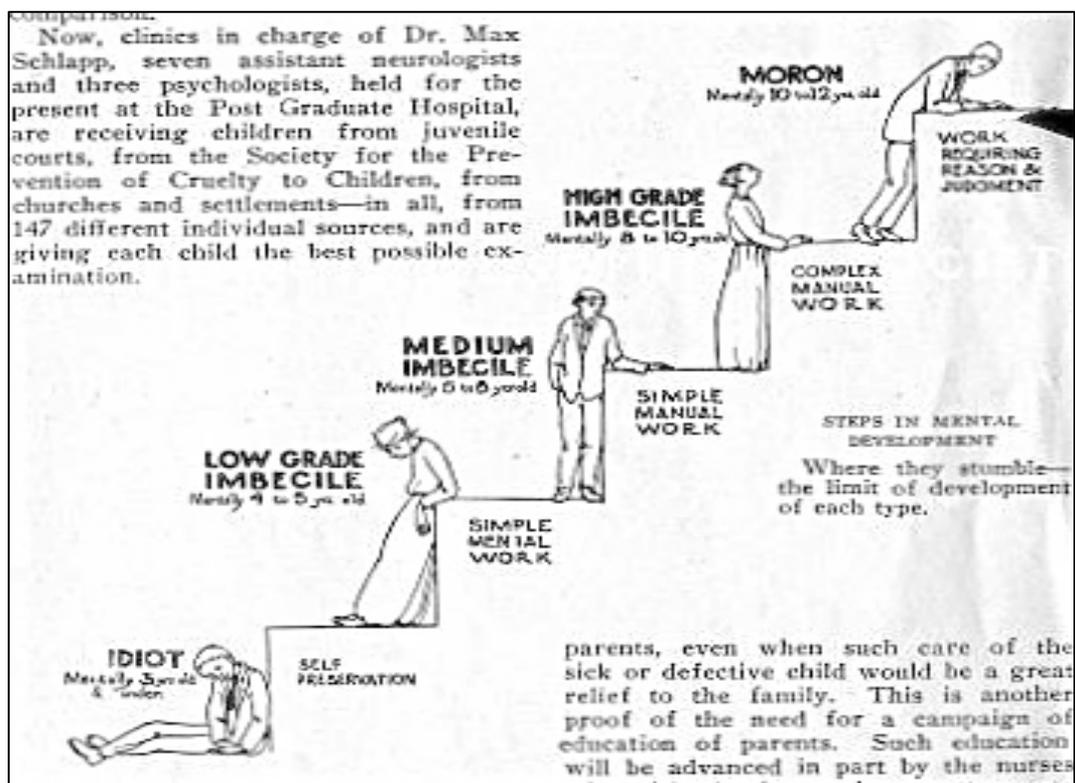


Figure 2.1 “Exhibit of Work and Educational Campaign for Juvenile Mental Defectives” (1913). Digital ID: APS img2232. Series 1, Box 35, Trait file A: 3133#3. Item A:3134-17. Negative # - 1231.

Intelligence Quotient (IQ) scores gradually replaced these designations as a means of classification (James Harris 43). The photographic essay *Christmas in Purgatory* by Blatt and Kaplan, published as a book in 1966 and later in LOOK magazine in 1967, acted as a catalyst to bring the stark realities of institutions for people with IDD into public consciousness and begin a slow evolution of alteration and progress (Figures 2.2 and 2.3). Blatt arranged to visit two institutions in the Eastern US and was accompanied by photographer Kaplan who hid a camera attached to his belt in order to record the abysmal conditions.



Figure 2.2 Institution Scene in 1966 (A) *Christmas in Purgatory*, Page 21. Photo by Fred Kaplan. *Christmas in Purgatory: A Photographic Essay on Mental Retardation*. Burton Blatt & Fred Kaplan. Boston: Allyn, 1966. Center on Human Policy, Syracuse University.



Figure 2.3 Institution scene in 1966 (B) *Christmas in Purgatory*, Page 23. Photo by Fred Kaplan. *Christmas in Purgatory: A Photographic Essay on Mental Retardation*. Burton Blatt & Fred Kaplan. Boston: Allyn, 1966. Center on Human Policy, Syracuse University.

Within Canada, progress currently lags behind England and Scotland, where there has been a commitment to put forth an equity-driven agenda. Oullette-Kuntz et al state that Canadian residents living with IDD receive subnormal healthcare (18). The dramatic shift from institutionalization to community care owing to normalization, while being a positive action, has nevertheless had consequences for Canadian families of persons with IDD, who often bear the “burden of care” (12).

The IQ test

Tests developed to quantify and measure cognitive abilities were instituted in the early twentieth century, and eventually resulted in the Binet-Simon IQ test, and the later version, the Stanford-Binet Scale. Often seen as a formal dividing line between ‘normal’ and ‘abnormal’, the IQ test did not, and still does not, assess adaptive or behavioral factors. The ubiquitous IQ test is a hard line and a crisp boundary; there is no ‘grey’ about it; once assessed as being below the IQ dividing line, an individual is essentialized as developmentally disabled (Philip Harris 348). Many countries no longer use the IQ test as a way to determine classification or level of need, seeing it as obsolete and opting instead for a more holistic assessment that conceivably disrupts cognitive disability ‘binaries’ that divide 70 from 71, dependent from independent, and incompetent from competent. At the time of writing, in British Columbia (BC), eligibility for services from Community Living BC¹⁸ is determined by having an IQ of 70 or below. Certainly many disability

¹⁸ CLBC is the provincial Crown Corporation that delivers supports and services to people with IDD in British Columbia.

scholars, professionals, families and people with disabilities would like to see the dismantling of this rigid and outdated classification tool.

To illustrate this binary constructed by the IQ test, Ferguson and Ferguson describe a possible scenario of a school psychologist giving news to parents that he has assessed their child as having an IQ of 64 (114). In doing so, the psychologist has 'made' the child intellectually disabled; it could be argued that the child was 'normal' up to the time of the determination of the IQ score. At that point, the lives of the child and the family change dramatically – life has a different meaning.

When IQ tests began to be used it was hoped that the tests would end any confusion and controversy over the question of how to identify and define mental retardation. However, although IQ tests did draw the quintessential line between normal and abnormal (Leighton 101), there has never been a satisfactory definition or way of determining IDD as a condition. The idea of intelligence as being established and defined by dated and narrow determinants needs to be challenged. Michael Bérubé describes being shocked when he realized how much emphasis was being placed on the results of his son's IQ test. Bérubé had assumed that other ways of measuring intelligence would be considered; he cites the theories of Elliot Eisner and Howard Gardner (*Life*). I have a personal interest in the theories of Eisner and Gardner regarding their concepts of multiple intelligences, which I believe to be very relevant to discussions concerning IDD, however, to discuss those ideas here would lead to being seriously sidetracked.¹⁹

¹⁹ For more information, see Gardner, Howard, *Frames of Mind: The Theory of Multiple Intelligences* (New York: Basic Books, 1983). E.W. Eisner works in the areas of art education, qualitative inquiry and curriculum development, and has written extensively about multiple intelligences.

2.4.2 Typology and Labelling

The designation 'mental retardation' is an essentialist definition that sums up over 150 years of abuse, institutionalization and discrimination towards people with IDD. Danforth and Navarro state that the term 'mental retardation' has been "repeatedly reconfirmed as a social identifier, a common means of constructing individual identity through subsummation under a categorical heading" (Danforth and Navarro 35). The term is a classic example of how a condition is socially constructed, as is demonstrated by the action of American authorities in 1973 to drop the IQ score needed by an individual to qualify as 'mentally retarded'; with that one document, many thousands of people became not 'mentally retarded'. Much of the history of 'mental retardation' has been taken up with an avid desire to classify, diagnose, label and categorize people (in an undoubtedly Foucaultian way) who differ in certain ways from what is perceived as normal. The term has a set of distinctives so unique and distinguishable that it results in immediate recognition. Using labels of mental retardation reinforces "a cultural judgment on this category of persons: few voices are raised to refute the truth-value of such reductionism" (35).

Definitions of mental retardation are grounded in typological thought. As described by J. David Smith, typology is a study of groups of individuals whose individual differences are thought to be eclipsed by underlying types or essences (62). Gelb defines typological thinking as "the belief that individual differences diverge around an underlying type of essence" (448); complex individual variations can all be 'boiled down' to human types or essences (Smith and Mitchell 146). In

1992, the AAMR²⁰ issued a list of over 350 different variations that come under the term 'mental retardation'; clearly the multitude of variations make an essentializing of 'mental retardation' problematic (Smith and Mitchell 146). As Gelb describes, society has been exceedingly persistent in its belief of mental retardation as a typological identity. When American men designated as 'mentally retarded' performed useful services in the army and in industry during World War II, rather than admit a faulty system of classification, authorities declared that all of the men had been incorrectly diagnosed before the war. In other words, because these men had displayed some degree of competence and usefulness, they could not be 'mentally retarded', instead they were labeled "pseudo-feeble-minded", a condition thought to mimic mental retardation ("Problem" 453).

Labeling is defining someone based on a singular trait, and generalizing about that person on that limited basis, or "substituting one trait of a person for the whole of that person" (Patterson and Satz 133). Edgerton, one of the first scholars to deal with the question of stigma and IDD, said that "mental retardation is as wounding a label as any one can experience" ("Foreword" vii). Once labels take hold, they are forever embedded in the cultural lexicon, possibly in a way not originally intended. As professional terms trickle down into the larger community, terms like 'retard', or from another era, 'idiot', 'moron' or 'imbecile', are now common jargon; even inanimate objects are sometimes described as "so retarded". Members of communities, and even those associated with people with IDD often persist in

²⁰ 'American Association on Mental Retardation', now known as 'American Association on Intellectual and Developmental Disabilities'.

referring to these adults as 'boys', 'girls' and 'kids', thereby infantizing those who are well past puberty.

As a category, IDD remains problematic; the inclusion of autism and dementia, together with Down Syndrome, for example, encompasses an enormous range of conditions that the term fails to accurately convey. Burke suggests that the term 'cognitive difference' may be preferable and states that "we have a political and ethical obligation to recognize the very fact that this kind of terminology is never adequate" (1).

2.4.3 Cognitive Ableism

Philosopher Licia Carlson has repeatedly drawn attention to the subject of the specific prejudice directed towards individuals with cognitive impairment. She describes the term 'cognitive ableism' as being "a prejudice or attitude of bias in favor of the interests of individuals who possess certain cognitive abilities (or the *potential* for them) against those who are believed not to actually or potentially possess them", and notes the "tendency to essentialize cognitive disability and the failure to address adequately the nature of cognitive privilege" ("Cognitive Ableism" 140). Carlson discusses and draws attention to the essentialism that sees a division between the cognitively able/disabled, and further asks, "to what extent does the assumption that persons with intellectual disabilities cannot lead meaningful lives underlie our philosophical discussions?" ("Philosophers" 557).²¹ I put forth that the

²¹ Carlson says in regards to cognitive privilege, "the question of what it might mean as philosophers to examine our own cognitively able and privileged identities presents perhaps the deepest challenge to the philosophical tradition and its assumptions regarding reason, cognitive ability, and personhood" ("Cognitive Ableism" 142).

subject of cognitive ableism within the humanities and the arts has been overlooked or even ignored; there is a scarcity of literature on this subject that is revealing and hints at attitudes of cognitive ableism itself.

The list of sites of cognitive ableism within society unfortunately is not static, but, rather, an ongoing and evolving inventory. An examination of cognitive ableism within the Canadian legal system and the law courts, for example, would supply ample material for several books.²² Rosemarie Garland Thomson, David Mitchell and Sharon Snyder have written extensively about disability and representation in contemporary culture in a way that includes people with IDD, while Boxall, Carson and Docherty address cognitive ableism within higher education in their article “Room at the Academy?” (105). One could also discuss the implications of eugenics as practiced in the not so distant past, and its influence on modern day society.

2.4.4 Disability Studies and Intellectual Disabilities

Within the interdisciplinary discipline of Disability Studies, there are some scholars who have not hesitated to call attention to what they consider a lack of attention to this population (Burke; Carlson; Chappell; Mahowald; Ward). Indeed, from the disability movement itself come voices that claim inequitable representation for this group in research (Campbell and Oliver; Goodley and Moore; Goodley and Rapley; Rapley, Kiernan and Antaki; Roets and Goedgeluck). Accusations of discrimination from within disability culture exist especially in regards

²² The case of Tracy Latimer comes to mind – the 12 year Canadian old girl who was murdered by her father in the name of mercy. One could conjecture that if Tracy had been physically challenged and not cognitively impaired as well, that she would not have suffered her fate.

to the way people with IDD themselves have been involved or excluded in research (Chappell; Danforth and Navarro; Humphrey). To cite an example, UPIAS (Union of the Physically Impaired Against Segregation), a powerful disability group in the UK, originally did not include people with IDD; after significant protests, this was later amended to be more inclusive. Most social model literature has been produced by people living with disabilities other than IDD and has not included the experiences of people with IDD (Boxall, Carson and Docherty 101; Goodley, “Learning” 212). People with IDD have remained discriminated against by works written from a social model perspective that tend to view IDD as a biological impairment and do not recognize the influences of social and cultural influences (Goodley, “Editorial” 49).

Chappell clearly locates the ongoing marginalization of people with IDD as a result of neglect by the social model of disability, and claims that scholarly work regarding IDD is “located currently in the backwaters of disability studies” (“Still Out” 219). This citing of the social model as flawed is echoed by Humphrey, who claims that the incorporation of people with developmental disabilities into the social model of disability is a ‘skewed’ inclusion within a ‘hierarchy of impairment’ (68). Tobin Siebers suggests that a “caste system” exists that ranks people with physical disabilities as higher than those with intellectual disabilities (*Disability Theory* 78). Indeed, it would seem that study concerning IDD is the quintessential ‘poor cousin’ at the party; when I attended a recent Disability Studies conference, observations were made that presentations concerning IDD traditionally drew the fewest attendees.²³

²³ Canadian Disability Studies Association, Concordia University, May 2010.

Progressing to an examination of how cognitive ableism plays out in academia, it is apparent that the university often locates itself as not directly related to, or directly in contact with IDD, other than as a topic within the fields of education and health. The academy also tends to educate professionals in helping professions to see IDD within a medical model.²⁴ In the past, “the relationship between the academy and people with learning difficulties has been damaging and disabling for people with learning difficulties”, providing support for institutionalization and sterilization on the basis of an apparent eugenic threat (Boxall, Carson and Docherty 110). Barnes notes that disability activism of the past two decades has acted to stimulate discussion and debate about the role and development of the social model within universities and the relations between academics and disability activists (“Disability Studies” 30). In their discussion regarding perceived acquiescence and people with IDD, Goodley and Rapley state that the belief that these individuals are undependable reporters of their own lives is well established and consequently silences this group; “what may, for another group be glossed as ‘disagreement’ is constructed as an essentialized incompetence” (129). Within philosophy, it is quite common to encounter discussions comparing the moral status of persons with IDD to animals, a comparison that has a long history (Carlson “Philosophers” 560).

On a positive note, some British journals have issued articles in plain language format co-written by self-advocates or ‘organic intellectuals’ (*British Journal of Learning Disabilities*), even requesting that all submissions be accompanied by a

²⁴ As a personal observation, the odd occasion that I see individuals who are developmentally disabled on a university campus, is because they are working in recycling.

Plain Language' summary²⁵ (Goodley, "Editorial" 50). The emergence of self-advocacy groups has resulted in an increase in activist oriented literature focusing on the life experience and needs of people with IDD (Goodley, "Who Is Disabled?" 119), and often utilizes oral history and narrative methods. Universities are beginning to incorporate Disability Studies programs that use an interdisciplinary approach. Britain continues to lead in this area, although the US and Australia also are strong contributors; Ryerson University and York University have strong Disability Studies programs, but other Canadian research universities do not appear to have initiated any such course of studies.

Genetic Technology

Newer concerns around prenatal testing and disability rights serve as the newest arena of conflict in regards to disability rights. Advances in genetic technology continue to define insufficiency as persons with cognitive disabilities; roles of genetic counselors and family doctors as the "gatekeepers" regarding the birth or termination of persons with IDD is being questioned. Several writers have debated the implications of new reproductive technology, as well as the effect that genetic counseling has on final outcomes, saying that the way this information is delivered to the parents is pivotal to the parents' decision. In other words, the information is often not presented in a value neutral fashion; given the statistics, one could assume that parents are given information that cites IDD as a less than acceptable

²⁵ Plain Language is described as "clear, straightforward expression, using only as many words as are necessary. It is language that avoids obscurity, inflated vocabulary and convoluted sentence construction" (<www.plainlanguage.gov>). The goal is to make information accessible, especially for people with low literacy skills.

condition for life (Patterson and Satz; Linda Ward).²⁶ It should be noted that most forms of IDD are not yet genetically determined (Ward 194).

There are implicit assumptions regarding the birth of a child with disabilities, for example, that the expectation that the birth of a child with Down Syndrome will be unwelcome, and the subsequent belief that the child will have a poor quality of life.²⁷ Kafer suggests that these widespread ableist assumptions are a by-product of previous forced sterilization programs (80). Down Syndrome is often used as a case study example in literature discussing this subject; it is one of the two conditions most often tested for in prenatal screening. As stated by Linda Ward, people with DS rarely experience physical pain or distress as a direct result of this impairment; Ward suggests that prenatal testing for Down Syndrome may be more about the 'suffering' of others than of the individual affected (190).

In summary, the various models of disability are helpful to understand current and past attitudes towards disability in general and individuals living with IDD in particular. IDD as a condition is uniquely situated physically, socially and culturally, thus requiring specific attention by scholars. Scholarship concerning disability has often been ghettoized in health-oriented disciplines, but emerging interdisciplinary Disability Studies faculties are beginning to appear at some universities. Cognitive ableism, as put forth by Carlson, helps to identify and situate the marginalization of people with IDD and provide a perspective with which to examine both scholarship and society, and in the next chapter, the arts.

²⁶Another area of recent medical development is that of cosmetic surgery being performed on children with disabilities, particularly children with Down Syndrome (Goering 2003).

²⁷As a point of interest, people with Down Syndrome often enjoy a good health and quality of life, and Down Syndrome itself is not seen as life threatening.

3 INTELLECTUAL DISABILITIES AND THE VISUAL ARTS

The question of how to situate artists with IDD and their work within the context of contemporary art has been rarely addressed. Although there have been many established and recognized artists with either physical or psychiatric disabilities, it is likely that an artist with IDD has never been documented before the last half of the twentieth century. Until fairly recently, creative work by people with IDD has tended to be associated with sheltered workshops or institutions (Kaitavuori 23) or normalization practices (Blandy, "Disability" 181), and traditionally has been associated with therapy and 'arts and crafts' with origins in the programming of institutions and day centres (Taylor 766). Inside the disability arts movement itself, less than proportionate attention has been directed toward artists with IDD. Petra Kuppers states that "within the disability arts community, [IDD] hold their own status historically; the struggle for equal rights within liberal discourse frameworks articulating a rhetoric of independence, found little place for the rights and needs of people who do not enter the rhetoric field as masters of political language"(Scar 73).

3.1 Therapy or Art Practice? Distinguishing Between Two Paradigms.

Art activity directed towards people with disabilities, and particularly, individuals with IDD, has traditionally had a therapeutic or rehabilitative agenda (Cocks 22; Lakin 4). Without wishing to attach a negative connotation to the practice of art therapy, which is a useful and valuable process for many individuals, it is important to emphasize that art therapy does have an attachment to the medical model. For reasons of clarification, the definition of art therapy as offered by the Canadian Art

Therapy Association website is as follows: “Art therapy combines the creative process and psychotherapy... [in a] creative therapeutic process.”²⁸ The objectives of therapeutic art making might be goals concerning the development of socialization skills or improving fine motor coordination, for example. Disability scholars have tended to not align themselves with the practice of art therapy, opting instead for a non-medical discourse that does not make ‘healing’ part of its agenda (Sandahl and Auslander 6; Watts and Ridley 150). Ignagni and Church describe art practice that is related to the medical model as follows:

‘Art’ is positioned as a tool for biomedicine. It is incorporated into biomedicine’s teleological narrative in which the body is ‘fixed’ in every sense. Art is a means of repair, rehabilitation and reconstitution of ‘broken’ bodies.... Such an approach maintains the disability/ability binary in which disability is produced as a wholly biological relation (628).

The perception that the arts linked with IDD have a therapeutic purpose continues to linger within the fields of both arts and disability.

In recent years various arts advocacy groups have begun to put forth an alternate discourse that focuses on rights, access and identity (Ineland and Sauer 46). Watts and Ridley assert that to consider the artistic production of disabled people simply as therapy would risk compromising both their identities as artists and the aesthetics of their work (150), and add that the distinction between art therapy and art practice “reflects the polarized distinction between two of the more commonly used models of disability respectively essentialist... perspectives of disability and social constructivism” (151). The presence of a therapeutic paradigm

²⁸ Canadian Art Therapy Association website: <<http://www.catainfo.ca/faq.php>>

within an arts program for persons with IDD would affect goals or intent; Boulangé asserts that an agenda of clinical objectives will very likely alter artistic creation (27).

Implications for Arts Groups That Serve Individuals with IDD

Theatre in a disability setting has a relatively long history in both the UK and in Sweden. Initially the purpose of disability theatre was rehabilitative and therapeutic, whereas in recent years artistic expression and excellence have become an important factor as well. Applying both neo-institutional and disability theory to Sweden's social system, Jens Ineland discusses ideological tensions between artistic logic and therapeutic logic. In his examination of the Swedish theatre group Olla²⁹, Ineland describes the practical implications of this conflict, saying that "the artistic logic is formulated in an us/them discourse and the therapeutic logic is formulated in a normality/deviance discourse" ("Between Art" 71).

In Sweden, the theatres (or substitute 'art centres') for people with IDD are formally within disability services, and therefore must operate under institutional rules and guidelines. This is comparable to Canada; nearly all Canadian disability art centres or programs deliver services under the auspices of a community living group or similar organization responsible for people with disabilities, as opposed to services offered by an arts institution or art centre. According to Ineland, a theatre for people with IDD must operate within two different logics to achieve legitimacy, which "is dependent on a loosely coupled formal structure between process and product, art and therapy", and which leaves the theatre of centre "balancing

²⁹ Theatre groups for people with IDD are popular in Sweden, as in the UK. Disability discourse in Sweden has been heavily influenced by the UK as well, leading to a current disability discourse of social construction.

between being a normalization project or disability art which puts emphasis on the celebration of difference” (“Logics” 749).

Ineland’s discussion helps to provide insight into the way society and arts communities perceive artists with IDD. Situating the individuals exclusively as artists is usually complicated by beliefs informed by the medical model, and specifically by notions of therapy and rehabilitation. Ineland offers a summary as follows:

On the one hand, *Olla* is a therapeutic practice in which the logic is essentially directed towards people changing and normalization. On the other hand, *Olla* may be seen as an arena for culture and art, whose ambition is to produce cultural activities and future performances. From a discourse perspective, this gives rise to a rather new and ambivalent relationship between the traditional charity model and the normality/deviance discourse and a new celebration of disability within the us/them discourse. ... the relationship presents a potential dilemma in how we view people with intellectual disabilities (“Logics” 760).

The specific theory Ineland utilizes concerns how organizational or institutionalized fields are characterized by the rules and regulations to which individual groups must conform if they are to receive support. Programs and policies of organizations are supported and affirmed by public opinion and validated by the educational system. How does this apply to disability arts groups? Ineland theorizes that the reason that theatre groups for people with IDD have become more common is the widespread notion that the theatre programs are very successful at bringing about rehabilitative results, particularly in regards to normalization, which remains a powerful discourse in Sweden.

In order to receive the necessary support from the larger organization, *Olla* must show that the focus of attention is on the actors with IDD and meeting their ‘needs’; success must be framed by the personal growth and development of the actors in

relation to socialization goals. However, to achieve legitimacy as a theatre group, *Olla* must produce work of high quality that is accepted within the arts community, not despite or because of the actor's disabilities, but regardless of it.

The situation that Swedish arts groups for people with IDD find themselves in relates significantly to Canadian experience. Disability leaders and facilitators must find a workable balance between the two logics to achieve success; to locate the artists or group more in one discourse is to lose identity, and to situate in the other is to lose financial support. Arts Project Australia (APA) Director Cheryl Daye describes this challenge of "being perceived as outside the funding guidelines for either arts or disability services ... often found ourselves being shuttled back and forth between government departments" ("Studio Workshop"10). One way that disability arts groups could avoid this situation would be to receive full support through arts funding instead of from funders with a social services orientation. However, this would require a massive shift in attitudes concerning people with IDD and a dramatic increase in arts funding as a whole. Until then groups aiming to bring artistic opportunities to people with IDD will have to continue the balancing act necessitated by being in a proverbial 'catch-22' situation.

Following are examples of disability arts groups that position themselves as having other than a therapeutic focus. The following is a statement from Daye, explaining APA's approach:

... our belief [is] that people with an [IDD] are not 'ill' in the sense that the notion of therapy presupposes, even though there may indeed be therapeutic benefits from artistic involvement... The educative approach taken at APA is based much more directly on viewing artistic involvement as an issue of access and equity, and in providing a viable and socially valued alternative to existing art programs and institutions ("Studio Workshop" 11).

Tom di Maria, the Executive Director of the oldest established art centre for people with IDD, Creative Growth Art Centre (CGAC) in Oakland, is very direct in stating that CGAC is not a therapy or rehabilitation centre:

The model for our studio is that we have artists from the community who are all working artists come here as staff people and form a partnership with our artists with disabilities, so it's a true artistic model. We do not have therapists who work here and we do not see ourselves as therapists (as qtd. in Fraser 514).

Thus, as Rivers states, CGAC does not see itself as therapeutic, but, rather, as a "life sustaining and enriching activity for the client" ("Working Process" 47).

3.2 Establishing a Theoretical Framework

At this juncture an examination of existing literature concerning the subject of artists living with IDD and their work within a theoretical context is needed. Still to be addressed by scholars is in-depth analysis that situates or examines the place of artists with IDD within the context of contemporary art practice. Wider discussions involving disability theory, as well as from a broader theoretical context, could surely be extended to focus on this specific topic of inquiry. Arguments supporting or validating artists with IDD tend to take one of two perspectives: discussions concerning the relevance of intellect within the visual arts or politically oriented support of equal rights and access.

3.2.1 The Question of Intelligence

The question of intelligence is the elephant in the room when artists living with IDD are considered within the realm of the contemporary art world; this topic

challenges long held notions about identity of artists and has thus far been largely ignored or avoided. Tobin Siebers attributes this lack of attention paid to artists with IDD to the predominant belief that equates artistic work of high calibre with a superior intelligence. In his article titled “Disability Aesthetics”, the scholar states:

Disability aesthetics refuses to recognize the representation of the healthy body – and its definition of harmony, integrity, and beauty – as the sole determination of the aesthetic. It is not a matter of representing the exclusion of disability from aesthetic history, since such an exclusion has not taken place, but of making the influence of disability obvious. The goal may take two forms: 1) to establish disability as a critical framework that questions the presuppositions underlying definitions of aesthetic production and appreciation; 2) to establish disability as a significant value in itself worthy of future development. (64)

Further developing this line of thought, Siebers identifies as a long-held belief the notion that art is conventionally understood to be produced by ‘genius’, a term that can also be understood as an intelligence capacious enough to carry out works of art, or to use another term, ‘intention’. If art is to be made sense of in this way, then persons with an impaired intelligence cannot create art or are greatly limited in doing so. Siebers takes issue with this premise and asserts that an artist with IDD who produces artwork that is considered to be of a high standard challenges this notion and represents “an absolute rupture between mental disability and the work of art and applies more critical pressure on intention as a standard for identifying artists” (69). Siebers uses the case of fibre artist Judith Scott, an artist who had Down Syndrome and was deaf³⁰ to demonstrate his argument. Scott’s sculptures, Siebers writes, stand up to other works by major contemporary artists and project “a

³⁰ Scott lived in Oakland, California (1943-2005). She lived most of her life in an institution until a family member relocated her to California and facilitated her involvement at Creative Growth Centre.

sense of independence and autonomy almost unparalleled in the sculptural medium" ("Aesthetics" 70).

In another article, "Broken Beauty", Siebers further argues against the dominant paradigm that insists aesthetic expression is the work of intelligence. He argues that if intention is not accepted as a means of interpreting (or producing) art, then it should not be used to determine whether an artwork has value or an artist has talent, adding that art should be judged in its ability to affect the viewer's senses as well as the viewer's mind. Contemporary practice dictates that the intentions of artists do not control the impact or meanings of their work, and are of dubious value as far as interpreting or identifying art; therefore, as Siebers notes, intention is not valid as a criteria for identifying art or artists (15). Cheryl Rivers echoes this assertion in her writing about IDD artist Donald Mitchell and states that "his powerful work challenges assumptions about the creativity of artist with unusual mental states" ("Working Process" 50).

The majority of IDD artists have issues with communication, whether it is a lack of language altogether or a difficulty in expressing thoughts and emotions; Western thought traditionally values logical or linear thinking, rationality and has a bias towards abilities that are quantifiable or "readily testable" (Gardner 12; Miller 2). Koppers asserts that "feminist and disability scholars question this notion of the independent rational individual as the only way of figuring agency" (*Disability* 74). Linguistically produced thought is seen as having value; non-linguistic ways of producing meaning typically have been understood as having less value (Nash 198). This raises important questions that challenge mores about artists and their

practice; the sphere of visual arts, unique in its aspect of non-linguistic expression, has ironically created an inclusive environment with prejudices concerning linguistics. Jan Swineburne points out this paradox within the visual arts, saying that despite the notion that visual art is intended to express that for which words are inadequate, words are deemed necessary to accompany said works (“Linguistic” 1). Although effective art “is not dependent on linguistic facility for its production”, this facility has become both a requirement in the art world and a substantial barrier for artists with IDD (2).³¹

Some writers make reference to Howard Gardner’s ideas concerning ‘multiple intelligences’ that assert that people have differing cognitive strengths and contrasting cognitive styles. Gardner’s work presents a significant option to standardized IQ testing that often leads to and justifies generalized low expectations and works to provide “a theoretical base for expecting and recognizing that within any group of people there will be those with special aptitudes and abilities“ (Lakin 5). John MacGregor, who also writes about Judith Scott, states early in *Metamorphosis* that Gardner and his work were an influence on his own study of IDD and creativity, and suggests that the value of Gardner’s theories will work to shape and develop scholarship around IDD and creativity (xv). MacGregor makes use of Gardner’s theories when he writes that Judith Scott possessed spatial, bodily and kinesthetic intelligence (*Metamorphosis* 3). Although Gardner’s book, *Frames of the Mind: The Theory of Multiple Intelligences*, seems a natural fit to a discussion

³¹ There are, of course, forms of visual art that incorporate linguistics, however, in the broader scope of visual arts, linguistics are typically not a part of the creative process.

about disability, few writers make use of his theories despite the use of his work in other disciplines.³²

Lakin examines contemporary methods of testing creativity and notes that these assessments often do not take into account all the other attributes that creative people must have to ensure success like perseverance, motivation, special opportunities, inspiration, drive to create and support provided to them by others. Research that tests creativity is often problematic in that the procedure is usually tied to literacy, that is, the result is dependent on the research participant's ability to communicate; individuals with IDD are often likely to demonstrate their creative abilities in non-quantifiable ways (5).

Howard Miller questions the traditional paradigm of superior intellect as an essential factor in regards to creative potential and cites an article by Stamatelos and Mott titled "Creative Potential Among Persons Labeled Developmentally Delayed" as the first declarative statement on this subject (2). It has been surprising to find that some texts from the 1960s and 1970s are still useful and acted as early forerunners to the beginning of the contemporary disability movement; other early writers advocated for the importance of the arts in the lives of individuals with IDD, and maintained that people with IDD are or can be very creative. (Rapaport; Stabler; Sherrill). Stamatelos and Mott worked within the field of psychotherapy in the US, with a particular interest in the arts and IDD; although the cited article was written twenty-five years ago, it continues to be an important document.

³² The British Columbia Ministry of Education website currently lists his 'models of intelligences' within the "Special Programs" section. Also included on the website is a list of the "capabilities in seven areas" that correspond with the various intelligence models. British Columbia. Ministry of Education. Special Education. n.d. Web. 28 July 2010.
<<http://www.bced.gov.bc.ca/specialed/gifted/whoare.htm>>

Conclusions drawn from their qualitative research and clinical experience challenged the predominant belief that creativity is systematically related to intelligence (Stamatelos and Mott 101). The authors contended that people with IDD experience abstract thought and symbolic processes, that virtually all individuals living with IDD are capable of creative acts, and that traditional beliefs and treatments in the field of IDD have limited and devalued creative acts by this population (Miller 2). They also stated that there is evidence that persons with IDD produce visual art in a more abstract, unique and creative style than their nondisabled peers (emphasis added) (102). Although this period of time is seldom remembered as a positive one in regards to disability awareness, it did coincide with children with disabilities starting to attend public schools. In 1964, Rapaport wrote:

It appears that we are here face to face with an insight into the nature of human creativity. Here are the people from whom society expects the least, able to give forth telling commentaries on their own lives, and life in general, with the most economical means, and still able to relate the materials given them with handsome and sometimes moving results (16).

Divergent thought is often seen as necessary for creativity, but when disabled people demonstrate divergent thought, their behavior is often perceived as socially inappropriate (Stamatelos and Mott 102). The concept of 'normalization', for example, is one that seeks to have disabled people achieve social conformity. Stamatelos and Mott assert that individuals with IDD "think divergently to a greater extent than others, and divergent thinking is often a criteria for giftedness" (Miller 3).³³ Arts facilitator Ahti Isomaki, of the Kirsikoti School of Painting in Finland, states

³³ Stamatelos and Mott contend that an environment that respects authenticity, facilitates affective expression, and develops positive self-regard can encourage an emergence of creativity; reasons for a lack of creativity then are environmental and not related to intellectual impairment. Environments

that “my general impression is that intellectually disabled people are more artistic than average. Perhaps that’s because their thinking is less rigid” (Kaitavuori 21).

Although the existence of such hegemony is concrete within western culture, and as such, must be examined and challenged, it is important to recognize that this may not be a worldwide issue due to differing attitudes towards disability and art itself. Lubet discusses the “notion of musical ability as genius” and the West as a ‘talent culture’ as compared to other areas of the world that treat the arts as a way of life, not an exclusionist activity that requires a high degree of technical proficiency and ‘talent’ orientation. The concept of art and genius would appear to be a western one; “... cultures have tended to regard music either or as an activity of daily living accessible to and expected of nearly all. ‘Talent’ cultures such the West practice the most exclusionist form of music education...” (729).

3.2.2 A Political Agenda

Applying an equal rights platform to IDD and the arts extends the rationale that as equal citizens, people with IDD should have equal access and rights to the arts. The ‘rights’ argument, as it concerns the arts and people with IDD, applies not only to access to art-making opportunities, but also to access to information concerning museums, galleries and arts centres, and opportunity to fully participate as recognized artists. Earnscliffe states that “access to the arts is a human right” (5), and adds that “access to information is not just a matter of choice on the part of service providers, but a matter of civil rights for those people denied choice,

have been over-structured, which produces a population where “learned helplessness” is commonplace.

opportunity and involvement” (16). As early as 1987, Vic Finkelstein, a pioneer in the UK Disability Arts movement, proclaimed the rights of people with disabilities to “participate in the cultural life of our country” and emphasized that disabled people should control disability arts groups (1). This is in contrast to VSA (Very Special Arts), the largest disability arts group in the US, which Koppers cites as a paternalistic disability arts organization (*Scar* 211).

From Sweden, Ineland and Sauer state that IDD arts groups are a right under the disability law, which is part of a much broader welfare state context (47). Worthy of note is the United Nations Convention on the Rights of Persons With Disabilities. Signed by Canada in 2007 and ratified by Canada in 2010, the Convention recognizes accessibility to the “cultural environment” (3), as well as non-discrimination of rights and freedoms in cultural domains (4). “Equality of opportunity” and “Accessibility” are two of the guiding principles of the Convention (5). Article 30.2 states: “Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society”.

Disability Arts in the UK (the term is usually capitalized), which has been closely linked to the Disability Rights movement, has been focused on using art as an instrument of social change that seeks to create a group disability identity and sees disability art as a political instrument to confront oppressive beliefs that extend beyond access to the arts (Abbas et al 43; Price and Barron 821). This political

orientation can be seen in the writings by Casling, Hevey³⁴ and Masefield. Dennis Casling's much cited article "Art for Whose Sake?" argues that art production should not be limited to an elite chosen by class, race, disability or intelligence, The author maintains that the arts can play a central role as minority and marginalized groups create a discourse or group identity for themselves. Casling is in opposition to the exclusion of anyone from the 'community of art', and argues that all disability poetry (read 'art') is inherently political and therefore initiates and promotes action. As stated in the arts document *Doing, Showing and Going: Mencap's Arts Strategy* (UK), "every individual with a learning disability has an equal right to choice, opportunity and respect with the support they need; this applies as much to the arts as it does things like housing, education or employment" (Cramp 2). Disability groups in the UK have contested what they consider to be paternalistic ways of establishing and running disability arts groups and have insisted that their groups be fully controlled by disabled people.

The IDD community has often been left out of disability politics and except for a few exceptions, individuals with IDD usually rely on advocates to be activists on their behalf, although self-advocacy organizations are becoming more of a factor in many countries. As previously noted, cognitive ableism exists in virtually every segment of society, including the visual arts. It is discouraging to observe that contemporary art, whose artists often aim to expose hegemonic beliefs and break down societal barriers and boundaries, has yet to notice that it has almost completely excluded this segment of society. Most Canadian public art institutions

³⁴ David Hevey's book *The Creatures Time Forgot: Photography and Disability Imagery* "was seminal cultural theory that focused on the manipulation of disability identity" (Taylor 764).

appear to have failed to establish disability policies and remove barriers that prevent people with IDD from accessing their facilities. This is in sharp contrast to the UK, where public cultural institutions have been required since 2004 to develop a Disability Equality Scheme (DES) accompanied by a DES Action Plan; these DES plans can be accessed on institution websites.³⁵ The following quote from the Sir John Soane Museum DES describes the institution's diversity strategy:

To embrace and reflect diversity, harnessing the potential of all stakeholders (staff, volunteers, existing and potential audiences, key partners) in the development of a truly inclusive Museum, which inspires, promotes learning, creativity and participation.³⁶

The DES primarily addresses the issue of accessibility; the matter of the inclusion of artists with disabilities accessing gallery exhibition space at this point is likely a matter of the institution's commitment and interpretation of the legislation, however, this implementation and government involvement marks an enormous step toward full cultural inclusion. In a similar fashion, US museums have been required to remove barriers to accessibility in their facilities as directed by the Americans With Disabilities Act (ADA), which was passed in 1990. Although these directives concern visitor experience alone, they nevertheless mark progress; Charter of Rights protects the rights of Canadian with disabilities, there are no strict standards and few tools or models (Lord 8). Canada Heritage cites that "equality and full participation are human rights. All persons are entitled to equal access to the basic rights and fundamental freedoms that most people take for granted, e.g. health

³⁵ DES requirements are a more recent addition to the Disability Discrimination Act (DDA), which was passed in 1995 in the UK.

³⁶ Sir John Soane Museum. *Google*. Web. 5 Nov 2010. < www.soane.org >.

care, employment, education, participation in cultural activities” (emphasis added).³⁷

Adrian Martin references Edward Said’s ‘politics of difference’ when he supports making use of the concept to argue on behalf of artists with IDD “upon the right of all marginalized groups to be heard and be respected, to be part of (hopefully) equal, democratic dialogue within our society’s processes of representing, discussing and forming itself” (17). Chris McAuliffe adds that:

the politics of difference has begun to empower many marginalized groups, but, within the art world at least, people with an intellectual disability have not been invited to the party. Perhaps this is because the art world feels that by merely exploiting the rhetorics of outsiderism, it has already made room for them. If the art world is to embrace the politics of difference sincerely, such tokenism must be set aside in favour of genuine dialogue (“Different” 18).

In a postmodern climate that embraces pluralism, difference and the ‘marginal’, work by IDD artists is not accepted. It must be admitted that some minimal progress has been made; however, by no means could such work yet be considered inside the canon of western art. Despite acceptance of other artists who not so long ago might have been considered ‘outsider artists’, artists with IDD remain on the outside looking in and essentially unrecognized as legitimate artists.

3.3 The Question of ‘Outsider Art’

Outsider art is a broad and expansive category, full of dissension and constantly in flux.³⁸ As a classification, the genre is not determined by art history indicators, historical boundaries, style or group identity, although all of these factors are a part

³⁷ Canada Heritage: Human Rights and Disabilities.

³⁸ For literature concerning Outsider Art see: Cardinal, Roger, *Outsider Art*. London: Studio Vista, 1972; Rexler, Lyle, *How to Look at Outsider Art*. Abrams, 2005 and Rhodes, Colin. *Outsider Art: Spontaneous Alternatives*. London: Thames & Hudson, 2000, as well as journal *Raw Vision*.

of the whole (Kuppers, *Scar* 181). Scholar Colin Rhodes states that Outsiderism is that which is left out of “the mainstream of the professional (western) art world”, but is also distinguished “by exclusion from, or marginalization in relation to, the very culture that supports the market for mainstream art” (qtd. in Kuppers, *Scar* 181). The term Outsider Art is a roughly equivalent term to the French term *Art Brut*. Jean DuBuffet’s contribution to the art world in 1945 was to broaden the traditional parameters of what constitutes art by bringing forward work by unschooled artists in various mental institutions and the like³⁹. Dubuffet stated :

The imbecile (or those the intellectual calls imbeciles) shows greater aptitude... imbecile perhaps, but sparks fly from him, unlike Mr. Grammar School, who doesn’t spark at all... This distinction between normal and abnormal seems to us to be quite far-fetched: who is normal? Where is he, your normal man? Show him to us! The artistic act, with the extreme tension that it implies, the high fever that accompanies it, can it ever be considered normal? (594).

Art Brut has had an enormous influence on contemporary art, although opinions vary as to exactly what qualifies an artist or work to be recognized as such. The genre now encompasses folk art, naïve art, art from various kinds of institutions, children’s art and more. Outsider Art has become a very marketable commodity, and one might wonder - if work is featured in a commercial “Outsider Art” gallery - is it really Outsider Art?

Outsider Art and IDD

It is important to understand the benefits and limitations of the label ‘Outsider Artists’ concerning artists with IDD. Typifying the paradox that is Outsider Art, artists

³⁹ Origins of Art Brut lie in the early twentieth century with the work of German psychiatrist Hans Prinzhorn. DuBuffet was influenced by Prinzhorn and remains the most known proponent of Art Brut.

living with IDD and their work have been placed both inside the category (Cardinal, MacGregor) and outside (McAuliffe, Rivers) the category. Positively, the emergence of Outsider Art has served to bring such work to the attention of the art world where previously there was no acknowledgement of work by artists living with IDD at all, however, the disadvantages may outweigh that benefit. Situating some artists as 'Outsiders' works to constitute a binary of normal artists/ abnormal artists. The term 'Outsider' carries certain negative connotations; people with IDD live, not by choice, as literal outsiders in our culture. As MacGregor states:

While their creations may hang in Manhattan apartments, beside the works of Picasso, Pollock, or Bourgeois, the creators are unlikely to be invited to set foot in these same apartments, their appearance, their behavior, and the reality of their being leading to their exclusion from polite society. While Outsider Art is unquestionably 'in', Outsider Artists remain as far 'outside' as they have ever been' ("Creativity" 9).

The term Outsider Art does not work to promote an attitude or reality of inclusion. Classifying artists and work as such may serve to dictate to the artists with IDD, and the groups or individuals that support them, that they may succeed only as they remain within their established 'genre'. Grouping the various sub-groups within Outsider Artists together, for example, artists with IDD, artists with mental illness, 'southern preacher' artists, recluses, and folk artists, minimizes the unique challenges that face artists living with IDD and prevent the construction of a group identity specific to IDD. The value of the work tends to be seen only in the aesthetic end product or work of art, without consideration of the larger social context in which that artist lives and which informs their work (Fraser 513).

MacGregor addresses the subject of Outsider Art and Art Brut, and places artists with IDD within this category ("Creativity" 8). He selects only four of the artists in the

book (*One is Adam One is Superman*) as being authentic Outsider Artists, meaning that their work is of a standard deemed high enough for this acknowledgement.

MacGregor's use of the genre as a way to discuss this subject can be seen as a way to 'anchor' the artists into the scope of art history, although many art historians might challenge his definition of Outsider Art.

American folk art expert Cheryl Rivers states that as the field of scholarship that includes Outsider Art, Art Brut and 'self taught' art continues to broaden, scholars tend to privilege artists who create their art "in spite of" or because of their different mental or emotional states, and adds that there is a tendency to persist in romanticizing Outsider Artists as geniuses who work in isolation ("Working Process" 47). This notion of working in isolation is problematized, however, because artists with IDD are not likely to work in an isolated or segregated fashion, but, instead create their work within a supported art centre setting. Artists with IDD who have achieved critical recognition have almost always been associated with a disability arts centre, and thus receive instruction or facilitation from educated art teachers; art centres also typically offer the artists opportunities to exhibit and receive recognition, again, also at odds with the definition of an Outsider Artists (47).

Dissension, unestablished boundaries, conflicts concerning theories about disability together with links to concerns around commodity all serve to indicate that Outsider Art as a genre is probably best avoided by artists with IDD.

3.4 Documented Artists Living with Intellectual Disabilities

It is my wish to acknowledge the artists here as those who have achieved a high standard of work and also received attention from writers and scholars. Scholarship referencing their work is critical to this project and any study concerning IDD and the visual arts. The following list identifies artists and some of the scholars who have examined their life and work; this list is not intended to be a comprehensive inventory. Included with each entry are author names from the thesis reference list.

Jane Cameron (1949 – 2000)

Cameron, who lived with Down Syndrome, has the distinction of being the only Canadian on this list. She worked in a textile workshop, *Le Fil d'Ariane*, for people with IDD in Montreal during the 1970s and became the atelier's chief designer. At the workshop, Cameron came to the attention of Dr. Max Kläger, a professor of art and education from Hamburg, Germany. Kläger wrote a book about Cameron (German language), and helped to show her work in the Heidelberg Textile Museum. Cameron later returned to Calgary and worked for many years out of the studio at In-Definite Arts Society (IDAS). Cameron is the sole visual artists with IDD cited in the Disability Arts report *Lights... Camera... Attitude! Introducing Disability Arts and Culture* published by Ryerson Institute for Disability Studies Research and Education. In the report Abbas et al state:

“[Cameron] was an artist, and as a disabled woman entered the arts not as a recipient of therapy, but as an artist with a vision to create and share her work. As such, with every piece she created she challenged the dominant discourses of both disability and art. Her critical success and her visibility as an artist clearly have implications outside her own artistic success” (30).

See: Abbas et al, Kläger, Schierbeck, and website:
<<http://www.janecameron.com/about.html>>
Archives are housed at IDAS.

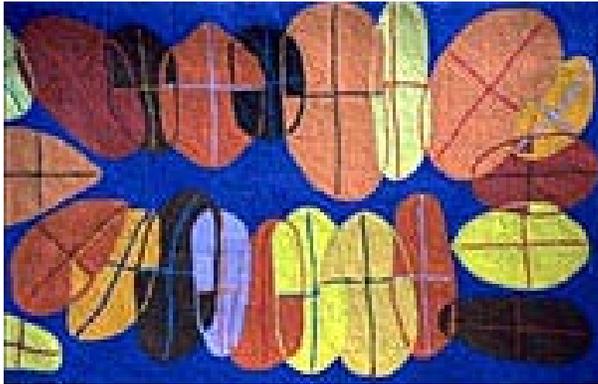


Figure 3.1 "Autumn Leaves" Jane Cameron.
<www.janecameron.com>.

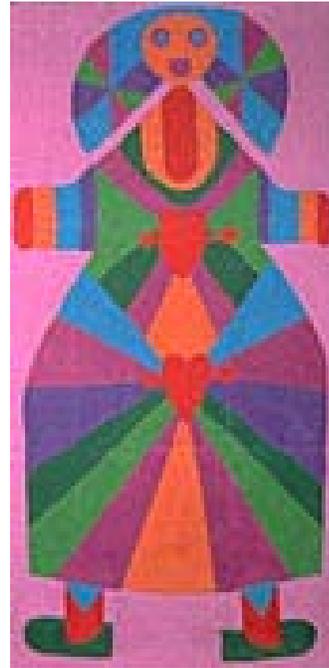


Figure 3.2 "Lady of Hearts" Jane Cameron.
<www.janecameron.com>



Figure 3.3 Jane Cameron
<www.janecameron.com>

Kunizo Matsumoto (1962-)

From Osaka, Japan, Matsumoto cannot read or write, but creates text based works using both real and imagined characters. He covers wall calendars and books as well as blank paper, and collects realms of theatre brochures, catalogues, guide books and other source material.

See: Koide.



Figure 3.4 Kunizo Matsumoto. (left) "Untitled, September" (1997) and (right) "Untitled, October" (1997) both 34.5 x 9.5 cm.

Dwight Mackintosh (1909 - 1996)

After fifty-six years in an institution, Mackintosh worked at Creative Growth in the San Francisco area from 1975 on. His energetic line drawings are often concerned with tightly configured figures and machines. He is the subject of a book by John MacGregor, who said that Mackintosh's "drawings possess a visual authority and originality.... free of cultural content" (MacGregor, *Dwight Mackintosh* 12).

See: MacGregor.

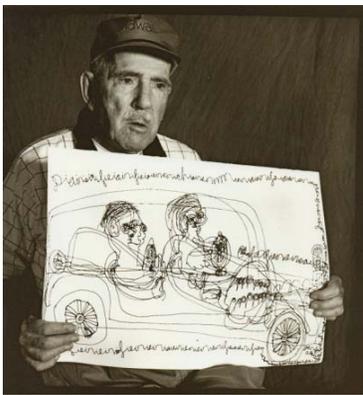


Figure 3.5 Dwight Mackintosh *One is Adam One is Superman*. Leon Borensztein. San Francisco: Chronicle, 2004. n.p.



Figure 3.6 "Two Clothed Figures, Transparent" Dwight Mackintosh. 23" x 17 9/16". (1987). Photo by Julie Polunsky. *Dwight Mackintosh: The Boy Who Time Forgot*. John MacGregor. CGAC: Oakland, 1990. Plate 30.

Donald Mitchell (1951-

Mitchell has been a studio artist at Creative Growth since 1976. He is the subject of a book edited by Cheryl Rivers that features essays by Colin Rhodes and Lyle Rexer among others. His work features crowds of small figures in repetitive formations and is usually tightly composed with a graphic quality.

See: Rhodes; Rivers.



Figure 3.7 Donald Mitchell. Photo by Leon Borensztein. *Donald Mitchell: Right Here Right Now*. Ed. Cheryl Rivers. Oakland: CGAC, 2004: 4. Used with permission from CGAC.

Judith Scott (1943-2005)

By far the most documented artist with IDD, Judith Scott was a fibre artist who had Down Syndrome and was deaf. After spending thirty-five years in an institution, Scott entered CGAC in Oakland, CA, and worked at that studio until the end of her life. John MacGregor's book, *Metamorphosis: the Fibre Art of Judith Scott*, exists as an outstanding document about Scott and her work.

Within a context of fine arts and disability studies, Scott provides an excellent case study for study. In his article "The Work of (Creating) Art", Fraser makes use of Scott's example to explore artistic process as productive work in an effort to connect artistic production and social/economic conditions of artists with IDD. Fraser points out that Scott's artwork and its "renumerated incorporation into the international art circuit, provide that opportunity to see the current limitations regarding the extent and nature of the communication that takes place between people with and without [IDD] in our society..." (521). Siebers discusses Scott as a tangible example of the unstable nature of the relationship between art and genius or intellect.

See: Fraser, MacGregor, Peiry, Sedgwick, Siebers. Velasco.



Figure 3.8 "Untitled" Judith Scott. 54" x 12" x 5". (1991). Photo by Leon Borensztein. *Metamorphosis: The Fibre Art of Judith Scott*. John MacGregor. Oakland: CGAC, 1999. Plate 27.



Figure 3.9 Judith Scott. Photo by Leon Borensztein. *Metamorphosis: The Fibre Art of Judith Scott*. John MacGregor. Oakland: CGAC, 1999. iv.



Figure 3.10 "Untitled" Judith Scott. 45.5" x 22" x 10". 1989. Photo by Leon Borensztein. *Metamorphosis: The Fibre Art of Judith Scott*. John MacGregor. Oakland: CGAC, 1999. Plate 34.

Harald Stoffers (1961-)

Stoffers has worked in an art studio for people with IDD in Hamburg, Germany since 1983. Almost every day, Stouffer draws freehand guidelines and writes in distinctive cursive text about his life in the form of a letter to his mother. The lines give the works the appearance of both a music notation, and at the same time a form of calligraphy.

See: Heidenwag.



Figure 3.11 "Letter 60" Harald Stouffers. 39.4" x 27.5". 2004. Raw Vision 64 (2008) 31.

4 UNIQUE BARRIERS AND BENEFITS

An examination of visual arts and adults with IDD must necessarily acknowledge inherent and unique characteristics to gain a complete perspective of implications and conditions that may affect artists with IDD both positively and negatively.

4.1 Unique Challenges

4.1.1 Undue Influence: Intervention in the Studio

People with IDD have historically never been situated as having power. They have ranked among the lowest in terms of socioeconomic status, authority and recognition. It is this history that arts facilitators must be aware of when they negotiate the power differential inherent in a relationship between an artist with an IDD and an artist without an IDD. The work of IDD artists who work in specialized art centres or studios can be subject to the interventions of their facilitators or instructors whose central role in the production of work by artists with IDD raises questions in regards to their involvement and control of the finished work. The extent to which an instructor can assist development in the artistic process before their involvement becomes undue influence is an ongoing dilemma; it can be deceptively easy for an arts worker to unwittingly direct an artist's work to their own aesthetic preferences and satisfaction under the guise of helping the participant (Daye, "Studio" 12). The response of a facilitator to an artist's work or a teacher's selection of subject, media, and work conditions in an art studio can exert tremendous external influence on the artist's expression and choices concerning their production of a work. Additionally, goals to produce 'exhibition worthy' work or

work of commercial value is a complicated one fraught with possibilities of intervention or influence.

Intervention not only involves issues related to content; a teacher may remove a work when it appears to them to be finished in an effort to prevent the artist from overworking the piece, or intervene if the artist appears to be unsure of how to proceed (Rivers, "Working Process" 49). These are, it could be argued, the same dilemmas faced by any art instructor. However, the potential for such influence is greater in the context of an artist with IDD due to the intrinsic power differences and possible low confidence or inexperience the artist may have in regards to problem solving, choice making or assertiveness (Daye, "Studio"12). The situation can become more challenging if an artist lacks communicative abilities, thus accentuating the perceived need for intervention by the facilitator. Different groups and facilitators employ varying guidelines and philosophies in regards to intervention in the studio. What may be perceived as intervention in some facilities may be instead seen as a kind of mentoring or teaching in others. There appear to be a variety of responses and differing philosophies, which are undoubtedly influenced by prevailing philosophies in both the particular region and the greater IDD world.

Theatre scholar Fran Leighton describes being in conflict when she experienced the desire to organize and expect what she recognized as 'theatre practice', including concepts of responsibility and commitment as applied to being part of a theatre group made of adults with IDD. She was also aware of the expectations of the audience and actors, and recognized that pushing this agenda would constitute

'normalizing' behavior (106). Eventually, as Leighton permitted a loosening of her expectations, a more open and unstructured way of working emerged (105).

Director of CREAHM, an arts centre for people with IDD in Belgium, Luc Boulangé states, "I have never physically intervened in the pictorial production of an artist with an intellectual disability"(26). Early in the evolution of the group, viewers claimed that they saw Boulanger's influence in the artist's work, so in reaction to this response the director took an extreme response that allowed to him to say that he never intervened (26).

In an exhibition catalogue about APA artist Dorothy Berry, arts facilitator Maxine Ryder discusses the tension between intervening to pull work away from Berry to prevent her from "destroying" the piece, and wanting the artist to make the decision herself about when the work was done, saying that "ultimately ... what we wanted, [was] for her to make her own decisions" (Bridie 8). Ryder also stated "that was the danger with Dorothy, that she could overwork her pictures...we tried to rescue the works at the early stage so that we didn't lose the imagery, because what was so beautiful about her work was her pure, direct line" (8). Obviously Ryder saw this action of interception as a way to help or support Berry to produce the strongest work possible; she was aware of Berry's capabilities. Cheryl Daye states "the underlying principle in the Studio Workshop [APA] is always to respond to the rights of the artist/participant and to make suggestions in keeping with his or her perceived intentions without being overly directive" ("Studio"12).

Optimally, a sensitive negotiation between student and teacher/facilitator is required to achieve a workable relationship that ensures the integrity of the

student's work. This constitutes a very delicate and difficult balance to achieve; there are times when participants may require specific guidance in order to learn a new skill or reach a new level of understanding. In general, however, the role of the facilitator is to set up the conditions whereby the participants are able to develop the quality of their creative experiences themselves by providing them with access to a range of materials and techniques that will enhance the quality of work and allow them to develop their own artistic style. Interventions must flow from the goals set by the art centre or teacher either as part of the general philosophy or as the individualized goals for and set by that particular student (Rivers, "Working Process" 49).

4.1.2 Ongoing Issues Concerning Accessibility

Within the field of the visual arts, the main barriers to accessibility appear to be location, lack of support, finances, stereotypes, communication (or lack of plain language) and access to information. Many individuals with IDD have multiple impairments and consequently require that other accessibility concerns be addressed. It should be observed that many people benefit from accessibility modifications, including individuals with learning disabilities and low literacy; other modifications can benefit seniors, or parents with young children.

In the UK, major steps have been taken to make all public institutions accessible to the entire population. As previously mentioned, the Disability Discrimination Act (DDA) states that all public bodies have a duty and obligation to promote disability equality. The DDA aims to change the way laws work in this area, from responding

to individual disabled people making a complaint, to expecting the public sector to be positive in removing barriers. Public authorities must promote equality of opportunity between disabled persons and other persons. Implementation of the DDA means that cultural institutions like galleries and museums must make information about their exhibitions available in a plain language format. Mencap, the largest charity for people with IDD in the UK, wants to “promote equal opportunity and diversity in the arts” (Rix 3). In 2002, Mencap conducted a major survey with self-advocates to develop a national arts plan, *Doing, Showing and Going: Mencap’s Arts Strategy*, and also produced an accessibility guide, *Welcoming People With a Learning Disability to Your Venue* (both in plain language format), which reported that the major barriers preventing arts access were money, information, transport, “not feeling welcome”, inconvenient timing of events and lack of support to help getting them there (Verrent, Flood and Garside 3).

Closer to home, a few Canadian documents have contained calls for arts accessibility for people with disabilities.⁴⁰ Geoff McMurchy states on behalf of Kickstart⁴¹ that “we believe strongly that everyone should have access to the arts experience. We also believe that artists with disabilities have a unique and important role to play in our society” (*Message 2*). Abbas et al address assumptions concerning access in the arts:

⁴⁰ See the following Canadian reports:
Abbas, J., et al. *Lights... Camera... Attitude!’ Introducing Disability Arts and Culture*. Ryerson RBC Institute for Disability Studies Research and Education. 2004.

<<http://www.ryerson.ca/ds/pdf/artsreport.pdf>>

Jacobsen, Rose and Alex Bulmer. *The Picasso Project: A Report From the Field of Disability Arts*. 2004. <<http://www.picassopro.org/resources.html>>

Jacobsen, Rose and Geoff McMurchy. *Focus on Disability & DEAF Arts*. 2009.

<<http://www.picassopro.org/focus.pdf>>

⁴¹ BC based disability arts organization.

Implicit in this mainstream discourse on arts and accessibility is the idea that disabled people's place in the art world (if they have a place at all) is as consumers, rather than producers of artistic work... How are disabled creators to be viewed as artists in a climate that devalues and/or pathologizes their work and frames it as treatment rather than aesthetic and/or political statement? (45).

Logistical and Multiple Impairments

Many artists with IDD also have other kinds of impairments. Strategies to address the subject of the arts and people with IDD must include some recognition of this reality. New York artist Tim Lefens received an offer from an acquaintance to share his work with a group of students at a residential institution in the area for individuals with multiple physical and intellectual disabilities. In his book, *Flying Colors*, the author describes the development of the group in detail until the culminating art show at a New York gallery. Lefens worked with students who were all in power wheelchairs and generally unable to control the movements of their bodies; many had difficulty with speech or communication. The author was very resourceful in creating techniques to allow the students total control of their mark-making. The first technique employed the wheels of their wheelchairs as drawing tools, and the second method used a tracker (helper) and a laser affixed to the side of the wheelchair headrest. By moving their heads, the artists could direct where the marks would go on the canvas to the tracker who would then paint where directed. The artist could direct and control virtually every aspect in the creation of the work, including the kind of line, color or the consistency of the paint. These techniques allowed the artists to make decisions themselves and engage in a creative choice making process (Figure 4.1).



Figure 4.1 Tim Lefens with student in studio. (September 27, 2004).
Princeton Weekly Bulletin 94.4 (2004). Photo by Jennifer Greenstein Altman.
 < <http://www.princeton.edu/pr/pwb/04/0927/7a.shtml> >

Christopher Lee details a similar strategy involving the use of laser pointers in his article “Re-Thinking Interdependence, Subjectivity, and Politics Through the Laser Eagles Art Guild”. The practices described by Lee and Lefens indicate a willingness and flexibility to adapt studio practice in such a way as to reduce barriers, promote accessibility and provide opportunity for independent self-expression.

4.1.3 Confronting Perceptions and Stereotypes

A primary barrier for people with IDD continues to be cultural stereotyping regarding generalized lower expectations (Cocks 20; Katz 8; Lakin 5). Mencap identifies stereotyping as a central barrier that prevents equal opportunity to the arts

(*Doing* 5). Common views that people with IDD are only capable of concrete thought processes and therefore best suited to repetitive and boring work still exist (Blandy, "Conceptions" 132) ; traditional standards of treatment and protocol within the field that perpetuate stereotypes have devalued and limited creative acts by persons with IDD (Stamatelos and Mott). Stereotyping also can take the form of making 'heroes' or 'overcomers' of IDD artists as well, or seeking to make individuals living with IDD purveyors of some kind of sublime truth. Kalha errs when he 'supercrips' the artists of Kirsikoti in describing their work as "a kind of miracle" produced by artists who have overcome hardships in an ennobling fashion (36). Leighton cautions against this kind of labeling of 'specialness' of people with IDD that amounts to another way of othering (101). In a lecture at a BRIAN⁴² seminar in March 2010, Catherine Frazee⁴³ noted that the media perpetuates stereotypes in their persistence to relate news stories about people with disabilities as stories of triumph and inspiration, rather than challenging commonly held notions or the examining dark history of disability.

Stereotyping can manifest in other unexpected ways; viewers can have predetermined views that frame what is acceptable in terms of what is creatively produced. Sometimes these expectations may arise from a sense of what is currently or 'politically' acceptable. Koppers discusses French theatre group Compagnie de L'Oiseau Mouche; the company consists of about twenty adults with IDD (*Disabilities* 74). One of the group's performances is titled *Labyrinthe*, a

⁴² BC Regional Integrated Arts Network. <<http://www.kickstart-arts.ca/BRIAN.html>>

⁴³ Frazee is a faculty member of at the Ryerson-RBC Institute for Disability Research and Education (Toronto) and a noted Disability Studies scholar in Canada. She has written extensively concerning Disability Art and was also co-curator of "Out From Under: Disability, History and Things to Remember", Royal Ontario Museum, 2008.

stylized dramatization based on the traditional minotaur story. The performance was professional caliber and the actors were paid, however, Kuppers reports that:

The performance put the gap of learning disability under erasure, but the gap hadn't vanished: the strong elemental images affected many powerfully, but at the same time, other voices wondered about the stereotyping of people with learning disabilities as animals, radical others, or idiot savants. (74).

The Shyster theatre group actively and purposely confronts stereotypes.

Karafistan argues that for these actors, having an IDD informs their individual creativity as would gender or ethnicity; they see themselves as developing a new language to “describe their individuality and celebrate their achievements...” (266).

However, Karafistan also states that “on the whole, actors with learning disabilities appear more able to negate their ego and as a result portray a real truth” (267).

Some would find this to be an essentialist observation; when does such a comment become stereotype?

Leighton engaged in a theatre research project with IDD adults in the UK; part of her data collection involved obtaining responses from the theatre audiences. Among the responses (both negative and positive) were comments that were stereotypical about people with IDD; audience members experienced the performance as either therapeutic and not worthy of an audience, ‘life affirming’ both in the sense of the ‘supercrip’ and the ‘count your own blessings’ variety, as well as public examples of disability to be medically diagnosed. Despite these acts of ‘othering’ by the theatergoers, Leighton still saw the performance as a success due to the immediate benefit of a positive cultural representation of people with IDD and the opportunity for people with IDD to access the institutions of theatre, and at the same time recognizing the inherent risks associated with challenging

stereotypes (109-111). This is the reality of the arts and people with IDD – the stereotypes will exist and will be confronted, alongside the benefits that accompany arts practice.

Some may argue that individuals with IDD have traditionally not exhibited creativity, thus validating stereotypical attitudes. MacGregor makes a valid point when he puts forth that despite all the years that people with IDD were made to work in institutions, they were never given any work that demanded or suggested creativity (*Metamorphosis 3*). If this had not been the case, perhaps creativity in these individuals might have emerged and been recognized at a much earlier time. Edelson states that involvement in the arts can act to dismantle stereotypes about individuals with IDD (95), and states that:

Art has an established historical and cultural value and a wealth of positive associations that can enhance and upgrade the images of individuals who are active participants in the art world. Art therefore can break through stereotypes of mental retardation... and the resulting social stigma. (92)

Borenzstein's book, *One is Adam One is Superman*, is a contemporary photographic acknowledgement of artists who have an IDD and stands as a powerful statement of identity that avoids typical photographic representations of persons with IDD 'victims' or 'supercrrips'. In the preface Borenzstein notes his desire to challenge stereotypical portrayals of people with IDD (6). As he determined his approach to the project, the photographer chose to avoid sentimentalizing or idealizing his subjects, and instead made a point of approaching the artists with professionalism. Rather than portraying his subjects in a way that would minimize their disabilities in an effort to 'dignify' them, the photographer opted instead to be "positively objective" (6). This book is unique for two reasons; firstly

that it serves as a visual document of artists with IDD, thus validating their identities as artists, and presenting the subjects in a manner unlike other similar publications. Secondly, the book stands as an example of an established contemporary artist approaching artists with IDD, negotiating representation and documenting that collaboration, thus offering a unique and rarely seen perspective.

4.1.4 Financial Factors

The majority of people living with IDD experience challenges concerning finances, both in understanding financial concepts and experiencing a lack of funds. Artists often need to contend with complicated issues of income tax, gallery fees, and the like which can be very difficult, sometimes even if support is given. Given this reality, the potential for financial abuse or mishandling is a concrete possibility and calls for protocols to be developed around compensation for artists with IDD. The commercial success of an artist like Judith Scott, whose work sold for several thousands of dollars, raises questions concerning possible exploitation (Fraser 520).

The practice of Creative Growth Art Centre (CGAC) is to give fifty percent of the sale of work to the artist and fifty percent back to CGAC. This is comparable with the practice of commercial art galleries; urban galleries keep up to sixty percent of a sale to cover their overhead expenses. CGAC would also have these kinds of operating costs as well as programming expenditures, so 50% appears to be a reasonable and fair breakdown of sale monies.

Another financial concern relates to that of governmental regulations and disability benefits. Currently in BC, individuals receiving disability benefits are not permitted to have more than \$3000 in cash assets, or earn more than \$500 per month; having funds beyond these limits leads to partial or complete loss of government benefits. A sale of art that leads to an overage of funds obviously could have very negative consequences for the artists if they are dependent on their monthly disability cheque. Such issues must be negotiated, with professional advice and with a strategy in place to ensure that the artists can benefit from their art-making commercially without disrupting their ongoing support. As discussed in Mencap's arts strategy, *Doing, Showing, and Going*, disability arts groups need to lobby for changes to income assistance programs so that vocational opportunities and goals can be realized by artists with IDD (13). Karafistan acknowledges these financial realities when she states that the actors in the Shysters theatre company were paid a minimal fee in order to avoid disruption of regular disability benefits and adds that this situation makes it difficult for some of the actors to view themselves as actual professionals because of their less than regular pay. Current government policies create a situation where an individual receiving income assistance must choose between living on a steady income at a poverty rate, or risk making more but with no safety net (274).

4.2 Benefits

Although Disability Arts as a movement has a non-therapeutic perspective, as do numerous individual disability arts groups, there nevertheless are unique benefits to

artists with IDD. It is helpful to identify these benefits in order to have a complete understanding of IDD and the visual arts. One could view these bonuses as side benefits that occur despite or alongside and notwithstanding a different intention.

4.2.1 Identity Formation

The issue of identity is an issue of critical importance in the disability world; this is particularly true for people with IDD, who are typically perceived as people with a disability in a way that eclipses all other possible identities (Lakin 4). However, as an artist with IDD develops their practice, their own 'style' and preferences become more and more apparent and their individuality becomes more evident to others as they produce work that reveals who they are (Edelson 94; Rix 3). For a person with IDD, working in the visual arts challenges the "spoiled identity" as described by Goffman by forging a different identity. Watts and Ridley state that "making music [or visual art] can play a critical part in the process of making identities and the issue becomes not how a particular piece of music or a performance reflects the people, but how it produced them" (150). As Duesenberry and MacDonald point out, "a social constructionist understanding of identity as plural allows individuals with [IDD] to be more than a 'person with a disability'"(11).

In another way, involvement and participation in an arts environment can cause individuals with IDD to view themselves as arts practitioners instead of as 'clients' or 'service consumers' as their involvement in a disability service model so often dictates (Ineland and Sauer 55). Thus, it is evident that when an arts group operates primarily as an arts practice driven organization, as opposed to having a

service model orientation, that this acts to encourage and form identity both in the sense of the individual and as a group (55).

Participating in an art exhibition has the benefit of allowing a person with IDD to claim the identity of artist or arts practitioner. Edelson argues that when a non-disabled viewer perceives individuals as skilled arts practitioners first, their identities as people with IDD become secondary (92). Lee agrees when he states that when an artist is able to express himself/herself, disability becomes only one aspect of identity (21).

4.2.2 Enhancement of Status

In an art program for individuals with IDD, an artist is treated with respect as a productive and expressive person, and their consequent self-image as an artist is emphasized (Katz 4). Edelson states that “art based activities of a high quality often have a halo effect on social acceptance and self esteem ...” (82), adding that “art has an historical and cultural value, and a wealth of positive associations... art, therefore can break through stereotypes of [IDD]... and the resulting social stigma” (92). Being an artist carries a certain cachet in our culture. Participation in artistic activities carries certain associated respect and benefits; this can act to enhance quality of life for artists with IDD as people around them perceive them differently (Blandy, “Community”- Based” 170; Boulangé 27; Cocks 20, 22). Involvement in arts groups can have the effect of raising the status of people with disabilities in the eyes of not only the public, but of their workers, which can in turn lead to improved

quality of life for their clients; this is often in direct response to choices indicated through the projects by the artists (Nash 19).

4.2.3 Increased Choice Making Opportunities

Individuals with IDD have traditionally been denied opportunities to make choices (Cavet 5; Malley, Dattilo and Gast 279; Perring, “Facilitation” 178). Decisions that other people make every day on an ongoing basis, like what to eat for breakfast or clothes to wear, for example, are not choices available to many people in this population. This lack of choice making activity has been linked to depression, lack of self-concept (or self-determination), stress and even mental illness for people with IDD (Malley et al 279). Choice making and self-determination lead to empowerment; research has shown that the more choice making activity is available, the greater the individual’s eagerness to participate in meaningful experiences (Wall and Dattilo 276).

The visual arts naturally facilitate choice making (Boulangé 27; Perring “Making” 81). Facilitators and instructors of the arts can help by creating option rich environments that allow the participants freedom to make choices in the art studio (Timmerman 115; Wall and Dattilo 290). Cheryl Daye of the APA Studio workshop program reports that facilitators work at supporting the artists to develop the quality of their work by providing a wide range of choices (“Studio” 12). Exercising choice making within the art-making environment gives participants a chance to exercise a degree of empowerment and independence.

4.2.4 Increased Opportunity for Personal Expression

As with choice making, opportunities for personal expression have historically been very limited for people with IDD (Malley, Dattilo and Gast 279); people with IDD have generally had to depend on others to tell their stories for them. The benefits of personal expression to this population have been linked to improvements in mental health (Mencap 3; Malley et al 279). This is not an unimportant matter as the estimated percentage of people with IDD who also have an issue with mental health is 38%, approximately double that of the rate for the general population.⁴⁴

The visual arts can facilitate a direct connection between people with IDD and non-disabled people (Cocks 20). Daye states that “for artists with an intellectual disability, art is not about producing pleasurable illusions in the tradition of Western realism – it is an essential tool in representing their experience and their responses to the world” (*Inner* iv). Visual art, like all the arts, has the potential to express feelings without language; for artists with IDD who are non-verbal or struggle with communication, art making is a way to express feelings in a non-verbal medium (Perring, “Making” 69; Timmerman 117). As an intuitive process, visual art offers an alternative form of communication, the importance of which cannot be overstated for people with diminished ability to express themselves (Daye, “Introduction” 6). Visual art is also a way for the non-disabled to gain direct insight into the lived experience of people with IDD particularly when communication is limited; “art conceived and made by disabled artists [IDD] reveals, reflects, and expresses disabled subjectivity” (Perring, “Facilitation” 187). In such cases, the artist’s work acts as “a kind of visual

⁴⁴ Statistic from “Dual Diagnosis Factsheet” prepared by National Coalition on Dual Diagnosis, Toronto (2008). < <http://care-id.com/images/File/Factsheet.pdf>>

equivalent and narrative of mental life: experience, imagination and desires” (Rhodes 28).

Founder of the California based art centres for artists with IDD, Creative Growth Art Centre (CGAC) and the National Institute of Art and Disabilities (NIAD), Elias Katz states that it is important for art centres to both meet the needs of participants to express themselves, and have a philosophy that includes the belief that creativity lies within the individual and must be expressed for well-being and growth (“Art Centres” 1). Timmerman agrees and emphasizes that individuals with IDD must be “able to express themselves in complete freedom, that they can determine their own processes, and are given the time, means and space to do so” (115).

4.2.6 Art Practice as Vocation

The opportunity to engage in meaningful work is yet another experience that eludes many people with IDD; finding a suitable work placement is often very difficult for a variety of reasons. In his paper, “The Work Of (Creating) Art”, Benjamin Fraser uses the case of artist Judith Scott and the art centre Scott worked at (Creative Growth Art Centre) to examine artistic creation as work in a socioeconomic context. Judith Scott’s successful career as an artist was not typical; as a case study, however, it does call for the inclusion of ‘artist’ in the list of potential vocations for people with IDD, which is good news given that statistically for this population, unemployment rates can be as high as 80% (Fraser 515).

Many art programs in Canada rely on regular government funding by providing studio classes or workshops as career or vocational training. In such situations,

rather than provide an arts program to a wider group from the community, employment training is provided to a small number of registrants who concentrate on working towards professional status. One of the goals of APA is to “advocate art as a valid vocational option for people with an intellectual disability” (Daye, “Studio” 11).

Work has other benefits; many people with IDD live lives that are quite passive (Cavet 5); involvement in the arts may be a way out of such passivity, allowing them to discover new ways of communicating lived experience. (Nash 199). Individuals who do not experience the degree of recognition and commercial success that Judith Scott did will likely still experience the sense of productivity or meaningful work when fully engaged in art making practice. With the importance of ‘work’ comes a sense of identity as ‘a worker’ and an opportunity to claim the identity of a worker. Art as work offers the benefit or provision of an environment where the individual with IDD can experience a high degree of self-determination (Fraser 518).

Artists with IDD face unique challenges and barriers that necessitate either support or advocacy. Challenges can be within the areas of access, stereotypical beliefs or studio intervention, financial concerns or the logistics of multiple impairments. As well, it must be acknowledged that involvement in the visual arts offers benefits to artists with IDD that go beyond the bonuses enjoyed by nondisabled artists. Artists with IDD will experience more opportunity for personal expression and development of identity, increased choice making opportunities, as well as possible enhancement of status and vocational options. An understanding of both the particular challenges and benefits affecting artists with IDD provides a

richer contextual understanding of how to both situate and advocate for artists with intellectual disabilities.

5 COOL ARTS SOCIETY AND “WE ARE ARTISTS”

5.1 Cool Arts

5.1.1 History

There were two personal experiences that resulted in the founding of Cool Arts Society. The first involved my son Jordan, who has enjoyed art-making since an early age. His intellectual disability is diagnosed to be in the ‘mild’ range; this has not deterred him from filling countless sketchbooks and unrelentingly covering every inch of wall in his room with collages that he has determined must be replaced every two months. Jordan’s high school art teacher nurtured this aptitude and ‘commissioned’ a painting (48”x 48”) that developed into a fantastical narrative work involving a dragon, mountains, night sky and an endangered village. The piece was compositionally sound, full of active energy and provided the genesis for an ongoing personal visual vocabulary that Jordan still draws on fifteen years later. I owe a personal debt to teacher Harry Tonn for helping me to realize what Jordan was creatively capable of. After high school, Jordan attended a ‘special-needs adult’ program at the local college; one of the courses was a creativity class, which he enjoyed immensely. However, his participation in this course could not go on indefinitely, so I began to look for opportunities in our local community that would enable him to further engage with art making.

The second catalyst for the inception of Cool Arts was my exposure to Vancouver based group *Kickstart*, previously named *Society for Disability Arts and Culture*. In 2001, I helped Jordan assemble a submission package for a disability arts exhibition. He was accepted into the show, and the subsequent exhibition was

an eye-opener for me; represented there were many BC artists with varying disabilities working in dance, music and visual arts. Once I became aware of the concept of arts accessibility and disability celebration and observed what existed so close to home, I also saw the potential for developing something similar in our own community. It seemed that this was what the arts was really about – personal expression for everyone.

Our local recreation centre offered many ‘adapted’ courses, including ‘arts and crafts’, which, although enjoyed by many, existed to fulfill social and recreational needs rather than to facilitate artistic expression. Projects in these programs tended to be formula driven and offered little opportunity for personal expression or choice making and although often worthy in other ways, could be seen as a negative influence in regards to expectations and beliefs concerning IDD and visual arts (Edelson 83). Jordan enrolled in a painting class at our local public art gallery. Although the instructor was supportive, the level of instruction and technical information given in the course was too difficult and taught at a pace that was too fast for Jordan to benefit from. In addition, at a fee of over one hundred dollars, the course was too expensive to be accessible for someone living on disability benefits unless receiving other assistance.

It became apparent that there was a need in our community for some kind of accessible arts program that offered opportunities for adults with IDD after they finished the adaptive college program (if they attended the college program at all), and was accessible in terms of instruction, cost, and location. It seemed to me that this was blatantly unfair; people with IDD should have the choice to develop their

interest and skills in the fine arts and have access to the resources that will support them to do this, as do other members of the community (Daye, *Studio 13*).

In 2003, I began to discuss this idea with a few of my artist friends, as well as some other individuals supportive of the arts and/or disability and determined that there was enough support to organize a group that could offer such opportunities on a rudimentary level. After a few brainstorming sessions, the first workshop took place in October 2003. The name, Cool Arts, was chosen from a number of suggestions at one of the meetings, and was a proposal from one of the self-advocates in attendance. Non-profit status as a provincial society was established in 2004, and status as a registered Canadian Charity was obtained in 2005.

Initially there were very few guidelines or rules. It was always assumed that CA would be open to anyone who received services from Community Living British Columbia (CLBC), thereby establishing their status as a person with IDD. The only stipulation was that if a participant needed to have someone with them for support, that they must provide either a worker, friend or family member to accompany them to CA, as provision of support workers was beyond the scope of the group. Images showing the evolution of the Cool Arts group can be seen on the group website <<http://www.coolarts.ca/>> and blog <<http://www.coolartssociety.blogspot.com/>>.

5.1.2 Philosophy and Mandate

CA is an independent, grass-roots organization - we had no overreaching framework or ideological concepts that could act as parameters or guidelines. The

other arts groups I knew of were part of a local Association of Community Living (ACL) or a similar kind of disability oriented group; I knew of no disability arts groups for people with IDD that were part of larger arts-oriented organizations. Establishing a mandate and philosophy for our group seemed daunting simply because I did not know of any other similar organizations to learn from. There were no local experts that I could call on for advice on how to set up such a organization.

I started to look online at what other groups in various parts of the world were citing as their mandate and guidelines. Most of these organizations seemed to be full-time Monday to Friday operations and received regular government funding to deliver vocational services. Operating in this way ensured ongoing funding to provide programming for clients of whatever ministry or government agency in that region delivered services to individuals with IDD. The information gleaned from these groups was very helpful and also served to demonstrate to me how varied and widespread disability arts was in regards to people with IDD. The groups that were particularly good examples of an arts-driven agenda were Creative Growth Centre in Oakland (CGC), Project Ability in Glasgow (PA) and Arts Project Australia (APA).⁴⁵ Borrowing concepts and ideas from some of these groups helped to ground CA within a wider context and also ensured that certain aspects of the group were articulated.

I determined that CA would have an educative, rather than therapeutic approach (Daye, "Studio" 11) after reading about the other groups and realizing the difference between the two perspectives; this was not obvious to me at first because I was

⁴⁵ See Appendix C for list of Disability Arts Groups

really only familiar with the medical model. There was a learning curve as far as gently educating directors and volunteers. It became apparent that funding requests needed to be framed in a way that placed focus on opportunity and access, yet tactfully accommodated the funder's wish to 'help' the individuals with IDD from a medical model context, thus relating to Ineland's discussions concerning the tensions of maintaining an artistic logic as well as a rehabilitative logic. The intent, then, was based on understanding that the experience CA offered was one of access and equity, as well as providing an alternative to existing art programs that typically followed either an 'arts and crafts' or therapeutic bent. (Daye, "Studio" 11). In short, the philosophy of Cool Arts was to offer Fine Arts opportunities to adults with IDD⁴⁶ by providing good materials, an accessible location, and competent instruction at a low cost.

Cool Arts has considered adapting the goals of APA as put forward by Daye, which are to provide the means by which people with IDD "can participate fully in the visual arts", to promote artwork by people with IDD "as integral to the broad spectrum of contemporary art practice", "to broaden understanding and awareness of art by people with intellectual disability amongst other artists and the general public" and "to advocate art as a valid vocational option for people with an intellectual disability" ("Studio" 11). In addition to these stated goals, the Studio Workshop Program at APA has established specific goals to "develop artistic skills and awareness", "encourage the development of personal symbols and expression", "promote artistic independence through the provision of a supportive environment, which in turn can lead to greater opportunities for integration" or

⁴⁶ Grade 12 or age 18 and over.

inclusion, “encourage meaningful artistic exchange between artists with or without a disability” and to “facilitate participation in mainstream courses and exhibition and interaction with the wider community” (11).

The initial planning group determined that CA needed to feel welcoming, supportive and safe, as well as respectful to the participants; a basis of respect is a quality cited as being important for other arts groups (Daye, “Introduction” 5). The emphasis would be on access and opportunity, although teaching techniques would necessarily be a part of the studio activity, but not a central goal in itself (Kaitavuori 20). We saw ourselves as facilitators and assistants that could provide support and encouragement where needed, while at the same time working to provide a sense of creative freedom for the artists to express themselves in the studio without having to follow a prescribed routine or formula (Bridie 7). In regards to the studio practice, the basic idea was to ‘interfere’ or ‘influence’ as little as possible and to encourage the artists to make their own choices and do their own work.

A matter established at the onset was that of professional level artists and art teachers as workshop facilitators; this is what would set CA apart from arts and crafts classes and day program activities. I believe that this is a critical factor in ensuring that the work produced in the workshops will be of the highest level possible (Edelson 85). This policy of using professionals to teach the workshops is endorsed by many established disability arts centres serving people with IDD as a way to ensure the quality of the student’s work (Daye, “Studio” 11; Gibson; Kaitavuori 23).

Initially I was unsure about whether CA instructors needed some special training to work with adults with IDD. My own experience with this population had mainly been with individuals who are described as ‘high functioning’, and I felt apprehensive about whether some of the artists would have needs or present situations that we would not know how to approach or negotiate. I worried about our lack of disability training and the possibility of CA volunteers doing something ‘wrong’ according to what I assumed was established protocol of how to work with people with IDD. In short, I was quite anxious that CA do things correctly. In time, however, after searching out counsel and observing the workshops, I realized that no one else, including the caregivers, was concerned about such things. Our policy required that individuals needing support had to bring an attendant (worker, friend or family) with them to a workshop; this ensured that artists with (non-art) needs would have those needs addressed by their companions. Luc Boulangé, founder of the CREAHM art centre in Belgium,⁴⁷ states that “instructors do not need to have specialized training in teaching individuals with IDD, what they need to be able to do is organize, facilitate and inspire the participants to express themselves through art” (26).

Our philosophy in the studio has developed over time. In the first few years, there were a variety of volunteer instructors and their individual attitudes towards intervention and influencing the participants generally adhered to the theme of working independently, although some kept to this concept more than others. In recent years this aspect has been more consistent. Our intent is to help the artists bring the work to completion. Some of the CA artists can be quick to announce that

⁴⁷ CREAHM – Créativité et Handicap Mental

their work is finished after a short period of time; the work may indeed be finished, but at other times, the work may call for more time and attention before it can legitimately be considered completed. Some of this is simply inexperience in art making; I recall my own studio instructors in art school telling other students or myself that our work was not finished regardless of our opinions on the matter.

Accessibility

The issue of accessibility has involved a number of factors. It was determined quickly that the cost of the workshops would be very minimal; on occasion the fee was waived when a participant said that they did not have the funds. The director of the local ACL heard of our plans and immediately offered their facility as a location for weekend workshops at no charge. Although materials could not be stored there, the location was otherwise very good, with wheelchair accessibility, 'handicap' parking and a multipurpose room close to a sink/cleanup area. Another excellent feature to this location was that it was very central in our city and close to bus routes; accessibility of location is a central issue for people with IDD (Verrent, Flood and Garside 5).

Accessibility also means pacing activities so that participants do not feel overly stressed or anxious about being able to complete their work. In general, activities in art centres for this population proceed at a slower pace than in typical art workshops (Kaitavuori 18; Puhakka 15). Participants might often arrive late, and often for reasons out of their control. Some participants were extremely hesitant and fearful about making a decision or a mark on a paper. Therefore, in order to ensure

that the environment was as welcoming and stress-free as possible, a relaxed pace was set with a plan in place for those who completed projects more quickly.

5.1.3 Slow But Steady Progress

CA has developed at a stately pace. The group is now receiving annual funding from the city as well as provincial gaming monies, however, these annual funds are applied for on an annual basis and never guaranteed. The past couple of years have seen new sources of funding emerge, from special project grants, fundraising events, and private donations. The newest program is an 'advanced class' for the most committed participants who are ready to work on longer-term projects. There are now also a minimum of two regular Saturday workshops per month. The directors and contract staff modify and evaluate the programming and practice on an ongoing basis in regards to workshop activities, role of volunteers, choice of projects, and so on (Daye, "Studio" 11).

The nature of intellectual disability is such that the process of artistic development is often lengthy. Many participants have difficulty in understanding complex verbal instructions or abstract concepts, so the teaching methodology within the classes tends to concentrate on the concrete and the specific. IDD manifests in a variety of ways depending on the severity or nature of the disability; for this reason, after the initial group instruction most of the teaching occurs on an individual basis (Daye, "Studio"12). The intent of the studio practice is that the artists are enabled to "explore and develop to their fullest artistic potential" (11). An ongoing goal is to help the artists to develop the ability to critique their own work as

well as the work of others. The artwork produced at CA is necessarily of varying caliber and exhibits a broad range of style and choice of medium. What I have seen happen over a period of time with the artists who participate on a regular basis is the evolution of a personal style and unique visual vocabulary.

For the first few years, CA held workshops on Saturdays, and then gradually introduced some mid-week daytime classes. This necessitated finding another workspace, and for the first few years, CA did not have the resources to pay any fees for room rental. After approaching the local museum and public art gallery, shorter activities for CA were included as collaborative educational programming, thus enabling CA to offer mid-week classes to individuals not able to attend on Saturday. This also benefited the institutions by giving them opportunity to lay claim to serving a more diverse population to their own funders. CA now offers regular midweek programming in a rented classroom.

Individuals attending day programs appear to be more likely to attend a shorter CA session during the week as organized by their day program. For some reason, these individuals are usually not able to access the weekend activities; my conclusion has been that their caregivers either cannot or choose not to transport or accompany them (if needed) to a Saturday workshop. This would seem to indicate that there is a population of people in day programs that can only access arts activities either at their day program or somewhere else as organized by their day programs. In the future, CA would like to both assess and develop programming to address this need.

An ongoing challenge is the access CA has to the local population living with IDD. CA is largely dependent on 'word of mouth' to ensure that potential participants, their caregivers and support networks are aware of CA and what the group offers (Verrent, Flood and Garside 4). For reasons concerning confidentiality, there are no lists or databases that CA can access in order to target information. There are many individuals with IDD who are fairly isolated within the community; CA is dependent on social workers, other professionals, friends and family to pass along information and organize support if needed.

For the past five years, CA has participated in a large annual community art fair; the group has a booth to display and sell their work and talk to the public. This has been an overwhelmingly positive experience for the artists who participate; for many of them, selling their artwork is the first time they have earned income. The process of selling work to someone in the community has also provided the artists with an opportunity to interact with the greater community (Edelson 94). Involvement with this art fair, as well as various other community events, has allowed CA to maintain a public profile and increase awareness about the group.

I have observed how the CA artists easily claim the identity of artist, perhaps aided by their enthusiasm to embrace an identity other than that of a disabled person. As discussed by Dusenberry and MacDonald, this identity is made available and publicly recognized through participation in exhibitions and art fairs (11). As time has passed, CA has begun to assume a group identity; the organization is becoming known locally and the artists understand CA as an arts group that exhibits and sells work. Without exception, all of the artists who have been coming for over a

year or so see themselves as artists; in this way, CA is working to provide these participants with a positive identity other than being a person with a disability (Watts and Ridley 151).

One minor challenge has been negativity from proponents of normalization, who see disability-oriented groups as anti-inclusionist. Initially I struggled with this aspect myself. Jordan began public school during the 1980s in a newly integrated system instigated by normalization principles and I was appreciative of that. However, I began to realize that while normalization had played a critical role in deinstitutionalization and school integration, a more contemporary ideology allowing for personal expression and group identity had emerged. One of the chief arguments against the normalization perspective as applied to the art making setting is that such a setting would prevent or negate the opportunity of a natural evolution of the establishment of a group identity. As Casling asserts, the arts can play a central role as minority and marginalized groups create a unique discourse for themselves. Group identity brings the kind of power and authority that one individual living with IDD would be unlikely to possess.

At this point in time I can report that CA has a solid reputation as a stable non-profit with a history free of turmoil. The group can now point to various project grants as proof of its viability as a legitimate arts group. A half-time facilitator now works on a contract basis for CA teaching, planning and looking after administrative details. This has been very successful and marks an evolution from an almost entirely volunteer operated organization to one that is able to employ a trained worker albeit on a part time basis. However, until CA has the use of a facility during

the mid-week, there will continue to be restrictions concerning programming; the benefits of a more regular studio practice will not be available to the CA artists until this occurs.

5.2 “We Are Artists” Exhibition

5.2.1 Concept and Planning

In 2007, the Education Director from the local public art gallery and I began to discuss the possibility of mounting an exhibition of work by Cool Arts artists; this collaborative effort was to be built on an existing relationship between CA and the Kelowna Art Gallery. The space to be used for the exhibition was the ‘community’ space, a window filled area that faced to the street and sidewalk. The area was also used for the school education program and event rental; planning the installation would have to provide adequate open space to accommodate this as well as the need to move temporary walls to accommodate events.

These conditions are obviously not ideal for an art exhibition. However, I already knew that the likelihood of the gallery opening up the curated exhibition galleries was virtually nil. Previous discussion with the curator to pose such a future eventuality earned no response whatsoever. Furthermore, I could not cite any other Canadian public gallery exhibiting work by an artist(s) living with IDD. The only possible gambit that might possibly persuade curators to consider such an undertaking might be to propose an exhibition of ‘Outsider Art’, in which artists with IDD were part of a wider body of work, however, I had no interest in pursuing such a project. There was clearly no interest in disability arts or artists with IDD as

legitimate artists to be considered for gallery exhibitions. Consequently, the 'community' space became the exhibition site.

The predominant themes addressed in the planning phase of this project were accessibility, public awareness and recognition of the CA exhibitors as legitimate artists. The issue of accessibility included the obvious features of wheelchair accessibility and 'handicap' parking (both of which existed), as well as any associated costs for both artists and gallery visitors, and access of information. Any published material and gallery signage had to be in 'Plain Language'. In regards to people with IDD and signage or published materials in galleries/museums that use non-inclusive language, Earnscliffe states that "access to information is not just a matter of choice on the part of service providers, but a matter of civil rights for those people denied choice, opportunity and involvement" (16). It was decided that the artists would receive CARFAC fees,⁴⁸ as do other artists exhibiting in public galleries.

I spent some time mulling over possible themes for the exhibition, and the concept that I kept coming back to was identity. This was to be an extraordinary opportunity for these artists (and their supporters) to present themselves as artists to the community, and for the community to embrace that identity. Although I considered a number of possible titles for the exhibition, I settled on a straightforward and uncompromising statement of identity – "We Are Artists". As curator for the exhibition, I had to decide which artists would be selected to exhibit

⁴⁸ Canadian Artists Representation/Le Front des arts canadiens (CARFAC) is the national voice of Canadian professional visual artists. CARFAC issues a fee schedule of what are considered minimum payments for the use of the copyrights and /or the professional services of visual and media artists.

<<http://www.carfac.ca/>>

their work in the show. To select work on the basis of critical examination as a jury might, seemed to me to not be in the spirit of the exhibition. This was to be a celebration of arts access and artists with disabilities. This was problematic in some sense, because the majority of artists with IDD depend on their caregivers or others to organize and manage their transportation and scheduling that allows them to attend CA. Nevertheless, a major theme of the exhibition was equal opportunity in the arts; accordingly I felt that the most important thing to consider in selecting the individuals was his or her desire to be an artist.

A thirteenth member was added to the group; a man who often attended CA mid-week sessions, but was not able to attend the Saturday workshops. Pat Easley spent a great deal of time drawing, and it was apparent that producing art was integral to his identity. I wanted to include him in the exhibition just by virtue of his dedication to art practice; his unique vision results in highly idiosyncratic and fantastical drawings that are very strong works.

The intent was for the artists to show work that revealed their unique voices; it was important to show that they had individual identities and that their shared disability did not extend to form a homogenous identity. The artists in the exhibition had been coming to CA for some time, and had developed their own unique expressive styles. As Puhakkla notes, “the only thing the artists have in common is the fact that they are intellectually disabled” (15), and within in that commonality is a wide scope of dissemblance.

Early on, it was decided to publish an exhibition catalogue, which is standard practice for exhibitions in public art institutions. This publication would be a

permanent document of the exhibition and contain information about the individual artists, CA and the wider scope of disability arts. Most of the exhibition catalogues from other disability arts groups I had seen were published by the arts group themselves; a catalogue published by a publicly funded arts institution carries considerably more weight and prestige. The gallery was also part of a distribution program that ensured that their publications were sent to public galleries all over the country; the WAA catalogue would be included in this mail out. The catalogue was thus a critical component of the project, especially concerning the dissemination of information and knowledge translation. The Education Director and I agreed to collaboratively fundraise to ensure that the catalogue costs would be covered. In addition to the catalogue, I hoped to be able to produce some short videos that would contain interviews with the exhibition artists and some clips of workshop activity. An opening event was planned, as well as a discussion panel that would occur the following day.

I indicated that I would like to have a training session for the staff and docents concerning disability awareness, possibly facilitated by a local self-advocate, in the hopes that doing so would work to avoid misinformation and perceptions informed by the medical model of disability. I also believed that some of the staff and docents might be feel more comfortable with having this kind of information (Verrent, Flood and Garside 7, 12), although unfortunately this awareness training did not take place.

5.2.2 The Exhibition

Twelve self-portrait installations formed the central part of the exhibition. Each installation consisted of a canvas (22" x 28"), a chair and a pair of shoes. All the second-hand chairs were donated by a local business, as well as a used wheelchair for the artist that uses a wheelchair. The size of the canvasses represented a larger scale than the artists had previously worked on; they were accustomed to one-day projects whereas these pieces were worked on over a period of several months. The installations were placed around the exhibition area so that all backed onto either a permanent or temporary wall. Each canvas was hung on the wall at standard hanging height with the chair placed below it and the shoes on the floor. Each artist was asked what kind of shoes they wanted to paint, and the instructor then searched local thrift stores to meet their requirements for the type and size of shoe. One artist requested "princess shoes", some wanted sandals, and others



Figure 5.1 "We Are Artists" exhibition installation. Kelowna Art Gallery. November 2010. Photo by Sara Lige.

wanted hiking boots or athletic shoes. Each artist painted the canvas, chair and shoes as they wished in ways that described or shared something about themselves. It was explained to the artists that these works did not have to be self-portraits in the traditional sense, but could be about them, their lived experience and their way of perceiving the world.

The resulting work revealed a diversification of content and style, as well as a broad range of imagery. Some of the artists drew on their own rich and established image banks, just as some returned to favorite palettes of colors. Some used



Figure 5.2 Annaliis Autio "Self Portrait" installation. Photo by Sara Lige.



Figure 5.3 Scott Gould "Self Portrait" installation. Photo by Sara Lige.

imagery from interior worlds, while others drew from the world outside. Some works were completed with paint alone, and others revealed a variety of media.

Composition ranged from static and geometric to organic or chaotic. Some of the artists used collage to demonstrate their identification with pop culture. Some used only paint and others used paint and collage; some used sparkles, or buttons or ribbons. The choice of palette varied from soft pastels to bold and contrasting. The body of work showed a process of appropriation, incorporation and synthesis.

Although I was very aware of each artist's way of working and personal style, I was still surprised by the individuality shown. I had been a little concerned that given the identical components in each installation, that there might be a 'sameness' in the assembled group of installations. However, each installation was immediately recognizable as being made by a particular artist. As discussed by Gibson in relation to Project Ability, each artist retained a unique vision and style and thus did not indicate that they had been overly influenced by other's work.⁴⁹

An adjacent area was also used for the exhibition and featured the work of other artists from a local day program (Premium Productions) that often either brought art teachers into their facility or attended Cool Arts or KAG activities. One of the day program attendees was one of the thirteen artists featured in the main area.

The exhibition opening was overwhelmingly successful. The gallery reported that it was one of the best-attended openings in their history with over three hundred people in attendance. Local politicians attended the event, including the mayor, who made a short speech. The disability community and the larger arts community were

⁴⁹ See Chapter 6 discussion concerning heterogeneity as applied to artists with IDD (6.4.3 & 6.4.3).

well represented, as were the artists themselves, and all had many family members and friends present. Before the opening, I put in a call to the local TV station, and a filming crew and local TV host arrived. A short segment with a number of short interviews was consequently aired which further advertised the exhibition. The opening and the exhibition received media attention in the local newspapers and CBC Radio. Ineland makes an important point regarding the news media; he says that the media is an important factor as far as [a disability arts] group gaining legitimacy; “by employing a cultural rhetoric, the media represent institutional rules held by broader audiences and public opinion” and the group is thus empowered to make stronger demands in relation to administration by the institution (“Logics” 756). The recognition of the media served to affirm and encourage the artists of Cool Arts as well as help to reinforce the group’s artistic identity and legitimacy.

The following day a panel discussion was held at the gallery. Beside myself, the panel members were an art historian, a disability arts activist from Vancouver, one of the CA Artists and an academic who served as moderator. The panel was fairly well attended and videotaped.

5.2.3 After the Gallery

The total number of gallery visitors who viewed the exhibition over a four-month period was over 7300. After the de-installation of the WAA show in March 2010, the work was requested for exhibition at local venues. The locations did not always accommodate the chairs and shoes for reasons of either space or security; the canvasses were the mainstay works. In October 2010, the WAA work was

transported to Whistler, BC to be exhibited at the national conference for the Canadian Association of Community Living.⁵⁰ The catalogue continues to be a source of dissemination. Sending the document to international disability groups has resulted in images from the catalogue being shown on the Mencap ArtSpider website.⁵¹ The catalogue is now in the UBC Library system.⁵² I believe that the document will be an enduring source of information concerning visual arts and adults with IDD.



Figure 5.4 “We Are Artists” exhibition catalogue. Pages 20-21.

⁵⁰ This event was also the annual conference for the BC Association of Community Living and the Family Support Institute.

⁵¹ ArtSpider website - <http://www.artspider.org.uk/>

⁵² Call # N8355.W4 2009 (multiple holdings)

In March 2010, I was asked to present information about the WAA exhibition and CA to the BC Regional Integrated Arts Network (BRIAN) in Vancouver; this event was part of the cultural initiative funded by the 2010 Olympic/Paralympics. In June 2010, art historian Carolyn MacHardy and I presented a paper about the exhibition at the Canadian Disability Studies Conference at Concordia University in Montreal.

5.2.4 Evaluation, Reflection and Recommendations

The overwhelmingly positive response at the exhibition opening was very encouraging to the artists who were in the show as well as the other CA artists. Public recognition of the artists and their work resulted in the artists seeing themselves definitively as visual artists. However, for individuals familiar with the Canadian public gallery system, positive response to the exhibition may have been tempered by connotations associated with exhibitions situated in the community space of the gallery.

The curator of a public gallery oversees the selection and installation of exhibitions in designated gallery spaces, thereby endorsing the work as legitimate and worthy. The exhibition of work in the designated 'community' or 'public education' space, which is an area dedicated to installations not curated by the gallery curator. This suggests that while the work is worthy of the 'community space', the caliber of the work does not render it acceptable for the 'real gallery', although there are exceptions to this. This is how people familiar with galleries might read this placement, whether they agree or disagree with it in principle. While celebrating the institution's efforts to educate and empower the artists, this

containment of artists with IDD and their work within the confines of community art can serve to continue to reinforce popular stereotypes about people with IDD and inherent power relations. Instead of relegating work by artists with IDD to the community art space or public education, curators could choose to bring this work into focus within the parameters of contemporary art and consequently make a strong comment on “the borderlines, hierarchies and preconceptions of art (and thereby of our society)” (Kalha 33). Whether or not the WAA work should have been placed in the community space or in a curated gallery is not at issue; on the contrary, the point is that such a possibility was simply not an option by virtue of the artists identities.

The exhibition catalogue included an essay by myself, an interview between art historian Carolyn MacHardy and myself, a glossary and two pages for each artist; all text was in plain language. The production of the catalogue, however, was subject to intervention by the gallery director. Although the gallery director was ostensibly supportive of the project, her lack of understanding regarding disability, and in particular, IDD was apparent. Her suggestion that printing the catalogue after the exhibition opening would allow for photos of the artists “having a good time at the opening” was astonishing. In my perusal of many exhibition catalogues, I have yet to see any such images, unless perhaps of an archival nature. Deleting the glossary was also suggested, which was quickly rejected by myself, as well as having a group photo of all the artists on the catalogue cover -again, I can think of no precedent for this. The theme of the exhibition, in the gallery director’s understanding, was the collaboration between the gallery and CA; conversely, I

maintained that the theme of the exhibition was artists with IDD and their work. My insistence on having the catalogue ready for the opening, which is standard gallery practice, and which would greatly enhance the goal of accessible information and dissemination, prevailed, but not without a great deal of frustration. Although the director was positive after the event, and very pleased about the attendance at the opening, the gallery curator, who edited the catalogue, chose to remain neutral. No comments whatsoever concerning the exhibition, the opening, discussion panel or the catalogue were offered; I could not help but interpret this as a choice on her part to remain detached from the concept of the project.

I believe the project was successful in creating awareness around intellectual disabilities, disability arts and equal access to the arts. The opening in particular was very effective as far as creating public consciousness; the profile of disability arts was increased in both the arts community and the disability community. The WAA exhibition provided a tangible example for the debate about the nature of creativity and intellectual disability by challenging stereotypical and ableist notions about the creative potential of people living with an IDD, as well as conventional gallery practice (Daye, "Introduction" 6).

Given some of the challenges faced in mounting the *We Are Artists* exhibition, CA will continue to explore other venues for exhibitions. At the same time, CA will also continue to advocate for equal inclusion in public art galleries for artists producing strong work, because of the legitimacy that public art galleries confer.⁵³ For future projects at public galleries, it is recommended that staff and docents

⁵³ It should be noted that some individuals and disability groups believe that Disability Arts should remain separate from the recognized public gallery structure and that to become associated with that established system is to give credence to the hegemonic concept of 'normal'.

attend a session in disability awareness, and that these sessions be taught by self – advocates, if possible.

I recommend that Canadian cultural institutions each be required to develop a disability equality scheme similar to what is required by law in the UK, with an attendant action plan. These initiatives should address access and education, but must also concern the inclusion of disabled artists within gallery exhibitions or in other words, full equality. In her article “Reciprocity, Accountability, Empowerment: Emancipatory Principles and Practices in the Museum”, Heather Hollins states:

Factors such as the need for staff training and the limited availability of resources for the implementation of access improvements might frequently be cited as barriers which continue to prevent museums from moving forward, but a more fundamental issue lies behind the slow progress most museums have made. The development of a holistically inclusive museum require that thinking behind the scenes gives priority to disability access and representation through a fundamental rethink of organizational practice and behaviour – a process which results in ensuring access not simply to museum buildings but to the process of decision making which shapes the museum’s services and facilities (235).

Hollins goes on to identify four stages that cultural institutions progress through before becoming truly inclusive museums. The first stage describes the museum staff as decision makers regarding issues of access, the second stage moves to “access to consultation” with disabled people, and the third stage is “access to discourse”, whereby a longer term consultation is developed between the museum and disabled people, although power remains with the museum. The fourth and final stage is “access to decision making”, which allows for collaboration concerning policy and practice and demonstrates shared authority (236-237).

An online search indicated that up until the present time, no artists living with an IDD have exhibited their work in a curated gallery within a Canadian public art

gallery.⁵⁴ I had hoped that a work by artist Jane Cameron might be included in a gallery collection. It is certainly possible I missed locating existing information in my search; however, it should be noted that no such examples surfaced during the time I researched this thesis project.

5.3 Connection to Thesis

Although the WAA exhibition was held before my thesis was completed, it served to act as an ‘embedded’ project that supports my thesis. In the long term, the WAA exhibition served as the dissemination component of my thesis project. While written theses are available on academic databases, in accordance with my orientation to emancipatory qualitative research and advocacy, dissemination is a priority in order to effect change concerning hegemonic attitudes towards people with IDD, both within the arts community and without. Therefore, the WAA exhibition can be seen as a kind of knowledge translation that acts to support the thesis, and although not formal qualitative research, is congruent with an emancipatory philosophy.

⁵⁴ I am referring to public art galleries over a certain size.

6 QUALITATIVE RESEARCH

Within an otherwise humanities oriented thesis project, I have embedded a qualitative research component with participants who are artists with IDD as a way to support my literary research and consequent findings. All of the research has been motivated by an ethical commitment to the subject and a desire to conduct research that is emancipatory in nature; this supports the notion of research that not only provides a description of lived experience of people with IDD, but contains accounts by those individuals themselves and therefore challenges existing research practice and societal power structures. This qualitative research does not exist as a separate project, but serves to complement the larger Humanities positioned work. Asserting that there is a 'gap' in the literature in this subject, my aim is to add to the knowledge base and to empower artists with IDD by documenting and, therefore, validating their artistic processes. In this chapter, methodologies refer to the theoretical underpinnings or framework that directs research, and methods refers to specific strategies or techniques for data collection (Mercer 242). Research consisted of a qualitative case study of three artists from Cool Arts Society (CA) with an emphasis on individual experience.

It should be noted that the primary texts for designing my research plan are Denzin and Lincoln, Oliver ("Changing") and Mercer. I situate myself as a non-disabled researcher, a family member of a person with IDD, founder and president of CA, and someone in a continuing relationship with the participants in that group. I believe I qualify as having 'insider' status, and as an 'insider', I have initiated the desire for empowerment (Oliver, "Changing" 111). As noted by Walmsley, most

people with IDD need advocates to conduct research with or for them (198). This project was guided by an emancipatory framework that is informed by Critical Theory (Mercer; Oliver, “Changing”) and Feminism (Crow; Oleson). My theoretical positioning informs my desire to place the experience and words of the participants as central to research and is commensurate with my commitment to social change and empowerment. I conducted this qualitative research with a vulnerable population, therefore my ‘fine arts’ question has been answered within a ‘social science’ context utilizing established social science strategies in regards to research and ethics. Research concerning people with IDD appears to be generally positioned within the social sciences or health sciences; hopefully there will come a time when this group of people will not be segregated as such within research practice.

6.1 Research Question

The research question for this portion of my thesis is “what is the experience of artists living with IDD in the context of their art-making practice, and how does this experience act to help establish that artists with IDD can have an authentic art-making practice?” It is of critical importance to note that the ‘text’ in this project is not the end product or artwork, but, rather, is the actual art-making process or experience engaged in by the participants. Text does not need to be print or a document of some kind, but can take on a variety of forms (Brantlinger, Klinger and Richardson 95).

Situated within an emancipatory paradigm, this research is seen as a process, with each piece of research building on contributing to our understanding. This research acts as a building block in a thus under-researched field; within academia I have not found any similar research. John McGregor's in-depth documentation of Judith Scott and Dwight Mackintosh, as well as selected essays published by Arts Project Australia (APA) have included extensive documentation and consequent validation of working artists with IDD; although these works are not 'academic' per se, they are scholarly nonetheless. And, it is important to note that within the scope of this humanities thesis project, it has only been possible to conduct this qualitative research in the most minimal way.

6.2 Literature Review

Qualitative research has become an established and popular mode of inquiry during the past three decades and is informed by multiple paradigms and a variety of theoretical frameworks (Denzin and Lincoln; Marshall and Rossman; Patton). My research approach is informed by feminist poststructural ideas as described by Lather and Richardson, meaning that there is an emphasis on reflexivity and openness to finding new ways of knowing (Richardson and St Pierre). Knowledge is seen as situated, local, temporal and grounded in human activity (Roets and Goedgeluck). Feminist research supplies an emphasis on multiple ways of knowing (Olesen); while other feminist writers are influential in matters of representation, voice and authority (Fine, Weiss, Weseert and Wong). An important aspect of this thesis is to explore how people with IDD experience and describe the experience of

art-making, thus centering the experiences of the participants with IDD (Olesen). As such, the choice of qualitative research in this project is consistent with this cross-disciplinary research and adds a valuable component to this humanities based thesis (Brantlinger, Klinger and Richardson).

In addition to feminist poststructural ideas, disability theory is a central theoretical framework. Disability theory in this project draws on the social model, which sees disability as a social construct, as put forth by Barnes and Mercer, and Oliver (“Changing”). That perspective is substantially enhanced by Mercer, broadening emancipatory research guidelines to be more accessible for research with persons with IDD, and suggesting modifications to allow for differing degrees of participation and more emphasis on making research accessible. My understanding of disability is enhanced by readings concerning the nature of ‘normal’ (Davis, *Constructing*; Garland Thomson, *Extraordinary*); other theories that inform my understanding of disability are those writings by theorists Carlson, McRuer, Siebers (*Disability*) and Tremain, who build on foundational ideas from Butler and Foucault.

6.3 Framework

6.3.1 Paradigm

The ‘net’ or conceptual model that holds the set of ontological, epistemological and methodological beliefs that guided my research can be called a paradigm or framework (Denzin and Lincoln; Guba). As reflected in this work, contemporary research is often a combination or “blurring” of genres (Denzin and Lincoln 24-25; Kinchloe 304-305). Not only is there an interdisciplinary aspect to my research

question (Fine Arts, Critical Studies and Social Sciences), but also the paradigmatic framework itself encompasses several views. Research will be informed by the following models.

The concepts of bricolage, montage and pentimento (Denzin and Lincoln 5) are of great interest to me, which is not surprising, given that in my studio practice I am naturally drawn to the technique of collage and working in layers. While understanding that these ideas are present in all qualitative research, I wish to place emphasis on these concepts. The term 'bricolage' describes my choice of strategies, an active construction of multiple methods and an epistemology of complexity (Fine, Weis, Weseert and Wong; Kinchloe and McLaren). There appears to be a relationship or kinship between these ideas and that of Richardson's "crystal" approach that understands truths, knowledge and ideas as consisting of fragments of other truths, knowledge and ideas (Denzin and Lincoln 8). It is the working in layers and with complexities that informs the intricacies of my methodology which draws on emancipatory research practices, feminist and poststructural theories.

Emancipatory Paradigm

Emancipatory research uses the social model of disability as an underpinning premise as put forth by Oliver ("Changing") and Barnes ("Emancipatory") and as further discussed by Mercer. This should be qualified, however, by saying that my understanding of the social model has been further influenced by feminist disability writers (Crow; Moosa-Mitha; Morris) who assert that a more evolved social model is

necessary. These scholars posit that in redefining the social model as one that assigns disability to society rather than the individual, the lived experience of the person with the impairment has been lost. I concur with this position; in my research, I place value in validating the lived experience of the disabled individual as being important and including or not including, the experience of living with cognitive impairment as the participants deem important. This element is, then, a further evolution of the social model and does not take away from the importance of a concept of a socially constructed understanding of the social model of disability.

Emancipatory research is situated within critical theory precepts and in disability research is informed by the social model of disability (Mercer 233). An early concept of Critical Social Theory is that of conscientization, which implies a “reflection on everyday realities and common-sense knowledge” (Mercer 231). Thus, the praxis orientation of emancipatory research aims to empower socially oppressed groups of people. In fact, Mercer asserts that the test of the emancipatory research should be how effectively it empowers disabled individuals and also states that “the broad intention is to make transparent how the research unfolds, from design through data collection, analysis and recommendations” (Mercer 242). The emancipatory framework thus makes explicit a commitment to inclusivity.

Broadly defined, the emancipatory paradigm “is about the facilitating of a politics of the possible by confronting social oppression at whatever levels it occurs” (Oliver, “Changing” 110). Mercer states that emancipatory research is “geared to praxis-oriented research that exposes social oppression and facilitates political action to transform society” (233). The minimal level of literature concerning my specific

topic, as well as in regards to people with IDD in general, works to situate this project as one that is emancipatory in nature by its status as research that challenges existing power structures.

Research containing accounts given by people with IDD can “be seen as challenging conventional wisdom suggesting that [these] accounts... are not sophisticated enough to be subjected to formal analysis techniques” (Lloyd, Gatherer and Kalsey 1391). However, research with individuals with IDD does not need to be any less rigorous than other research, indeed, it should have as high a standard of rigor as any other good research (Stalker 16). In fact, Stalker cautions researchers working with this population to avoid the pitfall of “cognitive ableism”, as Carlson describes elite intellectual prejudicial attitude, however subtle, towards people with low cognitive ability. In regards to calls for research becoming more inclusive, Roets and Goedgeluck have set an example of scholarly research co-authored by an academic and a self advocate; Roets (academic) states her relationship to Goedgeluck (self advocate) as being Goedgeluck’s “compagnon de route” (105). By bringing attention to the lack of attention to the needs and issues of this population, research communities are exposed (Lloyd, Gatherer and Kalsey 1391).

In addition to inclusivity, Oliver (Emancipatory 107) calls for reciprocity in the emancipatory paradigm. There is an emphasis on reciprocity in the relationship between researcher and participant, proven by a recognition of individuals being researched as ‘expert-knowers’. Lather states that reciprocity should be addressed by practicing full self-disclosure and negotiation of meaning, thus working to

empower the researched and build useful theory. It must be acknowledged that in the case of research with people with IDD, it can prove difficult in some cases for participants to articulate this knowledge, as is further discussed by Sample.

There are areas within the emancipatory viewpoint that my project differed. One main distinctive of this framework is that control is placed with the participant, not the researcher. Logistical considerations prevented this from being a distinguishing feature in my thesis project; I necessarily had to plan, choose methods, choose participants and evaluate the research activities myself. Although time was a primary factor, my intention in this project was to abide by the underlying spirit of the emancipatory paradigm.

To summarize, through this research I aim to combat oppression by challenging dominant research paradigms and hegemonic beliefs, by providing a description of the lived experience of IDD, and by supplying an account given directly by individuals with IDD.

Feminist Theory

Complementing the emancipatory aims of this project are the influence of feminist theories. My interpretation of the social model has been modified by feminist calls to give voice to the subjective experience of disability and the recognition of non-disabled researchers as allies and collaborators (Gilbert; Morris *Personaf*). Feminist research is seen as congruent and beneficial to disability research (Mays; Roet and Goedgeluck), as well as non-hierarchical, non-authoritarian and non-manipulative (Bhopal). It brings an emphasis on embodied

experience, reflexivity, relational aspects of research and exposing power asymmetry; research with people with IDD can benefit from looking to feminist research to facilitate processes of empowerment (Bhopal; Lloyd, Gatherer and Kalsey; Oliver, “Changing”). Truth claims are contextualized within subjective and specific lived experience and an acknowledgement of multiple ways of knowing which are derived from everyday experience (Moosa-Mitha). Validity of methods is reflected in an emphasis on the quality of the relationship between the researcher and the participant; “friendliness, openness and general close rapport with participants [has] acquired a confirmatory status” (Mercer 243).

Morris makes an important point when she observes that disability scholars, in their eagerness to advocate for the social model and repudiate the medical model, have insisted that the personal experience of disability is not relevant, and have maintained that only that which is socially constructed is valid (*Personal*). If the reality of the experience of impairment is not included in what is purported to be an account of the experience of disability, then how can that account be held to be truthful or complete? “To experience disability is to experience the frailty of the human body” (164). Other feminist/disability scholars that share this view are Crow and Wendell.

Postmodern and Poststructuralist Perspectives

Perspectives of postmodernity or poststructuralism in this work suggest multiple truths or “partiality of all truths” (Guba and Lincoln) and an assumption of diverse meanings. The participants’ own interpretations of their experiences assume a

prominent place within my research (Biklen and Mosesly). The postmodern epistemological concept of 'multiple realities' and of knowledge as fluid (Moosa-Mitha) fit within emancipatory, critical theory and feminist perspectives. From within a postmodern context, my research approach is informed by poststructural ideas (e.g., Lather; Richardson), meaning there is an emphasis on reflexivity and an openness to explore new ways of knowing (Richardson and St Pierre 961-964). Liamputtong describes postmodern research as advocating 'mini-narratives' situated within specific social and cultural contexts and containing descriptive explanations of particular processes, that "all stories and expressions are valid and no one story or expression is privileged over others", "a strong focus on self-disclosure" as well as an emphasis on bringing the 'Other' into research (15-17).

Researchers influenced by postmodern or poststructural thought seek alternative methods for evaluating work, such as "verisimilitude, emotionality, personal responsibility, an ethic of caring, political praxis, multi-voiced texts and dialogues with subjects" are used as criteria (Denzin and Lincoln 15). Phil Smith suggests that research turn to postmodern modes of alternative textual practices like poetry, fiction, drama, visual arts, and performance to change how people think about and understand intellectual disabilities, rather than descriptions and explanations in scientific prose. He sees this 'plural text' as having subjects of inquiry that are "multiply faceted, ever-changing, active, and responsive beings-that-don't-stand-still" (*Inquiry* 384).

6.3.2 Assumptions

Based on my paradigmatic positioning outlined above, my research presumes particular positions about research practices informed by the following assumptions, one being that this research does not operate under the illusion of being objective or neutral and reality is viewed as being socially constructed and as existing in many versions (Mercer 231). Ontological assumptions are relativist, that is, consisting of multiple constructed realities (Denzin and Lincoln 22; Moosa-Mitha 57-60). The emancipatory paradigm is situated epistemologically within the social model of disability (Mercer 245); knowledge is, therefore, seen as situated, local, temporal and grounded in human activity (Roets and Goedgeluck), as well as being tied to relations of power (Moosa-Mitha 58). Research is multi-disciplinary in nature and open to using multiple theoretical perspectives in order to advance the research goals. In this project, the research participants are seen as the experts and the researcher as someone who learns from the participants; as such, based in the participants' experiences of art making, this thesis is seen as part of a building or advancement of knowledge rather than a proving of a hypothesis. (Knox, Mok and Parmenter 49).

6.4 Methods

This research is an exploratory Qualitative Research project. A case study approach was used. This type of sampling is referred to as "typical case" and acts to highlight "what is normal or average" within an art making setting or group for

adults with intellectual/developmental disabilities (emphasis added) (Miles and Hubberman 28).

6.4.1 Sampling and Recruitment

In keeping with the methodology, sampling was purposive and followed a nested 'within case' approach or a "selection of participants within a specific group" (Higgenbottom 15). The inclusion criteria for participation were: an established member of the Cool Arts group with regular attendance for at least one year; a desire to be involved in the project; and an ability to work independently with a degree of focus. Criteria was theory driven in that participants were chosen who were capable and willing to demonstrate art making activity, thereby providing a 'typical case' example of an under documented activity.

Sampling was not intended to be generalisable, but, rather, was applied to the specific population of adult artists with IDD (Creswell; Higgenbottom; Marshall and Rossman). As noted, sampling was a small group of people for optimal in-depth study, unlike quantitative sampling that tends to look for larger groups of people and see statistical information (Miles and Huberman; Patton). A small sample number is appropriate to provide information rich data and 'thick description' (Marshall and Rossman). Conducting research with developmentally disabled individuals carries its own unique set of challenges; potentially difficult areas can include the demands of ensuring that the participants understand the research process to the best of their ability, as well as a much greater demand on time, as described by Stalker and

Rodgers. Existing or prior relationship with the participants is seen as an important factor in research with individuals with IDD (Stalker 11).

The selection of participants was reliant on my established relationship with the participants and their families; the existing relationships enabled the participants and their families to engage in the project without misgivings and also rely on the continuation of the relationship after the research was over. Disruption of relationships can be a common occurrence in the lives of people with IDD (Munford et al 340).

Ethics Protocol

Before data collection began, I met with each potential participant and another individual of the participant's choosing (i.e. family, caregiver, worker, self-advocate). The research project was described in an accessible manner and the consent form, which was written in Plain Language, was discussed (Rodgers). The consent form was left with the participant for about a week and included my personal contact information in case of any questions. At the second meeting, I answered any questions, reviewed and completed the form with the participant, ensured that the participant understood the informed consent process as much as possible (Gilbert; Ward and Trigler), and set the time for the first art making session. I did not anticipate that the project would pose risks to the participants or their caregivers.

As an acknowledgement of thanks, a gift certificate was given to each participant at the end of the data collection phase of the project.⁵⁵ I offered

⁵⁵ Gift certificate for art supplies.

compensation to offset any expenses (gas, parking, lost wages or childcare) to participants or other persons assisting with their attendance at the sessions.

6.4.2 Participants

Three participants consented to take part in this research. Having more than one artist participant supported the idea of multiple voices, multiple truths, multiple ways of knowing, and unique experience. It also avoided the suggestion of trying to create an art-making 'template' for IDD.

All participants used verbal communication with the exception of Laura. The term "doubly vulnerable" can describe research participants who experience more than one factor that diminishes their autonomy and further marginalizes their lives (Liamputtong 3). Because of her challenges with communication, Laura could be described as such, furthermore, both Laura and Emma could be described as being doubly vulnerable by virtue of being women. The inclusion of Laura as a participant provides a link to artist Judith Scott, who was deaf and had very limited communicative ability, and also acts to represent a sector of the IDD population who are nonverbal or have communication difficulties. If research with people with IDD is limited to those who are able to speak or sign, then those who cannot will not be represented and be further marginalized (Boxall and Ralph 48).

6.4.3 Data Collection Methods

There were two phases to the data collection. First was a videotaped art-making session with each individual participant and, secondly, was a follow-up interview. All

of the art-making sessions were located at Kelowna and District Society of Community Living (KDSCL), which was known to the participants (Biklen and Mosesly), central, fully accessible, available and cost effective. Participants identified with this site as being the home of the Cool Arts group. The location for the second session was at the home of the participant, except for Emma, in which case the interview session was at KDSCL. When the art making sessions and interview took place, the KDSCL's building was unused, Time of day was the choice of the participant and caregiver.

The Art-Making Process

The 'text' in this project is the process and experience of art making, not the finished art work, video or interview. Text is in keeping with "sociological tradition, [which] treats text as a window into human experience" (Brantlinger, Klinger and Richardson 100). Priority was given to the participant 'taking the lead' in selection of art materials, topic of artwork, choice making in art making process, and the interviews (Booth and Booth, "Against"). My prior relationship to participants and their caregivers rendered an early period of getting to know each other ahead of time, noted in literature as critical (Mactavish, Mahon and Lutifiyya; Stalker), as unnecessary. This was a tremendous advantage in terms of time management.

It should be noted that my choice of interacting as little as possible during the art making session was not to set myself up as an overseer, or position myself as having higher status than the artists. Rather, my decision was informed by both my relationship with the participants in the Cool Arts sessions being that of facilitator as

opposed to teacher, and a desire for the participants to experience the greatest degree of choice-making possible, which could be undermined by my active presence. If I was to be an 'active participant observer' and engage in art making myself, I believe that my own art making may have influenced or distracted the artists. I have noticed in previous workshops that often my close proximity and consequent conversation can, although not always, inhibit or distract an artist. Furthermore, the philosophy of Cool Arts is to provide an atmosphere of optimal self-initiation, and provide help only when asked for or appears to be clearly needed.

One camera was stationed to view the general working area, including the body of the artist and the entire work surface, therefore capturing body language and facial expression (Kvale). The second camera was focused on the work area only and utilized a time-lapse apparatus.⁵⁶ Both time-lapse sequences were used in the same way, for cross checking, elicitation, analysis and dissemination. Using participant observation and video recording together is a "blended approach", one that has benefits of generating additional data that can increase depth of observation and enhance validity of the researcher's interpretation (Paterson, Bottorff and Hewat).

Video elicitation technique is similar to photo elicitation in that it works to stimulate discussion during the interview that follows the videotaped art-making session, and helps to trigger the memory of the participant as she or he describes their process (Banks; Hinck; Pink; Prosser; Radley and Taylor; Rose 240-243).

⁵⁶ I was able to record in time-lapse mode, using a second camera in art-making sessions with Scott and Emma, but not for the session with Laura.

Although the videotaping served to document and validate the art-making process of the participants, the videotape itself was secondary to the artist's process, their comments regarding that process and my observations gained from watching both the actual process and the taped action. This was not a 'video' project, and the use of video is not tied to a particular theory or methodology, rather, use of the video is "simply means to certain ends" (Rose 238).

Follow-up Interviews

Subsequent to the filmed art-making sessions, face-to-face interviews were conducted with the participants. The gap in knowledge about this topic suggests that the use of interviews as a source of data is important; information is needed directly from people with IDD (Finlay and Lyons; Mactavish, Mahon and Lutfiyya). Interviews with this population can present difficulties or a need for adaptation due to issues of communication or capabilities of the participant (Booth and Booth, "Sounds"; Finlay and Lyons; Lloyd, Gatherer and Kalsey). Several writers have addressed the perceived issue of acquiescence when interviewing people with IDD (Heal and Sigelman; Shaw and Budd; Sigelman, Budd and Spanhel; Sigelman Budd and Winer et al); traditionally, it is suggested to use 'either/or' questions. I prefer the perspective offered by Stalker, who suggests that the reason for this 'acquiescence' on the part of interviewees with IDD, is not the condition of their impairment, but that choice-making in the lives of people with IDD is extremely limited (6).

The participants were prompted to reflect on their art-making process while viewing the videotape in the interview. The strategy of video elicitation is similar to photo elicitation in that it works to stimulate discussion during an interview and helps to trigger the memory of the participant as she or he describes their process (Boxall and Ralph 47; Rose 240-243). As per researchers who have conducted research with people with IDD, interviews were unstructured and used open-ended to more directive/closed-ended questions depending on the need of the artist for direction; questions were “designed to encourage people to talk about what is important to them” (Taylor and Bogdan 244).

Given the level of trust in my relationship with the artists, I took as unstructured an approach to the interview questions as possible, using strategies such as rephrasing questions, asking questions in more than one way, and asking about one element at a time (Biklen and Mosesly; Finlay and Lyons; Heal and Sigelman; Rodgers). The process was a ‘guided conversation’ using ‘neutral probes’; I sought in-depth clarification of answers as much as possible, and explored any seemingly profitable directions that emerged. The intent was to obtain as detailed and ‘thick’ a description of their art making process as possible from the interviewee. In the case of Laura, the participant with limited communicative ability, I was more dependent on my observation of her art making process, and bodily and facial expressions. The interviews were digitally recorded and transcribed verbatim.

6.4.4 Critique of Methods

The methods of participant observation, video documentation, observation and unstructured interviews were unproblematic and posed no surprises in their execution and outcome. However the aspect of video elicitation as a means to draw out comments and observations from the participants proved somewhat disappointing. While the artists were interested, to varying degrees, in the video and watched without complaint, they offered little in the way of comment and even when questioned about their actions and choices in the video, gave little in the way of clarification or explanation.

In the interview session, Scott appeared to be overly acquiescent, agreeing with anything I said and answering in the affirmative to any questions I asked. When further questioned, sometimes he would then switch to “no” and burst out laughing. Whether Scott’s manner was indicative of a “learned response” of passivity is unknown; it is possible that he may have become more animated if we had had more sessions together. I also suspect that the questions made Scott a little anxious. He and Laura did appear to become somewhat bored as the video went on, which is understandable as the footage had minimal dialogue and required close attention in order to register the progress being made by the artists. During the interview, Laura, when asked, would indicate on her drawing what she was working on in the video, however, she did not offer any comments and often even chose to nod or shake her head rather than say “yes” or “no”. Whether this was due to the presence of her family is impossible to say.

Emma was the most conversant in the interview session. However, and this is a potential risk to any research involving technology,⁵⁷ the possibility of human error and equipment malfunction exists to varying degrees. Unfortunately, the audio portion of Emma's interview is not audible; furthermore, because I was relying on the videotape as backup, I did not record all Emma's comments in written form and thus learned a lesson regarding the importance of firsthand notation.

In regards to how I could have done things differently to increase success concerning the aspect of video elicitation, I am unsure. It may have been prudent to select portions of the footage to show to the participants rather than the entire footage, all of which were about forty to fifty minutes in length. Minimal literature exists concerning video elicitation, especially concerning people with IDD. Although there is a substantial amount of information concerning photo elicitation, there are significant differences between photo elicitation and video elicitation. Photos can be easily transported and considered over time and in various settings, for example, however, videos must be viewed with a player and monitor or TV and require a degree of competence to manage. Video elicitation could be very useful for research with people with IDD and I would be open to using this strategy again in future research, but clearly some strategies would need to be developed.

⁵⁷ I fully admit that I am more than a little challenged by technology, and although I made my best efforts to successfully videotape the research sessions, managed to sabotage the audio component of the videotaping of Emma's interview. In future projects, it may be worthwhile for me to engage the services of a competent videographer as this would also enable me to more fully concentrate on the research process itself.

6.4.5 Analysis

Thematic analysis is a foundational method used widely within qualitative inquiry and across methodologies that allows for theoretical and methodological freedom. It “can potentially provide a rich and detailed, yet complex, account of the data” (Braun and Clarke 78). Use of this sort of analysis is congruent with emancipatory research informed by a poststructuralist perspective.

Transcription

Within literature there is an acknowledgement of the act of transcribing being more than a process of transferring data; transcription, and the ongoing decision making involved, reflects theoretical and methodological underpinnings of a research project (Bird; Kvale; Lapadat and Lindsay; Tilley). Decisions regarding the representation of data were motivated not by a need to replicate data exactly and exhaustively, but “rather how to selectively reduce the data in a way that preserves the possibility of different analyses and interpretations” (Lapadat and Lindsay 69). I therefore was able to analyze content while transcribing and had opportunity to utilize reflexivity by attempting to maintain transparency during transcription (Tilley 751). Transcripts were not seen as having ‘privileged status within the data collection and analysis process, but as a way to further, but not objectively or completely reiterate the participants interview. I made up Excel sheet templates (landscape orientation) with columns for Session One (‘Time’, ‘Observation’, ‘Dialogue’, ‘Notes’, ‘Body Language’ and Session Two (‘Time’, ‘Dialogue’, ‘Notes inc. Body Language’ and, finally, ‘Analysis’. Transcription data was entered into

'Dialogue columns with time entered in 'Time' column. Observations made in my notes during the session, or while viewing the footage, were entered into the 'Notes' or 'Body Language' column.

Thematic Analysis

After the data collection was completed, I went through transcripts and re-viewed video footage to identify 'themes', looked for phrases, words or general impressions (Aronson), and highlighted these with yellow highlighter. I went through the Excel sheets again and noted potential themes in the 'Analysis' column. Using the information in the "Analysis" column, major themes were then identified, and consolidated as appropriate, with an end result of 'essential' themes'. According to Braun and Clarke, thematic analysis can be an essentialist or realist method, thereby reporting the experiences and reality of the participant, or it can be a constructionist method, which examines or contextualizes that reality or experience in light of various discourses (81). In reference to these positions, my qualitative research with the three artists situates itself as both realist, in that the research serves as a necessary documentation of experience, and contextual as situated within an evolved social model of disability.

As noted by Lietz, Langer and Furman, the notions of validity and rigor as applied to research that is postmodern in outlook is problematic; Lincoln agrees and adds "the poststructural, postmodern argument [is] that texts, any texts, are always partial and incomplete... and can therefore never represent any truth except those truths that exhibit the same characteristics" (280). Consequently rigor does not need

to operate in the traditional inflexible mode, but as trustworthiness, “engaging in efforts that increase our confidence that ... findings represent the meanings presented by our participants” (Lietz, Langer and Furman 443).

Guba and Lincoln (1992) discuss validity as poststructural transgression or resistance, citing Richardson’s concept of the crystalline to problematize reliability, validity and truth. As reported in Guba and Lincoln, Richardson asserts that transgressive forms of inquiry allow a researcher to develop new ways of knowing and telling. The manner in which crystallization deconstructs the conventional idea of validity offers a deeper and more complex understanding of a topic. Brewster states that interpretations of data within a context of a longer period of time and personal involvement acts to offer greater reliability (169).

Throughout the project I utilized the practice of self-reflexivity (Lather) to reflect on the relationship between the participants and myself, and also to remain cognizant of the existing power relationships (Rossman and Rallis). Rather than triangulation, the concept of the crystal as the “central imaginary for validity for postmodern texts”, as explained by Richardson and St. Pierre is preferred. Crystallization disrupts the traditional concept of validity, allows texts to “validate themselves” and give us a “deepened, complex, and thoroughly partial understanding of the topic” (963).

6.5 Findings

6.5.1 Description of Data

Scott

Scott is a middle-aged man who has been attending Cool Arts on a regular basis for about three years. He is physically able and very agreeable in personality. Usually careful and deliberate in his actions and movements, Scott especially enjoys working with bright colours and says that painting is his favorite medium. Although his verbal skills are quite good, Scott is often quiet in a group.

Scott - Session One

I offered Scott the choice between two sizes of canvas and a variety of painting and drawing materials. Scott was absorbed in his art making immediately, intent and engaged, and gave his work his full attention; there was the slightest of smiles on his face and his mouth moved as he concentrated. Choosing orange paint, he applied a loaded brush to the canvas and painted with steady and repetitive strokes. He did not look at me or seek direction, but instead relied on his own judgment.

Scott indicated to me that he was going to paint a Halloween themed picture (the date of the session was Oct.15). Hesitating before making the first shape on the surface of the canvas, his brush hovered before making a mark, as if seeking inner confirmation of his choice. Later, when Scott hesitated again, I asked him what he was thinking of and Scott answered, "More orange." From time to time I asked him questions like this and observed that he mainly agreed with me or repeated what I said; this was not unusual for Scott.

He again paused and considered before making a mark, then made a circle with a steady hand in the central area of the canvas without hesitation. Scott was sure. He had made orange by mixing red and yellow and carefully painted around the perimeter of the canvas, so that the orange paint resembled a 'frame'.

My presence did not seem to deter or distract Scott from his work. The pace slowed a little as Scott thought about what to do next. As he pondered, he used the orange paint to touch up the perimeter and was carefully attentive to details in the work. Again, Scott paused, with his brush held still over the canvas, and his mouth working a little in concentration. Slowly he reached his brush into the red paint, and then hesitated as his brush stayed poised over the canvas. He appeared to be



Figure 6.1 Scott (Art-making research session). Photo by Sara Lige.

undecided about what to do next, and eventually decided not to use the red paint and put his brush back into the water.

Returning to the orange paint, Scott brushed and dabbed with it, then returned to the red and began to paint red around the perimeter, again, as a 'frame'. I offered to put some more colors out onto the plate, but he said, "No, no". Scott widened the red perimeter frame and began to paint a red line around the central circle shape. There was more deliberation and brush hovering in the air again; Scott's decision-making process was definitely marked by uncertainty. I asked if the shape was a pumpkin, and Scott answered that it was. He dipped his brush into the red and painted the pumpkin's cheeks red, looked at me, then asked how I liked his painting. This began a series of comments and questions from him about what I would be doing on Halloween. Scott talked as he painted; his big decisions seemed to be done with and he was able to chat and paint at the same time.

As he continued to paint the outline of the pumpkin, Scott carefully added dots to the eyes and also gently painted red on the round cheeks. He paused once more... thinking, thinking. His brush went into the water and again he painted over an already painted area. Very slowly he washed his brush as he considered and dabbed more orange paint on, then paused again, looking at his work.

Scott chose some blue paint to paint his name on the canvas. In choosing blue, he selected the complementary colour to orange although I doubt that this was something Scott was aware of. He painted his name onto the canvas in a way that integrated the text into the arrangement; Scott's signature acted as a strong compositional element because of the contrasting colour. He worked at the painted

red 'frame', smoothing out the surface with long steady strokes, then announced that he was done.

Scott - Session 2

Scott was quite interested in watching himself painting on the video, although at times his attention wandered. When I asked if he remembered how he felt during the art making session, Scott replied, "Happy." His body language in this session, as in the first session, was relaxed and open. When he observed himself on video washing his brush in the water, Scott told me why it is important to keep the brush clean. Later on in the viewing, Scott spoke again about the importance of cleaning out brushes; this was his favourite topic in second session.

Towards the end of the interview, Scott did become more animated when we had a conversation about the upcoming opening for the "We Are Artists" exhibition, which was about two weeks away. I asked him questions about how he felt about the impending exhibition opening:

Sara : "What is it about the opening that you are excited about?"

Scott : "I can show them what we do"

At the end of the video, I asked Scott what part of the video he liked best.

Scott : "All the colours."

Sara : "What do you mean?"

Scott : "Red. I did lots of orange."

Sara : "Why?"

Scott : "I don't know. I just like them."

Later on, Scott and I had this conversation:

Sara : “You like bright colours?”

Scott : “Yeah.”

Sara : “How does it make you feel?”

Scott : “Happy.” (nods head up and down)

Sara : “What if we have a project where we paint black?”

Scott : “Oooooohhhhhh.” (shakes his head, but looks at me and smiles)

Sara : “You don’t like that?”

Scott : “No....”

Emma

Emma is a lovely young woman who lives with Down Syndrome. She is easy going and cheerful by nature and possesses good social skills. Emma appears to be a confident person and converses without difficulty, although at times it can be challenging to understand all that she says. Always dressed fashionably, Emma seems to be very visually conscious. She never struggles to think of subject matter for her artwork, unlike some of the other CA artists.

Emma - Session One

Emma selected the larger canvas and began to draw an image on the canvas. When she finished the drawing of the image, she selected blue, yellow and red and squeezed the paint onto a palette in an orderly way. Emma quickly determined the

subject and composition and worked in her usual organized and quiet manner.⁵⁸

She started by painting a red shape, and indicated that this was a poppy, shown as a symmetrical four petalled flower (the date of the session is Nov.21). After lifting up her palette plate and mixing her colors, Emma loaded her brush, realized that her brush had too much paint, and worked to take off the excess. She was quite precise in her filling in of the flower shape, using the brush in different directions in order to make best use of the tip, first slanting, then holding it upright.

After first outlining the poppy in blue, Emma used a larger brush to paint red in a strip on the edge of the canvas which made a 'frame' around all four edges, not unlike what Scott painted on his canvas. Using long smooth even strokes of the brush, she appeared very confident and comfortable holding the brush. When Emma selected another brush, she tested the bristles on her hand to see if they were hard or soft. She used blue paint to paint another strip inside the red frame, and after that chose yellow to make a third 'frame' inside the blue, being careful to apply the paint in such a way that it would not mix with the already applied wet paint. She was, for the most part, successful in this. Some of the sides of the 'frame' were more even than others, but that did not appear to concern her.

With her head bent down towards the canvas, Emma's hair worked as a veil to shield most of her face from both me and the camera; this may have been intentional as Emma has always appeared to be a private sort of person, or perhaps more shy than private. As she continued to work, she maintained a methodical and rhythmic stroking of the brush. Once the striped 'frame' was completed, she worked

⁵⁸ It should be pointed out that I am very aware of the three artists' typical manner of working as I have known them and been with them in art classes for three years, and in Laura's case, seven years.



Figure 6.2 Emma (Art-making research session). Photo by Sara Lige.

to fill in the rest of the interior area with red, bringing the red paint right up to the image of the poppy, until all that separated the red poppy from the red background was a thin blue line. Emma then used more red paint to go around the poppy, reducing the width of the dark blue outline around the shape, thus creating an effect that was very understated and low in contrast. The poppy had evolved into a red flower floating on a red background. One could describe the red on red as very subtle; whether Emma intended subtlety is unknown. To create a central image with the same colour as the background is an unconventional choice, however, it was obvious that the symmetrical, geometric and balanced composition was carefully planned.

Using blue-black paint to paint her name on the bottom edge of the canvas, Emma then took a pencil and wrote her name again beside it with pencil. I asked

her why she wrote her name twice and she replied that some people have trouble reading her name. Emma put down her pencil, smiled and sat back; she looked satisfied and happy. She sighed deeply, as if to signal “I’m done”.

There was time left before the end of the session, so I asked Emma if she would like to paint a smaller canvas. She answered in the affirmative, and without hesitation drew an image onto the canvas with pencil. The image was comprised of block letters spelling ‘Merry Christmas’, and Emma began to paint the letters in red. She then mixed up green from yellow and blue paint. I asked Emma if she liked mixing up colors and she answered, “I do”.

With her head bent down close to her work and appearing calm and focused, Emma worked to fill in the canvas around the block letters with green paint. She then painted a red block of color in the top right corner of the canvas, extended the shape over the letters spelling ‘Christmas’ around the left side and under, eventually leaving a white rectangle shape behind the word. Emma consciously made choices concerning the composition and appeared to again be favouring geometric shapes and a somewhat symmetrical and balanced composition. She did hesitate at times when considering her next move, although not quite as much as did Scott.

Taking a smaller brush, Emma touched up around ‘Christmas’ until there was no white visible. The red letters were then on a red background, making them somewhat difficult to see, and possibly intentionally inconspicuous. After touching up the sides of the canvas with yellow, Emma signed her name to the side edge of the canvas.

*Emma – Session Two*⁵⁹

While watching the start of the video, Emma remarked that in the art making session she had planned to paint Remembrance Day poppies; holidays appear to be an important theme for her. As in the art making session, Emma's body language indicated that she was relaxed and feeling positive. She told me that she feels "happy" when she is making art, and told me about her experiences in her high school art class. She received an A+ as a grade in that class and is very proud of that achievement; Emma has told me about her grades in high school art a few times before. I asked her what she thought an artist is, and Emma replied that an artist is famous. She also said that artists sign their name to their work.



Figure 6.3 Emma (Interview research session). Photo by Sara Lige.

⁵⁹ Unfortunately, the audio portion of Session Two with Emma was inaudible. The few comments I have made are from notes.

Laura

I have known Laura for about fifteen years or so, beginning with Special Olympics and later in Cool Arts. Laura has a chromosomal condition that has impaired her cognitive abilities. She also does not have vision in one eye and has a hearing impairment, although that has improved in the past few years with the help of a hearing aid. Laura speaks infrequently and usually uses one or two words at a time. She does not sign, except for a few gestures. She and I have always had a good relationship; although we don't have long conversations, we enjoy each other's company. Laura is able to focus for long periods of time and is also very task oriented; she likes to see a job or project through to completion without getting sidetracked.

As Laura has limited ability to communicate, I was conscious of the difficulty of my position as researcher; at times I felt uncertain regarding my interpretations of Laura's actions, words or her pattern of thinking. At the same time, I believe that my long-term relationship with Laura worked in my favour to draw correct conclusions. (Bredin and Renblad 157).

Laura – Session One

Laura appeared to be happy about being with me for the research session. I chose drawing materials before the art making session, because drawing is her strongest medium. Out of the collection of materials offered to her, Laura chose pencil crayons to work with. My experience with Laura confirmed that pencil crayons

are her favorite drawing materials. I offered her two sizes of paper; she quickly chose the larger sheet of paper (22" x 30").

First choosing red pencil crayon (pc), Laura sat pulled up to the table, arms resting on the sheet of paper, and leaning forward with her face about twelve to fourteen inches from the area she was working on. She may have needed to be close to the paper to accommodate her vision. Laura worked at smoothing her hair; her mother reported to me later that this action indicated that Laura was nervous. It is possible that she was anxious about the video camera or concerned about pleasing me.

After changing to the blue pencil stick, Laura drew what looked like a face. She spoke a little, saying, "Sssh" to any noise outside the room. I asked, "Who's that, Laura?" pointing to the drawing. She answered, "It's me." Still leaning forward

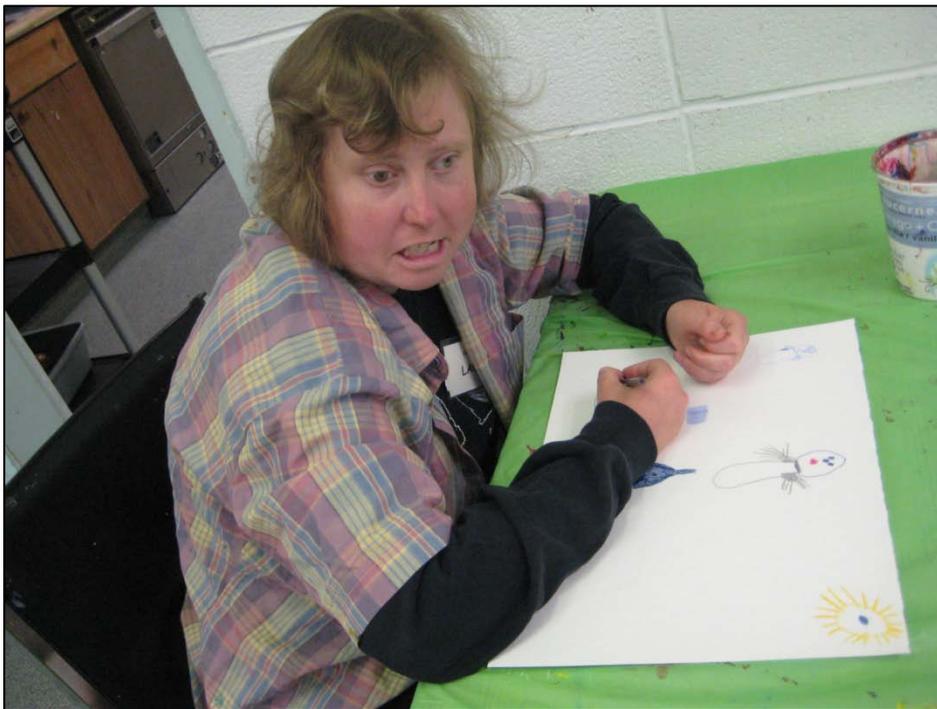


Figure 6.4 Laura (Drawing at Cool Arts). Photo by Sara Lige.

and working in a very focused manner, Laura drew the torso of the body and then the arms, which look like flippers. She filled in the flippers, looked at me sharpening, and said, “Sssshhh.”

Laura filled in the feet with purple, added the ears and filled them in. Still working intently and with concentration, Laura cleaned off the tip of the red pencil, and worked to make sure it had a clean end. She drew a protrusion coming out of the head. I asked her, “What’s that, Laura?” pointing to the bump on the head. “Hair”, she answered, and then added a second mound of hair. Laura filled in the body in a very orderly and methodical fashion consisting of rows that travelled horizontally back and forth. She had a system, a manner or style of working that I had not observed previously.

Laura continued to be absorbed in her art making and smiled as she worked. She held up a brown pc. I asked, “Do you want me to sharpen it?” Yeah”, she replied. I felt that I needed to clarify with Laura what she wanted or what she was doing, rather than rely on my own assumptions. An orange section was added to the top of the head. I asked, “What is it?” and pointed to the orange. She answered, “My hair.” Again, she was very orderly in her filling in of the shape.

The completion of the first figure took about half an hour and Laura then started a new figure, beginning with the face. She appeared to draw the features of a face in the same order each time – face outline, eyes (filled in), nose (filled in) and then mouth (filled in). Laura brushed off her drawing paper with her hands. I showed her how to blow off the bits of eraser to avoid making marks on the drawing surface, which she then did. She started to fill in the body with rows as before, then added

arms and fills those in as well. I asked, “Who’s this, Laura?” She answered, “It’s my sister.” At one point, what I thought was a green ear turned into hair, and then Laura drew the hair bigger, like a helmet. After this image, she started a new figure and told me that it was her “mom”. Again she filled in the body with rows of colouring, this time in purple. She started another figure and, after I asked, said that it was her dad. Family is an ongoing theme for Laura.

Laura - Session Two

Laura watches the laptop with a look of concentration and her head tilted to accommodate her limited vision. She has a puzzled look, but I know her well enough to know that this is Laura’s look of concentration. Sometimes Wulf, her father,⁶⁰ asked her a question like, “What were you doing, Laura?” “Paint,” she replied. Wulf asked, “Did you draw with colored pencils?” “Yeah,” she answered. Her father continued to try and get her to talk, but she answered him with smiles and nods and one-word answers, although she did pay close attention to the laptop.

The drawing she made in the art making session is in front of us on the coffee table; at times I stopped the laptop video and showed her on the drawing the spot where she was working in the video or I asked her to show me. This is one way to test whether Laura was making a connection between the laptop video and the

⁶⁰ Laura’s family chose to be present at in the interview session, which was in their home. I determined that this was acceptable and might be advantageous as her family might understand her responses if I did not. This could be described as using a proxy respondent for participants with communication difficulties, as described by Liamputtong (101) and Boxall and Ralph (48), in which case people who know the person well and are able to interpret their communications can speak on their behalf. However, partway through watching the video, her family went out of the room when I asked them if they thought doing so would help Laura to focus better on the video. As it happened, I was able to understand Laura’s limited responses.

actual drawing in front of her, which she seemed to do as she readily pointed to the figure.

When Wulf pointed to various figures on the drawing and asked Laura to identify them to us, she did, although not with the same answers as the day she drew them. Either she didn't remember or it was not important to her or, perhaps she was having fun with us.

Part ways through the video, I said, "Laura, I thought after you drew 'Laura', you would stop. And then when you drew the second person, I thought, well, maybe you would stop, but no – you just kept going." Her mother Joan said, "It's important to have everyone."

In the video, Laura was drawing hair. Laura pointed at her head and said "My hair." Wulf asked, "What is your hair?" Laura replied, "Brown." Wulf asked what the orange was, and she answered, "Orange." He asked if it was something different. Laura replied, "Different."

Wulf: "Like a hat? A toque?"

Laura nodded, "Yeah."

Sara : "You don't have an orange toque yourself, do you?"

Wulf : "Yeah, or yellow."

After awhile, Laura's attention was in and out, distracted by the cat and growing uninterested in the video. She grew tired, and the video must have seemed boring to her; I continued asking Laura questions, but just got nods for answers. Laura's level of focus during the session was actually very good, all things considered. After five or ten minutes or so, the video can appear somewhat monotonous.

6.5.2 Themes

Theme One – Art-making Practice of the Participants

Theme One concerns technical or formal aspects of the artists' art making practice; data indicated that the artists' manner of working was characteristic or typical of the way that artists work, meaning that their understanding of, knowledge of and practice concerning materials, tools and technique indicated experience, knowledge and a desire to 'act like' or 'identify' as an artist.

a) All the artists demonstrated knowledge of materials, tools and technique.

All three artists demonstrated attention to their materials, whether it was cleaning the brushes (Scott) or making sure pencil crayons were sharp and the paper surface clean (Laura). In particular, Scott paid a great deal of attention to the cleaning of his brushes, and in the interview session emphasized that that this was an important task and explained why. During the art making sessions, I observed that all three artists worked in a confident manner and without hesitation in regards to practical aspects.

Emma and Scott both mixed up colours from other hues, demonstrating that they knew how to blend colours, that they preferred to mix their own, and that they did not need prompting or help to do so. I asked Emma if she liked mixing up colours and she answered, "I do".

b) All the artists have an individual style or manner in the way that they work at their art practice.

I have observed Laura in art workshops for about eight years and Scott and Emma for about three years. This enabled me to be able to place their actions in the art making session within the context of their usual practice. All of the artists worked in a way that was congruent and consistent with their usual approach to their work.

Scott tends to work in a self-motivated way; he may ask for help at times, but generally makes his own decisions. Emma also typically works in a quiet fashion, generally having little interaction with other people who might be around her; she makes her decisions quickly and gets right to work. With a hearing impairment, as well as having sight in just one eye, Laura works at the workshops without much distraction possibly because of her sensory disabilities. She occasionally looks around with a puzzled expression, but tends to stay very focused on her work. Close observation of Laura's mark-making during the first session revealed that she has a very orderly and consistent system of filling in shapes with her pencil crayons.

c) *All the artists independently created an image*

All of the subjects autonomously and without help produced a work of art by a process of mark-making on a canvas or paper surface, thereby fulfilling the most basic requirement of an artist in the traditional sense.⁶¹ Image making was self-initiated and completed without consultation with me or any other person. All the images were carried through to completion, except Laura's, whose session was cut

⁶¹ In the contemporary art world, such a requirement is not applicable; newer genres of art such as sound, installation and performance, have moved mark making outside traditional boundaries.

short by the early arrival of the HandiDart bus, although her intent to complete a drawing showing every member of her family was clear.

Scott and Emma both filled their canvasses and signed their names to their work, which was an indication that they considered their images completed. In contrast to their low-contrast compositions, they both chose to write their names in a contrasting colour so that the signature became an integral part of the image. In Emma's second work, she chose to sign her name on the edge of the canvas, thereby omitting her name from the composition while still ensuring its presence in the piece. Laura did not fully complete her drawing, and it is difficult to know whether she would have signed her name without prompting and if so, how she would have done so.

d) *All the artists exhibited choice making many times within the art making sessions.*

Creative art practice necessarily involves a series of choice-making scenarios. My observation of the artists showed that they continually made decisions concerning implements and materials, colors, certain kinds of marks and images.

Interestingly, both Scott and Emma visibly demonstrated when they were engaged in decision making. Scott's brush would hover a few inches above his canvas for perhaps as long as ten to twenty seconds as he pondered his next move. Other times Scott would appear to ponder while he slowly cleaned his brush; sometimes his mouth would work as he thought about the problem, or he would talk to himself in a low voice. In a similar way, Emma's brush would float over her

painting as she determined what to do, although for a shorter period of time. Laura showed no similar visible signs of hesitation or decision-making, instead working at a steady rate without pausing.

e) *All the artists exhibited focus and attention directed towards their work.*⁶²

All three artists worked attentively and with focus. Although they all offered comments to me on occasion, these were few and did not appear to slow down or interfere with their art making.

f) *Demonstration of desire to share work with others.*

Although not technically a requirement of an artist, this aspect is generally associated with what an artist does, that is, exhibit or share their artwork with the greater community in some way. For example, Scott volunteered that he was excited about the upcoming art show.

Sara: "What is it about the *We Are Artists* opening that you are excited about?"

Scott: "I can show them what we do."

Scott became visibly animated and excited when we were discussing the upcoming exhibition opening.

When I asked Emma why she wrote her name twice on her first canvas, she replied that some people have trouble reading her name.⁶³ She wanted people to

⁶² It should be noted that I purposely chose research subjects who would be able to concentrate as they worked; some of the CA artists tend to want to interact with others frequently at the workshops. I decided that to have such socially oriented artists, as subjects would be counter-productive the objectives of the research project.

⁶³ It is of interest that Emma does not say that that her writing is difficult to read; she sees this as a deficit being on the reader's part, not hers.

see her name. Emma also said that artists sign their name to their work. My previous experience with Laura has indicated to me that she is very enthusiastic about having others see her work, at times even physically pulling viewers over to where her work is displayed.

Theme Two – Confirming Heterogeneity

The second theme concerns the notion that people with IDD tend to be a homogeneous group or do things in a similar fashion, even as extends to their art making activity.

a) The artists differed in their choice of and application of materials.

When offered their choice of medium and materials, Scott and Emma immediately chose paint and canvas. Although I predetermined drawing as a medium for Laura because I knew it was her favourite, she unhesitatingly chose pencil crayons from within the assortment of drawing materials that I had placed on the table. Based on my experience over the years with the artists in the context of CA, I can confirm this characteristic of different choices concerning materials and techniques.

b) The artists differed in their choice of theme or subject matter, as well as compositional elements.

In the art making session, Laura drew her family. Afterwards her mother said in regards to her drawing, “It is important that everyone is together”, indicating that this

was a priority for Laura. In CA sessions, Laura usually draws herself, her family or her home; I cannot recall her selecting any other topic unless a different subject matter is indicated by the instructor as part of a workshop assignment.

Scott and Emma both selected a holiday or special day as the subject of their work (Scott chose Halloween, while Emma chose both Remembrance Day and Christmas). Why they chose these subjects and what these special days represent to them is a discussion for another day. What is important to note here is that the chosen subjects held importance for each of them. All of the holidays represented were close in date to the day of the art making sessions, so were current and likely forefront in both Scott and Emma's immediate plans and memories.

Both Scott and Emma's compositions were somewhat symmetrical, and both utilized a frame-like border structure. Although Laura's composition was centered, it could not be described as symmetrical. Interestingly, both of Emma's paintings were very low contrast in the main or central area of the arrangement and Scott's choice of color and tone also resulted in a low contrast work.

6.6 Discussion

Theme One - Art-making Practice of the Participants

a) *Demonstrated knowledge of materials and technique as a qualifying element of an artist.*

Scott repeatedly discussed with me the importance of cleaning his brush; he may have been telling me to make sure that I knew that he understood the importance of the task, and, thus, was a 'real artist'. Another possibility is that Scott

was confirming to himself that he was a 'real artist'. It is likely that knowledge of such matters has an impact on the artist's confidence and their ability to accept their identity as an artist or whether they call themselves artists. The potential for artists with IDD to achieve technical competence is confirmed by Kaija Kaitavuori, instructor at Finnish disability art centre Kirsikoti (16).

MacAuliffe points out that postmodern artists have "questioned the use of technical skill as a measure of artistic status" ("Different" 16), although a certain proficiency or rudimentary understanding of materials and tools is arguably necessary to produce work. He goes on to say that the Arts Project Australia (APA) artists "have succeeded in attaining sufficient control and understanding of a media to articulate a set of concerns to establish a system of communication, with which the viewer can engage with no more difficulty than any other art form"(17).

b) *All of the artists have a particular artistic style or manner in the way that they work at their art practice.*

As noted, all three artists produced works that were distinct from the others in terms of compositional elements and theme. My experience with the CA artists has shown that work is consistently produced that is unique to each artist. This is particularly noticeable after the participants have been in the CA group for a year or more and have gained confidence in their abilities and ideas. I can usually determine who the CA artist is of a work by observing the style, manner of handling the media and subject matter of a work.

c) *All of the artists independently created an image.*

This self-determining act sets these artists apart from those who copy images or create images as directed by others. In addition, all three artists created images that drew from their own lives and lived experience. While Scott and Emma addressed what was current in their lives in terms of experience (upcoming or recent holidays), Laura drew her family. During the art making sessions, I made a point of not offering any advice or comments that would lead or interfere with the artists own ideas. All of the artists were in control of their project and decided what subject matter would be, how the work would be produced and when it was finished.

d) *All of the artists engaged in choice making.*

All the artists engaged in a series of choice making to produce their work. This is commensurate with research conducted by Ridley and Fox of Brighton University who observed that artists with IDD made “carefully considered judgments“ during their art practice (“Overalls” 4). I found Emma and Scott’s choices regarding their low contrast compositions of interest because it suggested either an unawareness of traditional compositional practice (the most likely option), or a conscious desire to subvert that practice.⁶⁴

e) *All of the artists demonstrated focus and attention in regards to their work.*

The degree of focus and attention that the artists paid to their work may indicate

⁶⁴ Further investigation regarding this issue is warranted and would provide greater understanding of the art making process of artists with IDD, especially in regards to divergent thinking. The first option does offer a fascinating opportunity to view what happens when artists are unhampered by traditional artistic training, which is what ‘outsider artists’ are purported to be.

the artist's commitment and/or degree of interest to their art making.⁶⁵ It was obvious that all three artists were absorbed by their activity; what they were doing held their attention closely.

f) *All of the artists demonstrated a desire to share work with others.*

As noted, typically artists are expected to and desire to share their work with others, thus a desire to do so is a characteristic of an 'artist'. All three artists were very enthusiastic about the upcoming *We Are Artists* exhibition and opening, as indicated by the following example:

Sara : "What is it about the opening that you are excited about?"

Scott : "I can show them what we do"

The artists in the CA group exhibit their work every year at large art fair and always appear eager to do so. The CA artists have never indicated that they do not see themselves as artists in the community like any of the other artists exhibiting at the art fair. Ridley and Fox observe that when artists with IDD exhibit their work in the larger community, both their work and their identities as artists are validated" ("Testing"). Perusal of exhibition catalogues from Australia, US, Britain and Finland indicate that other artists with IDD have a similar ambition to exhibit their work.

Theme Two - Confirming Heterogeneity

Theme two concerns the aspect of heterogeneity as applied to artists with IDD and their practice. My experience with the three participants, as well as with the

⁶⁵ Having said this, it is obvious that some of the other CA artists simply do not possess the ability to focus on their work due to various conditions, but nevertheless usually manage to complete a project, although sometimes in an adapted or different way.

other CA artists, confirms heterogeneity within the group; all the artists have a unique image bank, or visual vocabulary that they draw from to produce their work, as well as an individual manner or style of creative process.

According to Elizabeth Gibson, Executive Director of Project Ability (PA) in Glasgow, although the artists in the PA “master class” have worked together for a number of years, they each retain a very unique vision and style, and do not appear to be overly influenced by other people’s work. Finnish art centre director Kaitavuori also affirms the diverse nature of artists with IDD (17). MacAuliffe notes in the APA exhibition catalogue *Inside Out/Outside In* that APA artists have developed their own manner of working, and affirms that “each artist has developed their own vocabulary of form, technique and motifs” (“Different” 17).

Summary

Two aspects of this project seem especially important. First is the issue of the documentation of the artist’s practice itself. Secondly is that of identity, both in terms of how the artists see themselves and how others perceive them.

The documentation of the process was very basic, largely because this qualitative research is limited to a chapter in my thesis. However, the intent of this thesis is to lay a groundwork concerning artists with IDD; in consideration of the fact that I could not locate any other similar research (except for the documentation done by John McGregor), it seemed equitable to ensure that this area of study was addressed and included in this thesis. Within the context of the arts community, artists with IDD are not traditionally accepted as legitimate artists outside the

disability arts movement. However, even within the realm of 'Disability Arts', artists with IDD have been neglected. Thus, it seems imperative that work be done to establish and authenticate their legitimacy as artists. The documentation and qualitative research in this project then becomes its own justification because of these circumstances. As Price and Barron state, "honouring artistic expression in this way is a political gesture" (828).

I argue that conducting this research in itself is an act of recognition and validation, an assertion that this subject be taken seriously and has value as legitimate research. It must be acknowledged that the work of John McGregor has been critically important in this regard; in particular, his scholarly documentation and discussion of artists Judith Scott and Dwight Mackintosh sets a standard for the depth of analysis and consideration paid to the working process of these artists.⁶⁶

Concerning the issue of identity, I believe that this research adds to and strengthens the argument that artists with IDD experience authentic art making, and works to help confirm their identification as artists. Identity is dependent on how people see themselves, but also how they are seen by others. One could argue that in the case of people with IDD, how others perceive them has more impact because of the inherent power differential in our society.

Emma mentioned in the interview that one identifier of an artist is that an artist signs their name on their work, thus making her own signing of her work an

⁶⁶ However, McGregor's work does not incorporate any ideas concerning disability theory or disability arts as a movement. It is distinctly possible that when he wrote his books that he was unaware of such as the Disability Rights movement as the fledgling discipline of Disability Studies was barely in existence. It would be of interest to see how he would address his topics through a lens of contemporary thought concerning disability scholarship. Furthermore, it must be acknowledged that McGregor does approach his subjects through a medical model lens, not surprising given his background as a psychiatrist.

acceptance of her identity as an artist. I would suggest that Scott's action of signing his work carried the same intent. My observation would be not that the three artists do not see themselves as artists, because they unquestionably self identify as artists, but rather that the existing challenge is to change the way others perceive them in terms of their identities as artists.

Therefore, establishing that the artists exhibit typical 'artist behaviour' in the way they work is important in establishing identity as artists because it is a factor in how others perceive or recognize them. This qualitative research then challenges stereotypical and limited notions concerning ideas about artists with IDD and works to affirm or strengthen the premise that people with IDD can be authentic artists.

6.7 Dissemination

This was, and continues to be, a crucial aspect of the project and serves to validate artists with IDD, empower the participants and other artists with IDD, and educate the arts community as well as the general public. Dissemination or the after-effects of research are a crucial aspect of emancipatory research; findings must be accessible or 'barrier-free', and available to the participants, and furthermore, put into their ownership. It is imperative to ask of this project, "Who is the research for?", "Who do I want to read it?" and "What impact do I want it to have?" Literature regarding research with people with IDD supports the concept of 'user friendly' dissemination (Gilbert; Goodley and Moore; Mallett, Runswick-Cole and Collingbourne; Rodgers; Ward and Flynn).

While it is obvious that the first audience will be that of academia, in order to fulfill the requirements of my M.A. program, it is of utmost important to me, and is commensurate with an emancipatory perspective, that the information be available and fully accessible to individuals with IDD, their support networks, and policy makers that can effect change in local arts accessibility for adults with IDD.

Although the findings of this qualitative research will not be disseminated in this way specifically, the findings of the research as a whole have been and hopefully will continue to be disseminated as discussed elsewhere in this thesis.

7 CONCLUSION

This chapter includes a review of this thesis with consequent findings and recommendations. Following the overview are discussions concerning potential applications of my research and areas that require more thorough investigation.

7.1 Summary

My research began with establishing a theoretical framework on which to build an examination of the experience and societal status of artists with IDD. I have provided a basic overview of Disability Theory including descriptions of the fundamental theoretical models of disability (medical, social and affirmative models) as well as theoretical aspects pertinent to research concerning IDD. Placing IDD in a historical context helps to locate this group within society at large, while typology and the IQ test are key issues that inform their current status. Referencing earlier writers, as well as noting current scholars who address issues around IDD, helps to situate the under-researched field within the wider scope of Disability Studies. Licia Carlson's theory of 'cognitive ableism' which she describes as being a "prejudice or attitude of bias in favor of the interest of individuals who possess certain cognitive abilities ..." is a crucial concept that is a common thread throughout this project (16).

The field of Disability Arts is undefined and underdeveloped. Art practice as carried out by people with IDD has traditionally been seen as therapeutic in nature, although this view has now been challenged by several writers. At times there is admittedly an overlap between art therapy and an arts orientation, however, arts-

driven practice remains a separate entity (Perring, "Facilitation" 176). As discussed by Ineland, maintaining a balance between these two ideologies is challenging and conflict-laden for arts organizations serving artists with IDD. Respected arts groups Arts Project Australia (APA) and Creative Growth Centre (CGAC) both identify themselves as arts-oriented groups and specifically state that their mandate is not therapy related.

In literature supporting artists with IDD as legitimate artists, writers take one of two approaches, either making use of a political perspective that asserts equal rights in the arts or challenging measurable intelligence (IQ) as a necessary requisite of a visual artist. Siebers challenges the commonly held notion that creativity is linked to genius, saying that if production of art is firmly linked to intelligence, then artists with IDD do not possess the ability to produce creative works of a high standard. He goes on to assert that the example of Judith Scott, who did produce work of high caliber and embodied both a lower measurable intelligence and a high degree of creativity, thoroughly ruptures this notion. Koppers reinforces this when she notes that feminist scholars question reason and independence as the only values or factors in determining competence (*Disability* 74). Recognition of other types of intelligence, as put forth by Gardner, further supports the legitimacy of artists with IDD who, although they may not possess a high degree of intelligence as assessed by standard IQ tests, may have high scores in other types of intelligence. I agree with Swineburne who questions the strong presence of linguistics within the field of contemporary art; she puts forth the notion that visual arts are intended to express that for which there are no words, but are

complicated by an environment that is dependent on a high degree of linguistic facility (2).

Discussions concerning equal rights and the arts tend to be generated from the UK where Disability Arts is strongly linked to political activism. The Disability Equality Scheme (DES) as legislated in the UK, along with the required action scheme, is the most progressive legislation that can be applied to an equal rights agenda in the arts and acts as an agent of social change. The United Nations Convention on the Rights of Persons With Disabilities, recently ratified by Canada, helps to lay a foundation for equal rights and specifically addresses cultural domains, stating that people with disabilities must have “opportunity to develop and utilize their creative, artistic and intellectual potential” (Article 30.2).

The subject of Outsider Art and artists with IDD is a controversial area; writers have varying perspectives as to whether artists with IDD should be included in this loosely defined category or not. Although being designated an ‘Outsider Artist’ can help to raise the profile of an artist with IDD, there are a number of disadvantages to being part of the genre. People with IDD are already seen as outsiders in society, thus an association with Outsider Art can carry negative connotations. Pooling artists with IDD together with a variety of artists from different backgrounds and circumstances can work to negate the unique social/political inequities of this population.

The inclusion of several artists living with IDD who have been documented in print acts to recognize these individuals as artists. Artist Judith Scott has received the greatest amount of attention from scholars, making her a fitting case study in

regards to various discussions concerning artists with IDD, including the aforementioned rupture of the intelligence/creative ability.

There are barriers and benefits specific to the art-making experience of artists with IDD. In Chapter Four the barriers of interference, access, stereotypes, and financial concerns are identified. Arts groups have taken various approaches concerning intervention (Boulangé, Bridie, Daye and Leighton); finding the right balance appears to be a careful negotiation dependent on a sensitive interaction related to the artist's ability to ask for help and at times complicated by end goals like exhibitions or sales. Accessibility has been legislated in the UK with the implementation of the DES; the arts branch of Mencap (UK) is a good source of literature concerning access to art making and works to educate arts organizations and cultural institutions. Other authors (Lee, Lefens) address accessibility as related to individuals who have both IDD and profound physical impairments. Stereotypes can be the conventional low expectations of people with IDD, or those of making 'heroes' or 'super-crips' of the artists, therefore 'othering' them in a more subtle and seemingly supportive fashion. The ostensible advantage of selling artwork must be negotiated carefully for artists with IDD or serious consequences may be created concerning disability benefits.

Although the purpose of this project is not to prove that involvement in the arts is necessary or advantageous to this population, there do appear to be some unique benefits for people with IDD; inclusion of these factors helps to provide a richer contextual understanding of how to both situate and advocate for artists with IDD. Identified benefits are identity formation, enhancement of status, increased choice-

making opportunities as well as additional options for personal expression and additional vocational choices. Assuming the identity of 'artist' can be profound for an individual who is chiefly identified and known as a person with a disability or a 'client', while positive attributes associated with the arts can enhance the status of an individual with IDD. This group typically experiences a low degree of choice making opportunities in their daily lives, however art-making can be rich in this regard, which in turn works to empower and increase self-determination. Arts groups often make a conscious decision to provide maximum choice making possible to their participants (Daye, "Studio" 12). Personal expression is of particular value to individuals with communication challenges and can act as an important tool to represent their experiences and responses to the world (Daye, "Inner" iv). Fraser asserts that art as a vocation is a valid option for certain individuals with IDD, and uses the example of Judith Scott to argue his case.

My involvement as founder and president of Cool Arts is intrinsic to this thesis as background, source of motivation and real-life example of my topic. Founding the group was a response to a need for accessible arts experiences for local adults with IDD. The philosophy has been to focus on opportunities and make those experiences open to the community in contrast to many groups that operate as day programs for a small number of individuals. The focus has been educative, rather than therapeutic, and instruction has consistently been provided by professional artists or art teachers; this quality of instruction has been what sets the group apart from other programs that have a more recreational or social focus. Accessibility is addressed by operating in a central location in a building that is wheelchair

accessible with 'handicap' parking, and by offering workshops at a very low cost to participants. Teaching content and style is adapted to what is optimal for the attending artists. Growth has been gradual and accompanied by a progressive building of steady funding and organizational structure to accommodate the developing group; however, growth will be somewhat restricted until a permanent location can be found. Currently Cool Arts offers weekend and midweek classes, involvement in community events and employs a director part-time. Participants who attend regularly appear to readily accept the identity of artist, and this is enhanced by interaction with the public and sales of work.

The "We Are Artists" exhibition in 2009/2010 was a collaboration between Cool Arts and the Kelowna Art Gallery (KAG). As curator, I had the opportunity to be a part of a real-life example of artists with IDD approaching the borderlines of contemporary art. The predominant aims addressed in the planning phase by the Education Director of KAG and myself were accessibility, public awareness and recognition of the exhibitors as legitimate artists. It was decided that all text in the catalogue as well as exhibition signage would be in Plain Language. The main theme of the exhibition was identity; the body of work was subsequently made up of self-portrait installations, each consisting of a painting, chair and shoes. The exhibition made a strong statement concerning IDD and the arts; it was visually arresting and varied yet cohesive. The opening was extremely well attended and a reflection of interest in the community. The forty-four page catalogue featured an essay, interview and two pages devoted to each of the thirteen artists. Aside from

some differences of view between myself and gallery staff concerning the catalogue, I consider the exhibition to have been very successful.

After the exhibition was uninstalled, various components of the work were shown in other venues, including a conference for the Canadian Association of Community Living in Whistler, BC. Staff at Art Spider, the art website hosted by Mencap, requested images from the show for their website. As far as I know, “We Are Artists” is the only exhibition by artists with IDD to be shown in a public art gallery in BC, or perhaps Canada. My hope is that before too long artists with IDD will have increased opportunities to show their work in curated spaces within Canadian public cultural institutions. As I write this conclusion in June 2011, it has come to my attention that the Berkeley Art Museum in California has recently mounted an exhibition titled “Create” featuring work by a number of artists with IDD from three nearby Disability Arts centres, including CGAC. This appears to be a groundbreaking project and I look forward to seeing what future projects are generated by this exhibition.⁶⁷

Operating as a related yet somewhat separate section, Chapter Six concerns qualitative research conducted with three Cool Arts artists. No other similar research was located in the literature, therefore it was of utmost importance to me to contribute towards a building of likeminded inquiry. The research question was “What is the experience of artists living with IDD in the context of their art making practice, and how does this experience act to help to establish that artists with IDD can have an authentic art-making practice?”; the examined text was the artist’s art-making process, not the finished artwork. My intent was to address a gap in the

⁶⁷ <<http://www.bampfa.berkeley.edu/exhibition/create>>

literature on this topic, and therefore add to the knowledge base as well as empowering the artists by documenting and accordingly validating their artistic processes. Research was informed by Emancipatory guidelines (Barnes, Mercer, Oliver) and further influenced by Feminist Theory and postmodern/poststructuralist perspectives. Each of the participants took part in two sessions: the first was an art-making session and the second was an interview. Footage of the studio sessions was used during the unstructured interviews in a video elicitation process; participants were asked to reflect and comment on what they were watching. Description of the data includes my observations from both sessions as well as segments of dialogue. The third participant (Laura) has limited ability to communicate, so descriptions of data in her case were more dependent on my observations and those of her family who were present for the second session.

Thematic analysis indicated two main themes. Theme One concerned formal or technical aspects of the artist's art-making practice; data indicated that the artists' manner of working was characteristic or typical of the ways that artists work, meaning that their understanding and practice concerning materials, tools and technique indicated experience, capability and a desire to 'act like' or 'identify' as an artist. Each artist had a particular manner of working, each independently created an image, all engaged in choice making as a part of the art-making process, all of the artists demonstrated focus in regards to their work, and, finally, all indicated a desire to share their work with others. Theme Two relates to the essentializing belief that people with IDD tend to be a homogeneous group or that they do things in a similar fashion, even as it extends to their art-making activity. My data challenged

this notion and indicated that the artists all have a unique image bank that they draw from in their work as well as a distinctive style and manner of working; these findings confirm heterogeneity within the group. This is supported by Gibson, Kaitavuori and MacAuliffe.

Two aspects of the qualitative research stood out as being particularly important: documentation of the artists' practice and the matter of identity. Documentation is in itself an act of recognition and validation, particularly as concerns a previously unresearched topic or/and a marginalized group. Problems concerning identity are concerned with how others perceive artists with IDD, not how artists with IDD see themselves. Therefore, establishing that artists with IDD exhibit typical 'artist-like behavior' in the way they work is critical to establishing their identity as artists because it is a crucial factor in how others perceive them. These findings then challenge stereotypical and limited notions concerning ideas about artists with IDD and work to reinforce the premise that people with IDD can be authentic artists.

In respects to an evaluation of the qualitative research, the methods of participant observation, video documentation, and unstructured interviews were largely unproblematic and posed no surprises in their execution, although my less than skilled use of the video equipment did result in loss of sound for one videotaped interview. The strategy of video elicitation was not as successful as hoped, but I believe that this method has the potential to be a useful research process and should be further explored as a method applicable to research with participants with IDD.

My intent was that the literature review and sourcing of any relevant literature was to be as comprehensive as possible with the intent of this thesis acting as a source or guide for other scholars. In particular, much of the 'grey literature' cannot be sourced through the usual academic databases and can be difficult to locate. I believe that interdisciplinary work, particularly in emerging areas of study, cannot be offered under the assumption that readers will be familiar with all disciplines being referenced, therefore I have made an effort to be clear and thorough in regards to foundational concepts.

7.2 Discussion and Conclusions

Any study or research concerning people with IDD should be theoretically informed (Fraser 520), and incorporate a Disability Studies perspective. As previously noted, a socially constructed view of disability as part of an affirmative model approach works to locate sites of cognitive ableism that oppress people with IDD. Study that includes an examination of the societal status of people with IDD requires a careful analysis of power as well as an understanding of historical factors in order to fully contextualize the unique status of this group. The concept of cognitive ableism as put forth by Carlson is essential to unmask hegemonic attitudes that are frequently seen as socially acceptable. I feel strongly that writers should not address the topic of artists with IDD without being aware of the context of this group; the increase in interdisciplinary approaches to scholarship and research necessitates this reminder.

Progressive arts groups that serve artists with IDD model an arts-oriented modus operandi and reject therapeutic approaches. In my opinion, this therapy/arts tension is a settled matter that will eventually take hold as more and more arts programs evolve and society is reeducated concerning the difference between people with IDD needing access as opposed to requiring help or therapy, although admittedly this may be a very slow process.

It is my position that the two positions used to argue for the inclusion of artists with IDD into the realm of contemporary art as legitimate artists are valid. Sieber's argument that disrupts the concept of artists with IDD being unable to create art because of a low IQ is solid. The evidence of high quality work, as produced by Scott, Mackintosh and others confront us with the possibility that "intellectual disabilities can allow for the emergence of unusual, even outstanding artistic abilities" (MacGregor, *One is Adam* 8). The DES as well as the UN document provide solid support for an equal rights agenda concerning artists with IDD. Although the DES is not in effect in North America, the UK is recognized as a leader in this area, thus their initiatives and strategies are seen as templates or models. Questioning linguistic ability as a necessary component of being a contemporary visual artist is a legitimate query and worthy of interrogation. I believe that Gardner's ideas concerning multiple intelligences are valid; his theories have significant applicability to this subject and merit further consideration.

Much of the current situation of artists with IDD involves challenging traditional stereotypes concerning intellect, ability and creativity. Arts groups must be aware of the inherent challenges in working with artists with IDD. Issues of accessibility are

fairly obvious difficulties, but factors of intervention and stereotypical attitudes can be more difficult to locate - such issues may need to be addressed in the group's guidelines for practice.

One potential challenge will be with art critics and writers, who may not be aware of disability issues or rights. McAuliffe states that writers of art criticism will need "to understand the artists' lived experience in more sophisticated ways [and] understand their experience and their art without repeatedly distancing and differentiating them from a norm..." ("Popular" 22). Avoiding perspectives that are essentializing, or that employ a cognitive ableist outlook will be difficult; however, one can look to previous marginalized populations that were gradually included into the art world and observe that these shifts took time and constant negotiation on the part of the minority groups. I suspect that part of the reason that the art world has not addressed this population is that this people with IDD have a nominal voice and minimal power in our society, and thus are overlooked or 'off the radar', so to speak.

My reading of websites and publications concerning other arts groups that support artists with IDD leads me to suggest that APA, CGAC and PA are the best examples of practice, ideology, exhibiting, and collaborations. Writing this thesis has provided me with the opportunity to position Cool Arts within the larger scope of Disability Arts and recognize that CA is doing well in respects to planning, philosophy and programming; the group does draw from a much smaller population base and this is reflected in funding and size of the group. The publication of the "We Are Artists" exhibition catalogue and subsequent dissemination, as noted in Chapter Five, show my intent to further extend this project in a way that will

empower the artists by formally acknowledging their identities as artists, their work as deserving of attention by the art community and exists as a lasting document that is unique in its attention to this population. This dissemination, furthered by increased public awareness as a result of the “We Are Artist” exhibition, supports my goal of this thesis having practical implications.

Throughout this thesis, I have cited from essays from various exhibition catalogues. However, at the same time, I have noticed that the only publications (reports or exhibition catalogues) written in Plain Language have been those from the UK, which conversely did not contain scholarly essays. Certainly there are more publications available than those I have located, and undoubtedly there are some in other languages – French, German, or Japanese, for example, judging from online searches of disability art centres. Even so, this poses the question of whether exhibition catalogues that involve artists with IDD must be one or the other - on the contrary, I believe that writing can be both scholarly and in Plain Language. As noted by Goodley, some scholarly journals like *British Journal of Learning Disabilities* are publishing articles in Plain Language (“Editorial” 50), suggesting that this is possible for exhibition catalogues as well.

In my qualitative research I have made every effort to be cognizant of power inequities and conscious of my own attitudes and feelings. The ethics board review was rigorous and ensured correct protocol. I believe that my previous relationships’ with the participants, and their families, as well as the participants’ lengthy involvement in Cool Arts worked to strengthen the research. My own visual arts background was helpful as well. The aspect of operating in an Emancipatory

framework was necessarily compromised by time constraints; involving the participants as true collaborative researchers in a way that they could share control of the project as per Emancipatory guidelines was impossible. As there were no other similar studies that I could compare my work to, I felt somewhat on my own doing this research. I tried to avoid analyzing the artists' intent or the content of their work, but to instead rely on observations without making assumptions. I believe my findings are sound, but I would like to be able to contextualize and compare them by reading about similar projects.

7.3 Recommendations and Areas for Future Research

Regarding future exhibitions in public art galleries, I recommend that disability awareness training be mandatory for all gallery staff and docents, and that self-advocates be involved in this training. Artists with IDD, and the groups that support them, should be encouraged to submit proposals to public art galleries for exhibition in the designated gallery exhibition spaces and to advocate for inclusion in public art galleries. Public art galleries need to re-think access to their institutions by looking to the example of the UK, where public art galleries and museums are required to develop a "Disability Equality Scheme", accompanied by an action plan; these protocols should be introduced in Canada to ensure full equality and diversity. As suggested by Verrent, Flood and Garside, public cultural institutions should be encouraged to feature work by artists with IDD, as well as take on people with IDD as employees or volunteers(14). Disability advisory groups and committees should include a person with IDD as an advisor on accessibility issues.

I have not addressed or incorporated art theory in this thesis and have instead focused on Disability Theory. There simply is not the time or space here to deal with the large area of art criticism and theory as it applies to artists with IDD. However, I believe that this would be a relevant area of study for future research, as long as the work is contextualized and referenced to Disability Studies to ensure equity for people with IDD. More literature concerning artists with IDD from Critical Theory and Creative Studies perspectives would help to fill the existing void. I believe that there is great value in research projects that incorporate IDD with the Humanities; for some reason this appears to be exceedingly rare.

Any qualitative research would be advantageous to conduct from an Emancipatory perspective, both to give creditability to the research and to bring empowerment and control of the project to the participants. As noted, further research concerning methodologies and methods as well as issues concerning Emancipatory research with people with IDD is needed as well. There is little research that examines the lived experience of people with IDD, particularly those that do not fall into the “high functioning” category. In regards to research becoming more inclusive, Roets and Goedgeluck have set an example of scholarly research co-authored by an academic and a self-advocate; Roets (academic) states her relationship to Goedgeluck (self-advocate) as being Goedgeluck’s “compagnon de route” (105).

Qualitative research that incorporates arts-based methodologies would be very useful in conducting similar research to mine. I believe that video elicitation is a method with potential for this population and merits further investigation; photo-

voice and various video-based methods are also methods to further explore with IDD participants. In my opinion, qualitative research incorporating collaborative art-making practice between an artist with IDD and a non-disabled artist would be an innovative and fascinating study.

7.4 Closing Words

I believe that the most important contribution of this thesis is to add to an under-researched field. This work has value as a source guide or literature review in the way that scholarship from a variety of disciplines have been brought together in a holistic inquiry of visual arts and adults with IDD. Aspects of the qualitative research will be of particular interest to other researchers working with people with IDD. If the thesis were to be reframed in less academic language, it could be useful as a resource for arts groups. Rather than this research project working to answer a single question, I believe it acts as part of a building process as referenced by Barnes, who contends that Emancipatory research must be part of a process that builds on what has gone before (“Emancipatory” 16). This is what I have attempted to do.

Work by artists with IDD acts to transform and challenge genres, artistic criticism, scholarship and hierarchies. In some ways, the condition of IDD and contemporary art have commonalities; according to Kalha, “both disability and art lie outside the social order, both challenging rationality and ‘the normal’” (38). I think this is very true. How to advocate for change? The most practical means may be to educate the arts community when afforded opportunity to do so and to expose

cognitive ableism whenever possible. Artists from non-western cultures were not accepted into the contemporary art world as such until the past century in the same way that female artists were also once seen as not belonging to that domain - is it not time to consider the incorporation of other still-excluded populations?

This thesis has been a labour of love because of my commitment and passion for this subject. However, despite my best efforts to advocate for and speak on behalf of artists with IDD, I cannot truly speak for them. Their work is their voice—more eloquent than their abilities to use words. It expresses who they are to the world.

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APPENDICES

APPENDIX A: Disability Arts Groups (Selected)

Organization	Address	Website	Notes
Abilities Arts Festival	67 Portland Street Toronto, ON Canada M5V 2M9	file://localhost:/file/www.abilitiesartsfestival.org/%253E	Disability arts organization that promotes diversity, inclusiveness and the power of art as a means of enriching the cultural fabric of our communities. Founded in 2003. Toronto based festival.
Arts Project Australia	24 High Street Northcote, Australia VIC 3070	http://www.artsproject.org.au/	APA Mission: To be a centre of excellence that supports artists with intellectual disabilities, promoting their work and advocating for inclusion within contemporary art practice. APA has published several excellent ex. catalogues.
Art Spider (Mencap)	Mencap 123 Golden Lane London, UK EC1Y 0RT	file://localhost:/http://www.artspider.org.uk	Mencap learning disability (IDD) arts website - excellent and extensive resource
BRIAN (BC Regional Integrated Arts Network)	#100 - 938 Howe St Vancouver, BC Canada V6Z 1N9	http://www.kickstart-arts.ca/BRIAN.html	Mandate is to serve the collective interests of BC's Integrated Arts Community serving both 'disability artists' and 'artists with disabilities'
Cool Arts	2920 Fieldstone Ct. Westbank, BC Canada V4T 1S9	http://www.coolarts.ca/	Cool Arts is dedicated to providing fine arts opportunities for adults with developmental disabilities living in the Central Okanagan.
Creative Growth Art Centre	355 24th Street Oakland, CA US 94612	http://creativegrowth.org/	CGAC serves artists with developmental, mental and physical disabilities, providing a stimulating environment for artistic instruction, gallery promotion and personal expression. Several excellent publications.
Creative Spirit Art Centre	999 Dovercourt Rd, Toronto, ON Canada M6H 2X7	http://www.creativespirit.on.ca	Mission: To provide studio space and art resources to artists with emotional, mental and physical disabilities. To collect, exhibit and be a resource centre concerning arts and disabilities.
In-Definite Arts Society	8038 Fairmount Dr. SE Calgary, AB Canada T2H 0Y1	http://www.indefinitearts.com/home.html	IDAS provides a community based creative arts program for over 180 artists who have developmental disabilities. Founded in 1980.

Interact	212 Third Ave. North Suite # 140, Minneapolis, MN USA 55401	http://www.interactcenter.com/index.html	Established 1996. Multidisciplinary Disability Arts Centre. Website: "...driven by a vision of radical inclusion..."
Intuit: The Center for Intuitive and Outsider Art	756 N Milwaukee Avenue Chicago, IL US 60642	http://www.art.org/	Mission: to promote public awareness, understanding, and appreciation of intuitive and outsider art through a program of education, exhibition, collecting and publishing.
Kickstart	#100 - 938 Howe St., Vancouver, BC Canada V6Z 1N9	http://www.kickstart-arts.ca/index.html	Kickstart works to produce Disability Arts Festivals. Mission is to produce and present works by artists with disabilities and to promote artistic excellence among artists with disabilities working in a variety of disciplines. Est. in 1998.
NIAD (National Institute of Art & Disabilities)	551 23rd Street Richmond, CA US 94804	http://www.niadart.org/	NIAD provides an art program that promotes creativity, independence, dignity, and community integration for people with developmental and other disabilities
Nina Haggerty Centre for the Arts	9225 - 118 Ave Edmonton, AB Canada T5G 0K6	http://www.ninahaggertyart.ca/home.php	Mission: To provide a supportive place where people with developmental disabilities can become practicing artists; to promote the Centre's collective of artists; to provide opportunities for exhibition and operate a public gallery.
Project Ability	105 Trongate Glasgow, Scotland G1 5HD	http://www.project-ability.co.uk/	PA serves children, teens and adults with IDD and mental health issues. PA creates opportunities to people express themselves, and achieve artistic excellence.
Raw Vision (Journal)	UK Based	http://www.rawvision.com/index.html	Main journal dedicated to 'Outsider Art' and Art Brut. Features artists with IDD from time to time.
Rockets	c/o School of Arts and Communication, Univ of Brighton, UK BN2 0JY	http://www.rocketartists.co.uk/index.html	Artists with IDD working in collaboration with art students at University of Brighton and connected to research activities.
Shape	Dean House Studios 27 Greenwood Place London UK NW5 1LB	http://www.shapearts.org.uk/aboutus/	Disability-led arts organization working to improve access and develop opportunities for disabled artists. Established in 1976.

APPENDIX B: Disability Arts Documents

DOCUMENT	ACCESS & INFORMATION	LOCATION
Abbas, J., et al. "Lights... Camera... Attitude! Introducing Disability Arts and Culture". <i>Ryerson RBC Institute for Disability Studies Research and Education. 2004.</i>	http://www.ryerson.ca/ds/pdf/artsreport.pdf 55 page paper concerning Disability Arts & Culture within a Canadian context.	Canada
"A Legacy For All Of Us: A Plan for the Development of Integrated Arts and Culture in British Columbia". <i>Report prepared for Kickstart, 2007.</i>	http://www.kickstart-arts.ca/BRIAN.html 60 page extensive report assessing including recommendations.	BC, Canada
Attenborough, Richard. <i>Arts and Disabled People</i> . London: Bedford P, 1985. Print.	Commonly referred to as <i>The Attenborough Report</i> , this document was significant in drawing attention to disability arts in the UK.	UK
"Celebrating Disability Arts".. London: Arts Council England, 2003.	http://www.artscouncil.org.uk 32 page document examines 30 years of Disability Arts in the UK	UK
"Creative Spirit Art Centre: Feasibility Study for a Universally Accessible Art Museum With Studio and Gallery". <i>Prepared by Lord Planning & Management. Toronto: Creative Spirit Art Centre. 2005.</i>	http://creativespirit.on.ca/files/pdfs/csacFeasibility-2Feb04.pdf Of interest for Canadian content regarding Disability Arts with Toronto focus.	Canadian
"Doing, Showing and Going: Mencap's Arts Strategy". Haywards Heath: Mencap, 2002.	< http://www.mencap.org.uk > 21 page document (pdf) written in the context of the Disability Discrimination Act (DDA) in the UK. The report aims to set out a strategy for improving the quality and quantity of opportunities in the arts for people with IDD.	UK

Earncliffe, Jayne. <i>In Through the Front Door</i> . Arts Council of Great Britain, 1992.	100 page guide to arts access in the UK. Includes examples of good practice.	UK
Finklestein, Vic. "London Disability Arts Forum: Disabled People and Our Culture Development". 1987.	Early days of Disability Arts in London. Vic Finklestein is considered a pioneer in the British Disability Arts movement.	UK
Finklestein, Vic and Elspeth Morrison. "Broken Arts and Cultural Repair: The Role of Culture in the Empowerment of Disabled People". <i>Shape</i> seminar, 1991.	Early years of Disability Arts	UK
Jacobsen, Rose and Alex Bulmer. <i>The Picasso Project: A Report From the Field of Disability Arts</i> . 2004.	< http://www.picassopro.org/resources.html > 68 page report that describes and gives examples of Disability Arts in Canada with focus on Toronto and Vancouver.	Canada
Jacobsen, Rose and Geoff McMurchy. <i>Focus on Disability & DEAF Arts</i> . 2009.	< http://www.picassopro.org/focus.pdf > 49 page report on Disability Arts in Canada. McMurchy is the founder and Artistic Director of Kickstart.	Canada
Leeds, Sarah, ed. "Disability Arts & Culture Papers: Transcripts of a Disability Arts & Culture Seminar". Shape: London, 1991.	< http://www.leeds.ac.uk/disability-studies/archiveuk/Lees/arts_and_culture.pdf > Documentation of the beginnings of Disability Arts in the UK.	England
Verrent, Jo; Karen Flood and Gus Garside. <i>Welcoming People With a Learning Disability To Your Venue</i> . London: Mencap, 2004.	< http://www.therfl.co.uk/~rflmedia/docs/venues_accessible_to_people_with_learning_disabilities.pdf > Guide for identifying barriers that prevent people with IDD from accessing the arts. Collaborative Project with U of Brighton Sussex Downs College and Carousel (local arts organization).	UK



APPENDIX C: Qualitative Research Forms

C.1 Information Letter

August 17 '09

INFORMATION LETTER

Research Project –
Visual Arts and Adults with Developmental Disabilities in the Community

Invitation to Take Part in the Research

This project is for Sara Lige's program at UBC Okanagan. Her goal is to show that adults with developmental disabilities have the same art-making experience that everyone else does and also show that they can be genuine and real artists. I am giving you this information on behalf of Sara, because this is the fair way for research to get started.

To do this research, Sara needs your help. She wants to hear from you -what you feel and think while you are making art. You are invited to take part because you have been a regular participant in Cool Arts for more than a year. You only have to participate in this project if you want to – if you don't want to, you don't have to, and once the project starts, you can leave anytime. If you decide not to participate, Sara will not mind at all and you can still be in Cool Arts.

How will the project work?

Sara will be asking people about their experience of making art. She will not be researching or examining the artwork you make, so you don't have to worry about making a masterpiece! While you are making the art, there will be one or two video cameras filming you. After you finish making the art, Sara will ask you a few questions. There will be no 'right or wrong' answers – you just have to tell her what you think or feel. This session will take between one and two hours. It can be at Kelowna and District Society for Community Living (KDSCL) or somewhere else if you prefer.

Researcher Stephen Foster (Principal Investigator.) Sara Lige (M.A. student) University of British Columbia Okanagan



A few days later Sara will meet with you and together you will look at the video of you working and talk about it. Sara will ask a few more questions. Again, this should take between one and two hours. This can be at KDSCL again or at your home, depending on what you would prefer. You can have someone else there at both sessions if you choose, like your caregiver, a friend or family member.

This project will not be confidential or private

The goal of this research is to show the arts community, the disability community and everyone else that adults with developmental disabilities can be authentic or real artists.

Next November, there will be an art show with all the Cool Arts artists at the Kelowna Art Gallery. The art show will not be research, but it will be a good opportunity to share some of the information from the research project. There will be a catalogue, or booklet, for the show. There will also be a video showing some of the research for people to see. We believe that it is important to have your name in the booklet and have people see you on the videotapes. This will to explain the project and also show you as an artist.

In the consent letter, you will also be asked if a researcher can use the information from this research again for another project. We think that the information from the video and the interview could be very useful again. This is called “Secondary Use of Data”.

What's next?

This letter is to tell you some basic information about the project. Please contact Sara if you have any questions. You may also want to talk to someone else about it, like your caregiver, friend or family member. If you don't have questions – that's fine.

Researcher Stephen Foster (Principal Investigator.) Sara Lige (M.A. student) University of British Columbia Okanagan



If you want to take part, Sara will need to meet with you to go over the consent form. This form is to make sure that you understand the project and want to take part.

Right now, we want you to think things over. If you want to participate, you must email or phone Sara to tell her. Sara is not allowed to contact you until you tell her that you want to participate. If you do not want to participate, you do not need to contact her.

In research, it is common for some people to choose to participate and others to decide not to participate in the research. If you do not want to be a participant in the research project, you can still stay in Cool Arts and your relationship with Sara will not be affected.

If you say yes, you will need to sign the consent form. You can ask a trusted person (for example, a family member, friend or caregiver) to help you with the consent form. Sara will also go over the form with you to help you understand and answer any questions you have.

You must contact Sara if you wish to participate, within two weeks if possible.

In two weeks, Sara will know how many people are interested in participating. She will choose three or four participants from those who responded to this letter.

Thank you.

Shauna Oddleifson

Researchers

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C.2 Consent Form

Date:

Consent Form

*Research Project –
Visual Arts and Adults with Developmental Disabilities*

PART ONE

Invitation to Take Part in the Research

This project is for Sara's thesis program at UBC Okanagan. The goal is to show that adults with developmental disabilities experience art-making like everyone else and can be genuine and real artists. We want to hear directly from you about what it is like to make art. We hope that this information will help to educate non-disabled people about what people with developmental disabilities can do.

Why are you asking me?

You are being invited because you have been a participant at Cool Arts for more than a year, and because you receive services from Community Living British Columbia (CLBC).

What will I have to do?

There will be an art making activity for you to participate in. Sara will bring all the supplies for you. She will be asking you about your experience while you make art. There will be two video cameras to videotape you while you are working and Sara will also be watching you as you work and making notes.

After you are done, Sara will ask you a few questions. These are not the kind of questions you can get wrong – any answer you give is fine. This session will take between one and two hours. It will be either be at Kelowna and District Society for Community Living (KDSCL), where Cool Arts usually is, or somewhere else if you prefer.

Researcher: Stephen Foster Assoc. Professor (Principal Investigator), Sara Lige (M.A. student at University of British Columbia Okanagan, Faculty of Creative and Critical Studies.



What happens after that?

About a week later, Sara will meet with you. You and she will watch the video of you working and talk about it. Sara will ask you some questions about what you were thinking or feeling while you worked on your art. This session will also take between one or two hours. This session can be at your home or KDSCL. You can have someone with you at both the art making activity and the meeting after that. That person should be someone you trust – your caregiver, a friend, or a family member.

Why is this project important?

This project is about showing the public that adults with developmental disabilities can be real artists.

Can I see what you write about me?

Yes. After all the information is collected, Sara will organize it and write it all down. She will check with you to make sure you agree with the results. You are part of this research!

What if I change my mind?

At any time during the project, you can decide to not answer a question or stop participating in the project. If you decide to not participate at any time, you can still be in the Cool Arts group and your relationship with Sara will not be affected. If you need to talk to someone, we will provide you with a list of people that can help you.

Do I get anything for being in the project?

At the end of the project, every participant will receive a \$40 gift certificate for art supplies. If you decide to leave the project partway through, you will still get the gift certificate. Any money that you or the person with you has to spend to take part in this project will be paid back. This includes babysitting, gas and parking.



Your signature here means that you are saying yes to taking part in this project.

Print Name

Signature

Date



Faculty of Creative and Critical Studies
3333 University Way
Kelowna, B.C., Canada V1V 1V7
Tel: 250.807.9761
Fax: 250.807.8027

PART TWO

Will what I say be private?

No, it won't. To do this project, we need to be able to share who you are and what you have said. This means that people will know you were involved with the project and what you said to Sara about how you think and feel when you make art.

We think that it is very important that you and the other research participants are recognized by other people as real artists, so your first and last names will be used in the research project.

In November 2009 there will be an art show to exhibit the work of all the Cool Arts artists. This art show will not be research. However, the show will be a great opportunity to share some of the comments made in the interviews and parts of the video. The artwork in the show will be what you make with the other Cool Arts artists on other days – not what you make during the research project.

If you decide later that you would rather not have people know what you said in the interviews, you can tell us and we will take those parts out.

Will people know that it will be me in the video?

Yes, they will. They will know because they will see your face and hear you talking. The reason that this is important is this: often in research about people with developmental disabilities, we only hear and see what people without disabilities say. We think it is really important to hear right from you and the other participants, because you are the experts about yourselves. Your name will be used in the video.

So if you have any concern or problem about people seeing you in the video or reading about you, you need to tell us. You don't have to explain why if you don't want to. If you don't want anyone to see you or read about you, it would be better if you did not take part in this project. You need to do what is right for you.

It is important for you to understand that in this project, identities and information are not confidential or private.



If you agree with these conditions, please sign below.
If you do not agree, do not sign.

Print Name

Signature

Date



PART THREE

We would like to use the research information again after the project is over.

If a researcher wants to use research notes or videotapes after a project is finished for another research project, that is called “Secondary Use of the Data”. For example, if Sara does another research project about Disability Arts in a couple of years and uses the information from this research project, that would be “Secondary use of the Data”.

We think that the information from this project will be very useful to have for other research projects to help more people understand about Disability Arts.

If you consent to having the information from this research used later as “Secondary Use of Data” please sign below.

If you do not agree and don’t want the research information used later, then do not sign .

Print Name

Signature

Date



If you have any questions, you can contact Sara Lige at 250 768-5548 or tslige@shaw.ca

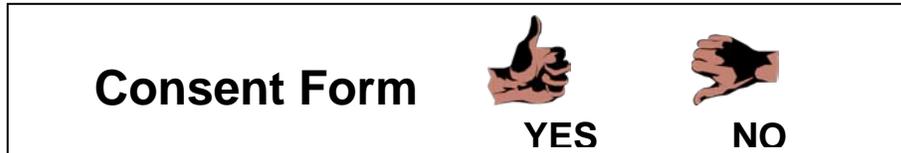
If you have any problems with the project or how you have been treated, you can call the Research Subject Information Line in the UBC office of Research Services at 604-833-8598 or RSIL@ors.ubc.ca



C.3 Pictorial Consent Form

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Fax: 250.807.8027

Date:



PART ONE

You are being asked to take part in a research project.



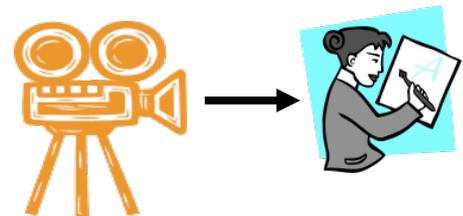
The person who will be doing the project with you will be Sara Lige, from the University of British Columbia Okanagan. You know her from Cool Arts.



Sara will ask you to come to an art activity. Then she will ask you questions.



While you are working on your art, you will be videotaped.



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Later you and Sara will meet again. You will both look at the video and talk about it.



This project will show others that people with developmental disabilities can be artists

Sara will write about you making art. She will show it to you later. You can change it if you like.



It is ok to leave the project at any time.



You can still be in Cool Arts and your relationship with Sara will not change.



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**You will get a \$40 gift certificate
for being in the project.**



**If you have any questions or want more
information, you can contact Stephen
Foster at 250-807-9767 or
Sara Lige at 250-768-5548 or tslige@shaw.ca**

**Your signature means that you want
to be involved with this project.**



PRINT NAME

SIGN NAME

DATE

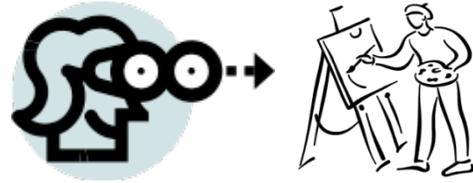
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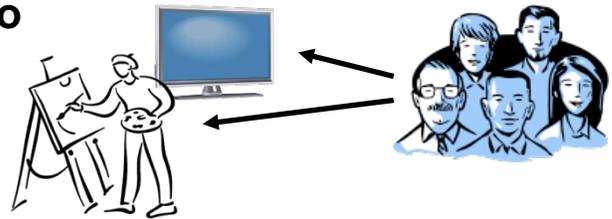


PART TWO

What you say in the research will not be private.



People will see you on video making art and hear what you say about it.



But if you want, you can say that you don't want anyone to see you on the video or know your name.



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Your signature means that you understand that people will see your face and know your name and that you do not mind.



If you do NOT want your face or name shown, then do NOT sign this sheet.



PRINT NAME

SIGN NAME

DATE

Researcher: Stephen Foster(Principal Investigator), Sara Lige (M.A. student at University of British Columbia Okanagan, Faculty of Creative and Critical Studies

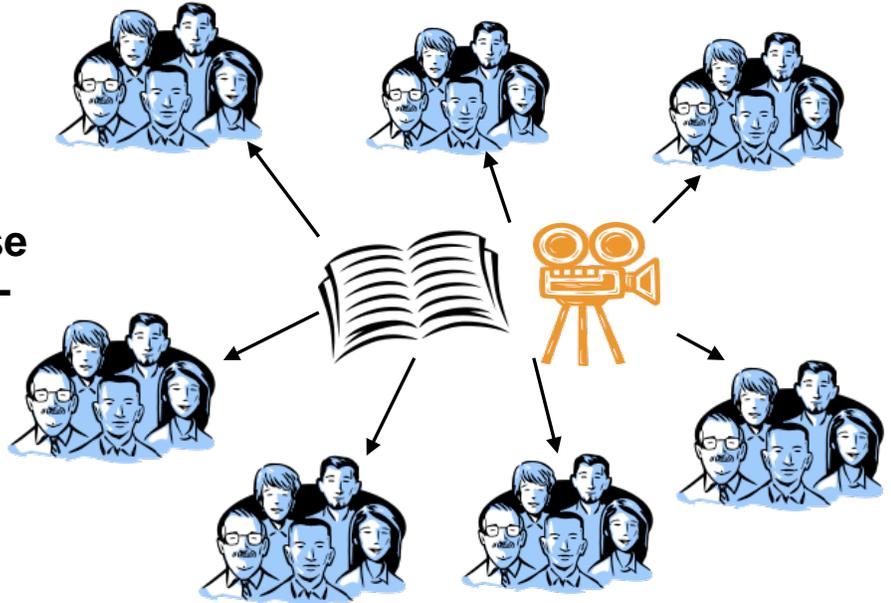
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PART THREE

We would like to use the research again - after the project is over for other research projects.



We think the video and interview will important information for other researchers.

This way – many people can read and see about people with developmental disabilities being artists.



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Your signature means that you understand and agree with the information being used again after the research is over for another research project.



If you do NOT want this research information used for another project then do NOT sign this sheet.



PRINT NAME

SIGN NAME

DATE

Researcher: Stephen Foster(Principal Investigator), Sara Lige (M.A. student at University of British Columbia Okanagan, Faculty of Creative and Critical Studies