

THE RIGHT TO BE AN ARTIST: OPERATIONALIZING STUDIO ART PRACTICES FOR  
PEOPLE WITH COGNITIVE AND INTELLECTUAL DISABILITIES

CHRISTINA YARMOL

A DISSERTATION SUBMITTED TO  
THE FACULTY OF GRADUATE STUDIES  
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS  
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

GRADUATE PROGRAM IN CRITICAL DISABILITY STUDIES  
YORK UNIVERSITY  
TORONTO, ONTARIO

October 2020

© Christina Yarmol, 2020

## Abstract

This dissertation, *The Right to be an Artist: Operationalizing Studio Art Practices for People with Cognitive and Intellectual Disabilities* examines the practical, philosophical, fiscal and social policy realities of people with cognitive and intellectual disabilities (CIDs) who want to live as artists in the community. It investigates the art practices of 16 local artists working in an urban studio endeavouring to realize their dreams against the barriers mounted by existing disability policies and the art world. Due to the nature of the participants' disabilities, the research also looks to eight individuals who support these artists' journeys, deepening the reader's understanding of studio processes and supports. This multi-methods study weaves narrative inquiry and arts-informed methodologies into an intricate tapestry employing methods such as review of literature, face-to-face interviews, participant observation, collaborative artwork, art creation, art analysis and the researcher's journaled personal experiences as an artist, an art educator, and a researcher.

Since art making is central to knowledge-building in this dissertation, each chapter begins with an artwork and an artist's statement by the artist-teacher-researcher to orient the reader toward the author's thinking. The chapter outlining the narrative data of the participants also highlights a collaborative drawing project between the researcher and an artist at the studio. A series of seven handmade books entitled *Coffee Talk* hold graphically designed artists' statements written in conjunction with the study's artist-participants accompanied by a selection of artworks commending and crediting their knowledge. All pages can be inserted into the books' concertina bindings and viewed privately or withdrawn and mounted alongside artists' physical artworks in a formal, public-exhibition setting. Although society often labels their work under many banners such as Art Brut, Outsider Art, Naïve Art, it is the researcher's belief that this work should be labelled simply as Art whose unique style and rationale stem directly from each of the artists who created it.

## **Dedication**

Firstly, this dissertation is dedicated to the first two philosophers I knew, my dearly departed parents, Elsie Yarmol (née Lesia Stoyko) and Paul Yarmol. Their sage advice taught me to see the good in everyone and helped me become the person I am today.

Secondly, to all of artists at Creative Village Studio who have taught me more than they will ever know. They have deepened my scope of knowledge about what it means to be an artist.

## Acknowledgements

Thank you to my supervisor, Doctor Nancy Viva Davis Halifax, who encouraged me to be a more critical thinker and more attentive to language. She provided a firm direction and a grounding for my whirlwind of thoughts and runaway rhizomatic thinking. As an artist, she readily and intimately communed with my creative process and its results. I thank my committee Doctors Elizabeth Dauphinee and Marina Morrow who asked me pertinent questions, advised me on how to tweak my arguments to better the communication of my project. I also thank the members of the examination committee, Doctors Rachel da Silveira Gorman (chair), Cheryl van Daalen-Smith (internal member), and Maureen Connolly (external examiner), for their curiosity and inquisitiveness about how this research can impact its artist-participants to achieve cultural citizenship. It was invigorating to learn that there are many others in the world working to create praxis for people with cognitive and intellectual disabilities.

To Harold Tomlinson, who with his magnanimous spirit openly welcomed me into the Creative Village Studio community. I respect Harold's knowledge of the visual arts, disability, and social policy as it applies to social services. He has woven these strands together in his practice to create more than just an activity centre. His sense of judgement and keen instinct for people's needs, coupled with his compassionate nature makes everyone in the shared studio comfortable to be themselves. His positive, outgoing attitude and his boundless sense of adventure expand the possibilities for the artists at Creative Village Studio. His regard, respect and compassion for people make him an indispensable asset to any community in which he works. Without Harold's unwavering support, this study would not have been possible.

I thank the study participants including the artists, parents, volunteers, instructors, and gallery owner for sharing their personal stories and their wisdom. The artists were so generous in sharing their art making stories and their artwork with me. It was a pleasure to work along side them.

Thank you to Community Living Toronto whose members continuously advocate for the rights of people with disabilities.

Lastly, I thank my husband, Eric Matusiak who supported me socially, emotionally and physically through the lengthy duration of research and writing of this dissertation. Thank you to my children Erica (three cheers for her technical support), Michaela and Nathaniel Yarmol-

Matusiak who grew to value how important art and working with people with CIDs is to their mother. Their patience, understanding and support assisted me to see this work to its fruition.

## Table of Contents

Abstract .....	ii
Dedication .....	iii
Acknowledgements .....	iv
Table of Contents .....	vi
Frequently Used Acronyms .....	xi
List of Figures .....	xii
List of Illustrations .....	xvii
Note to the Reader .....	1
Chapter One: Preparing the Canvas .....	3
What is this Dissertation About? .....	4
What Contribution Will This Study Make to The Field? .....	4
Organization .....	9
Language & Terminology .....	12
Chapter Two: Weaving a Tapestry: Methodology and the Methods .....	16
Multiple-Methods: A Bricolage .....	18
Art-informed methodologies .....	19
A/r/tography. ....	21
The sketchbook as data. ....	25
Artwork. ....	27
Narrative Methodology .....	27
Narrative framework of Gabriela Spector-Mersel. ....	28
Model for interpreting narrative data. ....	31
Positionality of the researcher. ....	35
The researcher’s story .....	36
Paolo Freire: Transformation as an inspiration .....	39
Crip Theory .....	44
Methods .....	47
Limitations of study. ....	51
Chapter Three: Flexible Embodiment in Social Policy for People with Cognitive and Intellectual Disabilities .....	53
What is Disability Policy? .....	54
The History of Community Living .....	55

Sheltered Workshops as Social Policy.....	56
Visit to supported work & community activities (SWACA).....	60
Brands for Canada a.k.a. Windfall.....	63
Supports Available for People with Cognitive and Intellectual Disabilities .....	64
Federal supports.....	65
Provincial personal supports.....	66
Employment programs/ODSP.....	68
ODSP & Arts Grants Coalition.....	73
The Passport Initiative and How it Works.....	76
For whom is the Passport Program designed? .....	76
Why is Passport funding provided? .....	79
When is the Passport Initiative accessed?.....	81
What does Passport Initiative provide?.....	82
Where can one apply for Passport Funding?.....	84
How to gain access to the Passport Initiatives, assess service and support needs. .	84
Is individualized funding the answer?.....	87
Chapter Four: Being an Artist: Studio Process and the Resonance of Art Practice .....	92
The Art World.....	94
Personal Biography in Art .....	94
Art Brut, Outsider, Naïve Art —Just Call it Art.....	98
Outsider Art .....	101
The Role of the Curator & Curatorial Practice with a Disability Studies Bent .....	105
Studio Habits of Mind.....	115
What is Art Facilitation?.....	117
Chapter Five: What? What Do Participants Say?.....	120
What? .....	122
How Creative Village Studio Began.....	122
The Studio Setting.....	124
Data Collection .....	126
General findings for all CVS artists.....	131
Consider themselves to be artists. ....	131
Communicate a sense of pride in their work.....	134
Limited knowledge of financial issues.....	136

Findings for specific CVS artists. ....	141
Frequency and duration of participation.....	141
CVS artists for 6 to 10 years.....	142
CVS artists for 3 to 5 years.....	144
CVS artists for 1 to 2 years.....	145
Time at studio = increased level of confidence. ....	145
Development of style and subject matter. ....	149
Operationalization of studio experiences for people with CIDs. ....	156
Why do artists enjoy coming to the studio? “It is an enjoyable place to be” .	156
Predictable, organized, routine. ....	156
The importance of social aspects at the studio. ....	159
Safe and welcoming atmosphere. ....	161
Instructional methods, accommodations and supported learning through the facilitator, instructors, and volunteers. ....	163
See it, say it, do it approach.....	167
Supports for illustration.....	168
Exhibition: Names for the planned show. ....	173
Interviews with volunteers. ....	174
Why volunteer? .....	174
Training. ....	175
Essential attributes of a volunteer.....	176
How volunteers support artists in the studio. ....	177
How the instructor supports the artists. ....	179
Studio successes and challenges.....	179
Suggestions for improving the program. ....	181
Sharing their learning and end points of interviews.....	181
Interviews with parents. ....	183
Laura Parsonson’s view of program. ....	184
Artist as self-concept. ....	184
Available studio supports. ....	185
The funding process.....	185
Benefits and drawbacks of studio art programs.....	186
Anna Simonyi’s view of program. ....	190

Artist as self-image.....	191
Available studio supports.....	192
The funding process.....	192
Benefits and drawbacks of studio art programs.....	193
Shannon Groom’s view of program.....	194
Interviews with instructors.....	198
Yona Reznick.....	198
Cait Mitchell.....	200
Shannon Groom.....	203
Harold: The key facilitator at Creative Village Studio.....	208
Facilitator’s background.....	208
Goals for program.....	208
Accommodations.....	208
Essential skills of instructors for people with cognitive and intellectual disabilities.....	211
Successes and challenges of the job.....	213
Program payment.....	214
Evolution and growth of the studio model.....	215
Exhibition.....	215
Conclusion of Harold’s interview.....	216
Visiting Joshua Creek Heritage Art Centre.....	218
Chapter Six: So, What? New Understandings or Findings.....	220
Conclusion.....	223
Questions for further study.....	229
Now what?.....	229
References.....	233
Appendices.....	259
Appendix A: Tiled Images of Book Covers, Their Endpapers & Book’s Contents.....	259
Appendix B: Samples of Interior Endpapers of Books.....	260
Appendix C: Sample Book Pages with Quotes & Artists’ Statements.....	261
Appendix D: TCP2 (REB) Ethics Process.....	263
Appendix E: Process Documentation of Making a Frida Kahlo Marionette.....	264
Appendix F: Use of Human Participants Ethics Approval Notice.....	265

Appendix G: Snowball Sampling Poster .....	265
Appendix H: Letter of Information.....	267
Appendix I: Assent Form (Letter of Information) .....	269
Appendix J: Consent Form for Participation in Study and Video Tape Recording of Interview .....	270
Appendix K: Consent for Legal Guardian for Child/Ward’s Participation in Study and Videotape .....	271
Appendix L: Consent Form Photography and Use of Name .....	272
Appendix M: Consent for Legal Guardian Interview, Photography of Artwork and Artist’s Name .....	273
Appendix N: Consent Art Show Participation.....	274
Appendix O: Consent Form for Legal Guardian for Participant’s Art Show Participation..	275
Appendix P: Letter of Information for Administrators and Art Instructors.....	276
Appendix Q: Consent Form for Administrators and Art Instructors .....	278
Appendix R: Plain Language/Pictorial Consent Form Support for Letter of Information ...	279
Appendix S: Checklist for Consent Forms .....	283
Appendix T: Interview Questions.....	284
Appendix U: The Activism of Community Living Organizations .....	286
Appendix V: Federal Supports for People with Disabilities.....	292
Appendix W: What Galleries Want .....	294
Appendix X: Passport Program Assessor’s Rubric .....	296
Appendix Y: Passport Funding: What Can I Use It For? .....	297
Appendix Z: Exemplars Submitting Expenses Passport Forms .....	298

## **Frequently Used Acronyms**

CACL – Canadian Association for Community Living

CID – cognitive and intellectual disability

CIDs – cognitive and intellectual disabilities

CVS – Creative Village Studio

DSA – Developmental Services Act

DSO – Developmental Services Ontario

ID – Intellectual Disability

I/DD – Intellectual/Developmental Disability

IFCO – Individualized Funding Coalition for Ontario

MCSS – Ministry of Children, Community and Social Services

ODSP – Ontario Disability Support Program

OW – Ontario Works

SIPDDA – The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act

SWACA – Supported Work & Community Activities

## List of Figures

Figure 1: Sample Table Indicating Analysis of Coded Interview Data .....	33
Figure 2: Image of Exterior Community Living SWACA program, 288 Judson Avenue, Unit 17, Retrieved from <a href="https://www.google.com/maps/">https://www.google.com/maps/</a> .....	60
Figure 3: Yarmol, C. (2019). Sketchbook Plan of SWACA Space, Judson location, [Pencil on cartridge paper, 5" x 7"].....	61
Figure 4: <i>Creative Village Studio</i> (2019) exterior view location in the community, Retrieved from <a href="https://www.google.com/maps">https://www.google.com/maps</a> .....	124
Figure 5: Yarmol, C. (2020). <i>Creative Village Studio interior view facing north</i> . [Digital photograph].....	125
Figure 6: van Duffelen, E. and Yarmol, C. (2019), <i>Evelyn on Different Days</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	129
Figure 7: van Duffelen, E. and Yarmol, C. (2019), <i>Emily in Blue</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	131
Figure 8: <i>Interview with Emily Parsonson</i> . [Video Still of Emily Parsonson with acrylic on paper cardstock from card making, CVS class, 5" x 7"]. card. ....	132
Figure 9: Parsonson, E. <i>Emily's Spring Collection May 7, 2016 book cover memorabilia book compiled for Emily's show</i> . [Ink on Paper, 8 ½" x 11"].....	133
Figure 10: van Duffelen, E. and Yarmol, C. (2019), <i>Juan Meneses</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	133
Figure 11: Meneses, J. <i>Menzes Video Still</i> . (September 23, 2019). [Video Still of a sketch Juan created at home for a painting captured on his cell phone]. ....	134
Figure 12: van Duffelen, E. and Yarmol, C. (2019), <i>Sabrina</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	134
Figure 13: Simonyi, S. (2018) <i>Sabrina with artwork from an art show and close-up of painting sold, Frida Kahlo with Pet</i> . [Digital photograph].....	135
Figure 14: van Duffelen, E. and Yarmol, C. (2019), <i>Johnfredy</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	136

Figure 15: Interview with Johnfredy Salazar, Interview September 19, 2019, 3:06, <i>The Wall in Islington Village</i> . [Video Still containing digital print 18" x 24"].....	136
Figure 16: van Duffelen, E. and Yarmol, C. (2019), <i>Steve</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	137
Figure 17: van Duffelen, E. and Yarmol, C. (2019), <i>Astra</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	137
Figure 18: van Duffelen, E. and Yarmol, C. (2019), <i>Conrod</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	139
Figure 19: Yarmol, C. <i>Conrod on Dundas Street Showing Me His New Wheels</i> , (October 3, 2019). [Digital Photograph].	139
Figure 20: Milberg, A. (2018), <i>Be Kind &amp; Truthful in Your Life</i> . [Two scrapbook pages, glue, magazine, ink, crayon, and felt tip marker on cartridge paper, 17" x 22"].....	141
Figure 21: van Duffelen, E. and Yarmol, C. (2019), <i>Jack</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	143
Figure 22: Salazar, J. (2018), <i>Gyration</i> . [Digital Photograph, ink on photographic, 24" x 32"].....	144
Figure 23: van Duffelen, E. and Yarmol, C. (2019), <i>Neil</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	146
Figure 24: Clifford, N., (February 13, 2020), <i>Sketch of a proposed cityscape work</i> , [Pencil on cartridge paper, 8 ½" x 11"].....	146
Figure 25: Video still of Interview with Neil John Douglas Clifford (4:52), September 23, 2019, <i>City Scene in process</i> . [Acrylic on Canvas, 12" x 14" ] .....	147
Figure 26: Video still of Interview with Neil John Douglas Clifford (5:03), September 23, 2019, <i>Toronto</i> . [Acrylic on Canvas, 12" x 14" ].....	147
Figure 27, Matthew Sheeny, <i>Dandelion</i> . (September 1, 2019 Acrylic Painting Class creation), [Acrylic paint on canvas, 14" x 17"].....	148
Figure 28: <i>Joshua Creek Printmaking Studio</i> — from left to right the artwork of Conrod, Evelyn, Quyen, Neil, Evelyn, and Quyen hangs, December 9, 2019. [Digital photograph].	149

Figure 29: <i>Joshua Creek Studio</i> —from left to right the artwork of Donna, Quyen, Donna, and Conrod’s hangs, December 9, 2019. [Digital photograph].	149
Figure 30: van Duffelen, E. and Yarmol, C. (2019), <i>Donna</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].	150
Figure 31: Yarmol, C. <i>Donna Worotyneć holding an image of her sold painting</i> . (July 3, 2019), [Digital Photograph].	150
Figure 32: van Duffelen, E. and Yarmol, C. (2019), <i>Quyen</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].	151
Figure 33: Ngo, Q. (2019) <i>Quyen, Girlfriend and Mountain</i> . [Acrylic paint on canvas, 18" x 24"].	151
Figure 34: Ngo, Q. (2019), <i>Still-life with Flowers in process</i> . [Acrylic paint on canvas, 24"x 18"].	152
Figure 35: Skyers, C. (2019) <i>Canadian Scene</i> . [Acrylic paint on canvas, 24" x 32"].	153
Figure 36: Skyers, C. (2019), <i>Out of Africa</i> . [Acrylic paint on canvas, 24" x 32"].	153
Figure 37: Skyers, C. (October 3, 2019) <i>Video-Still of Conrod and Beyoncé Painting in Process</i> . [Acrylic on masonite, 48" x 72"].	154
Figure 38: Skyers, C. (2019) <i>Conrod and Beyoncé</i> . [Acrylic paint on masonite, 48" x 72"].....	154
Figure 39: van Duffelen, E. and Yarmol, C. (2019), <i>Lisa</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].	155
Figure 40: Tuckwell, L. (2019). <i>Video Still of Photograph of Mare and Foal</i> . [Photograph, digital print, ink on photographic paper 5" x 7"].	155
Figure 41: <i>Conrod’s “Window Painter” Space</i> . [Video still from C. Skyer, personal communication, October 3, 2019].	157
Figure 42: <i>Patricia’s Pink Bin</i> . [Digital photograph], February 13, 2020.	157
Figure 43: Meneses, J. (2020), <i>Flowers in Vase in Process</i> . [Acrylic paint on canvas, 26" x 24"].	158

Figure 44: van Duffelen, E. and Yarmol, C. (2019), <i>Matthew</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	159
Figure 45: Yarmol, C. (October 3, 2019). <i>Matthew Sheeny enjoying a coffee at a weekly painting class before he starts to work</i> . [Digital photograph].....	160
Figure 46: Yarmol, C. (February 13, 2020). <i>Matthew Sheeny working on a painting for Valentine's Day for his girlfriend</i> . [Digital photograph].....	160
Figure 47: van Duffelen, E. and Yarmol, C. (2019), <i>Betsy</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	161
Figure 48: van Duffelen, E. and Yarmol, C. (2019), <i>Patricia</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	161
Figure 49: Photograph of a Greeting card: <i>Tropical Flower</i> (2019), P. Habuda. [Felt tip marker and pencil crayon on cardstock, 7" x 5"].....	162
Figure 50: Salazar, J. (2019), <i>Peace. in progress</i> . [Acrylic paint on canvas Felt tip marker and pencil crayon on cartridge paper, 11" x 17"].....	169
Figure 51: van Duffelen, E. and Yarmol, C. (2019), <i>Lisa Painting</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	171
Figure 52: van Duffelen, E. (2018), <i>My Community</i> on the CVS wall. [Painting, mixed media, pencil crayon on paper, glue, acrylic on canvas, 24" x 36"].....	172
Figure 53: van Duffelen, E. and Yarmol, C. (2019), <i>Beverly</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	174
Figure 54: van Duffelen, E. and Yarmol, C. (2019), <i>Lois</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	177
Figure 55: van Duffelen, E. and Yarmol, C. (2019), <i>Pina</i> . [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].....	179
Figure 56: van Duffelen, E. and Yarmol, C. (2019), <i>Laura</i> . [Felt tip marker and pencil crayon on cartridge paper, 8½" x 11"].....	184
Figure 57: Parsonson, E. (2019). <i>Dancing with the Stars</i> . [Acrylic paint on canvas, 16" x 18"].....	185

Figure 58: van Duffelen, E. and Yarmol, C. (2019), *Anna*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"]..... 190

Figure 59: van Duffelen, E. and Yarmol, C. (2019), *Yona*. [Felt tip marker and pencil crayon on cartridge paper, 8½" x 11"]..... 198

Figure 60: van Duffelen, E. and Yarmol, C. (2019), *Cait*. [Felt tip marker and pencil crayon on cartridge paper, 8½" x 11"]..... 200

Figure 61: Mitchell, C. (2010). *The Photographers*. [Digital photograph]. ..... 201

Figure 62: Mitchell, C. (2010). *Contact Photography Exhibit: Creative Village Studio*. [Photograph of Participation in the Contact Photography Exhibit, Creative Village Studio from <https://caitmitchell.myportfolio.com/creative-village-studio>] ..... 202

Figure 63: van Duffelen, E. and Yarmol, C. (2019), *Shannon*. [Felt tip marker and pencil crayon on cartridge paper, 8" x 11"]..... 203

Figure 64: van Duffelen, E. and Yarmol, C. (2019), *Harold*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"]..... 208

Figure 65: Artist at CVS (2019). *Painting Exercise in Progress*. [Acrylic paint on canvas, 12" x 8"]..... 211

Figure 66. Yarmol, C. (2019), *Sybil*. [Sharpie on cartridge paper, 8 ½" x 11"]. ..... 218

Figure 67. Skyers, C. *The Chronicle Pamphlet from Art from the Heart Show 2020* (2019). Arctic. [Original artwork acrylic paint on canvas, 3' x 4']..... 219

## List of Illustrations

Illustration 1: Yarmol, C. (2018). <i>Replanting the Forest</i> . [Mixed media acrylic paint, tissue paper cartridge paper, newspaper, glue on wood panel, 24" x 28"]. .....	3
Illustration 2: Yarmol, C. (2018). <i>Thinking About Language</i> . [Sketchbook Drawing on paper with pencil and silkscreen ink in right, 3 pages, 8 ½" x 11"]. .....	14
Illustration 3: Yarmol, C. (2018). <i>BS Series: 2.7, Felt It!</i> [Sculpture with dyed felted fleece, 10" x 8"].....	16
Illustration 4: Yarmol, C. (2017). <i>BS Series: 2.7</i> . [Painting with aquarelles and water colour paint on paper, 8 ½" x 11"].....	18
Illustration 5: Yarmol, C. (2019). <i>BS Series: 2.6</i> . [Monoprint with aquarelle crayons on paper, 6" x 6"].....	19
Illustration 6: Yarmol, C. (2018). <i>BS Series: 2.4 Felt it!</i> [Sculpture with dyed felted fleece, 15 " x 11 " ].....	22
Illustration 7: Yarmol, C. (2019). <i>Artist/Researcher/Teacher: Connections</i> . [Sketchbook Drawing with coloured Sharpie and acrylic ink on paper), 11" x 11"].....	23
Illustration 8: Yarmol, C. (2019). <i>Being a Fly on the Wall...</i> [Drawing with pencil and black pen), 8 ½" x 11"].....	26
Illustration 9: Yarmol, C. (2017). <i>BS Series: 2.4</i> . [Painting with aquarelles and water colour on paper. 8 ½" x 11"].....	30
Illustration 10: Yarmol, C. (2011). <i>Frida Kahlo Marionette</i> . [Sculpture: Sculpey, acrylic paint, fishing line, wood, pressboard, cotton fabric, wooden beads, silk flowers, 36 h" x 11"w x 5"d].43	
Illustration 11: Yarmol, C. (2019). <i>BS Series: Hi, High</i> . [Monoprint with aquarelle crayons on paper, 6" x 6"].....	44
Illustration 12: Yarmol, C. (2019). <i>BS Series: The Forest on High Morning</i> . [Photography, digital print on paper, 8" x 11"].....	45
Illustration 13: davis halifax, n.v. (2016, February 7). <i>Thoughts on 'crip arts'</i> . [blog post]. Recounting Huronia website. [Poetry and Digital image]. Printed with permission from artist..	46

Illustration 14: Yarmol, C. (2016). <i>Flexible Embodiment</i> . [Sculpture with postal elastics, acrylic and wire mannequin form, magnetic handbag clasp, 54" long is 14" across and is 5" inches in width].	53
Illustration 15: Yarmol, C. (2020). <i>Coffee Talk</i> . [Digital photograph of exteriors of 7 finished albums, 9" x 11" each, book binding cloth, matt board, Japanese paper, double-sided tape, PVA glue]	92
Illustration 16: Yarmol, C. (2020). <i>Close up of Interior of Coffee Talk Book</i> . [Digital photograph of interior concertina and endpapers of book #6 , 9" x 11" each, book binding cloth, matt board, Japanese paper, double-sided tape, PVA glue].	92
Illustration 17: Yarmol, C. (2016). <i>Here to Stay</i> . [Sketchbook Drawing with felt-tip marker, 8 ½" x 14", Sculpture, low-fire clay and glaze. 4" x 10" x 1/4"].	115
Illustration 18: Yarmol, C. (2020), <i>Fly on the Wall</i> . [Egg tempera on wood panel with faux silver leaf and size, 16" x 20"].	120
Illustration 19: Yarmol, C. (2020), <i>Fly on a Bench</i> . [Egg tempera on wood panel, 12½" x 8"].	120
Illustration 20: Yarmol, C. (2019), <i>Participant-Observer Landscape</i> . (2019). [Acrylic paint, coloured pencil crayon on paper, 9" x 11"]. NOTE: Sketches like this one were created at CVS studio while observing the participants.	121
Illustration 21: Yarmol, C. (2019). <i>Meeting the Artists</i> . [Drawing with pen, coloured pencil crayon & aquarelle crayon), 8 ½" x 14"].	127
Illustration 22: Yarmol, C. (2019). <i>Coffee Talk-Leaving a Trace</i> . [Sketchbook Drawing, Coffee on paper, 12" x 9"].	173
Illustration 23: Yarmol, C. (2020), <i>Rhizomatic Engagement</i> . [Mixed media-acrylic paint on canvas, yarn, branches, glue, panel, Top panel: 16" x 18", Bottom panel: 40" x 22". Note that there is are two superimposed canvases but that the photographic representation exhibits the kinetic possibilities of the artwork.].	220
Illustration 24: Yarmol, C. (2018). <i>Thinking About Deleuze and Guattari</i> , [Sketchbook drawing with pen, coloured & aquarelle crayon, 11" x 8 ½"].	221

### **Note to the Reader**

As a visual artist, I create artwork to both broaden and deepen my understanding of the world. As a mode of knowledge construction, this artwork simultaneously acts to query theory and synthesizes my understanding of it. Since art making is central to this dissertation, each chapter opens with a photograph of an artwork by me, the artist-teacher-researcher accompanied by an artist's statement to orient the reader toward my thinking. These statements are presented in single-spaced format to differentiate them from the rest of the chapter.

Fine Art and Design practice-led and practice-based researchers Julian Malins and Carole Gray (2004) suggest that artwork as data involves, “meta-thinking—thinking about your thinking—and, self-evaluation” (p. 38) thus, screen shots of my sketchbook journaling, photographs, and video stills as data collection punctuate the dissertation. These illustrations and figures give the reader a view of how the study's progress was visually documented so that analysis could be performed, “in, on and for action” (p. 62). Artist, Education, Visual Art researcher, Sandra Weber (2006) says that artistic images, “can help us access those elusive, hard-to-put-into words aspects of knowledge that might otherwise remain hidden or are ignored. The use of visual images is not a luxury or add-on to scholarship but, in many situations, essential” (p. 5). Weber (2006) believes that it is the ability of images to transmit multiple messages, to ask questions, to point to both abstract and concrete thoughts that make them appropriate to communicate academic knowledge (p. 6). The images I produce employ a wide variety of visual forms including drawings, paintings, prints, photographs, film stills, collage, felted sculptures, and text-based imagery. I believe that the physical visualization of the theory makes the dissertation more relatable by supporting my translation of the concept directly to the viewer/reader.

Appendices A, B and C show a series of images documenting a physical display of seven hand-made books. These books house graphically designed composites of artwork and artists' statements created with the participants to credit their knowledge. A series of portraits of artists, volunteers, parents and instructors executed in a joint project between artist Evelyn van Duffelen and me. I illustrated the portraits and as a colourist, Evelyn breathed life into them. These artist's pages can be viewed privately within the books or removed from their pages to be mounted alongside the artists' material artworks in a formal exhibition setting. In the future, these artworks will be hung beside the study participants' artworks at a show entitled *Coffee*

*Talk*<sup>1</sup>. Copies of these portraits also are interspersed within the text of Chapter Five's *What? What Do Participants Say?* It is my hope that the artworks displayed may deepen the reader's comprehension of the research, the artists and the research site, Creative Village Studio, within which I have been immersed.

---

<sup>1</sup> Unfortunately, the circumstances of COVID 19 have prevented the art exhibit *Coffee Talk* exhibition from being mounted and the viewing of the artwork in-person. Digital presentations of the handmade books and their contents will provide a graphic account of the artwork created.

## Chapter One: Preparing the Canvas



Illustration 1: Yarmol, C. (2018). *Replanting the Forest*. [Mixed media acrylic paint, tissue paper cartridge paper, newspaper, glue on wood panel, 24" x 28"].

As I contemplated my dissertation, I thought about how disability policy plays such a critical role in the lives artists with Cognitive and Intellectual Disabilities. So much work still needs to be done to modify policies and their delivery in Ontario to achieve cultural rights for all. Metaphorically, we should burn some existing policies to the ground and establish more practical approaches that better fit those who want to live and work as artists. An on-the-ground review of social policy and application of new delivery modes could arise to support individuals with Cognitive and Intellectual Disabilities inclusion in society.

The metaphor of *controlled burns* describes setting forests alit, ridding forests of dead leaves, tree limbs, and other debris, reducing insect populations and destroying invasive plants to prevent greater destructive wildfires that might occur at later dates. The resulting ash can act as a nutrient-rich layer to rejuvenate the soil making it fertile for seed germination. Fertile soil coupled with additional sunlight and open space help new trees and plants to grow (National Geographic Society, 2019).

Birch trees as a symbol of renewal arose for me a variety of reasons. Aspen, Jack Pine, Lodgepole Pine, and White Birch re-establish quickly by sprouting from stumps and roots of burned trees (Natural Resources Canada, 2017). Peeling layers of bark reveal the layers below until eventually you reach a point where you stop. The tree's health relies on the integrity of this inner bark. This image is resonant with me. Social policy, like a Birch tree, can be stripped of countless layers - always with caution.

## **What is this Dissertation About?**

This dissertation examined the right to be an artist as a means of cultural citizenship and life enhancement for people over the age 21 years living with the label of Cognitive and Intellectual Disabilities (henceforth CIDs) in Ontario. A stated goal on the Ministry of Community and Social Services, Ontario's Vision for Developmental Services website, is, “to support people to live as independently as possible in the community and to support the full inclusion of Ontarians with disabilities in all aspects of society”. By employing multiple methodologies including arts-informed and narrative inquiry, the dissertation examined the everyday subjective conscious experience from participants’ storied lived-experiences (van Manen, 1990) of their art and art making. The study strived to understand the importance of art practice in their lives. It uncovered how positive studio experiences could be achieved. Through these methodologies, the inquiry also studied and scrutinized social policies that claim to support people with CIDs. The ultimate intent was to listen to the voices of artists and to commend and credit their knowledge of the arts through their perspectives. The title is *The Right to be an Artist: Operationalizing Studio Art Practices for People with Cognitive and Intellectual Disabilities* (For brevity the title will be shorten to *The Right to Be an Artist*). The starting point for my key questions was:

How can we operationalize and support successful studio art practices for people with cognitive and intellectual disabilities to exercise their right to become artists and achieve an aspect of cultural citizenship?

How can we support people with CIDs in new contexts to enhance their lives as artists?

How can we commend or credit the knowledge visual artists with CID communicate with their artwork?

These questions acted as the starting point of an exploration of practical, philosophical, fiscal and social policy realities of people with CIDs who want to live as artists in an urban centre.

## **What Contribution Will This Study Make to The Field?**

Although there are numerous studies about art education for children and youth with CIDs, there are few of studies available regarding the social policies and necessary art supports for artists with CIDs over age 21 years as they relate to personal choice and cultural citizenship in Canada. The Canada Council for the Arts (2018) asserts that, “[c]ultural citizenship is the embodiment of the arts at the heart of public life. Conceptually, it emphasizes the expression of diverse cultural practices and identities alongside full participation in and access to culture. It

envisions conditions for artists of all kinds to thrive, and for citizens to engage with arts and culture as a gesture of personal and collective freedom.” According to Judith LaRocque, former Deputy Minister, Department of Canadian Heritage:

Cultural participation is one of the key tools people use to build their sense of attachment and connection to each other. Cultural participation also bridges fault lines and builds common understanding where only difference existed.

Engagement with culture is hard to distinguish from community development and the growth of citizenship. When people engage with culture, they necessarily engage with each other, with people like them in some way, and inevitable with people who are different.

Cultural policy has the potential therefore to reach out beyond the traditional realm of industry, art, museum to influence citizenship, values, tolerance, and the very construction of Canadian society (2005, p. x).

LaRocque’s commentary speaks to the powerful potential of art to influence citizenship and the social fabric of Canadian society.

Few studies credit the voices of artists with CIDs within an art studio setting. Crystal Finely, author of the manual, *Access to the Visual Arts History and Programming for People with Disabilities* (2013) commissioned by the Vanderbilt Kennedy Centre for Excellence in Developmental Disabilities alleges that:

Most studies concerning art and disabilities are limited to people with mental illness or physical disabilities. Few studies discuss art specifically with people with intellectual and developmental disabilities (p. 15).

Taking Finely’s comment into consideration, *The Right to Be an Artist* will contribute to the body of knowledge about Visual Art, a form of cultural citizenship for people with CIDs. As Critical Disabilities philosopher Licia Carlson states, “intellectual disability remains relatively marginal within philosophical discourse” (2010, p. 3) thus this study adds to the philosophical discourse about cultural citizenship people with CIDs.

Exhibiting artist, and art educator Florence Ludins-Katz and clinical psychologist Elias Katz founders of Creative Growth Art Centre in Oakland, California developed one of the first models of an art center in the United States specifically designed for adults with intellectual and developmental disabilities. What started with an invitation for six students to create art in their home-garage, grew into an internationally recognized studio (Starin, 2015). Their landmark book, *Art and Disabilities: Establishing the Creative Art Centre for People with Disabilities*

(1990), outlined the basic components of a functioning art studio supporting people with CIDs from a pragmatic perspective. A studio offering space for independent art production for people with CIDs was unheard of in North American society at the time who, due to societal misconceptions about intellectual disabilities, was still institutionalizing people.

Ludins-Katz and Katz philosophize that creativity is a vital living force that lies within each individual and must be expressed for well-being and growth (p. 3). “Creative self-expression is the outward manifestation in an art form of what one feels internally,” even if an individual may not be fully aware of exactly how they feel, the sensation still exists (p. 3). The Katz’s state:

Our philosophy is that each person has the right to the richest and fullest development of which he is capable. Only then can society reach its fullest potential. Since we believe that creativity is the highest actualization of human functioning, it is of paramount importance to provide an environment in which creativity is appreciated, stimulated, and encouraged (p. 3).

Anyone who wants to exercise their right to be an artist should be allowed to use their creativity to achieve their goal of becoming an artist in a society whose attitudes, culture and policies will support them and be rewarded economically or otherwise for their efforts. The Katz’s believe that when the opportunity exists for people with CIDs, “a creative impulse bursts forth like a surge of flood water when the dam has been removed” (p. 5). *The Right to Be an Artist* showed how barriers erected in front of people with CIDs can impede their right to exercise their creativity.

According to disability historian James Trent (1995), CID has been viewed 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* [sic]” (p. 2). Furthermore, Trent asserts that these views are sometimes constructed in the name of science, care and social control. They “have accompanied and reflected shifts in the social, political, economic and cultural order in the United States” (p. 2). Licia Carlson (2010) explains that two models of disability have emerged responding to overriding conceptualizations of disability as “a pathology and a tragedy” (pp. 4-5). Historically through the medical model, an individual’s character traits depart from *normal species functioning* resulting in “beliefs and practices surrounding disability and the disabled [sic]” (p. 5). This ‘personal tragedy model’ assumes that “disability is objectively bad, and thus something to be pitied, a personal for the individual and her family,

something to be prevented and, if possible, cured<sup>2</sup>”... it has been medicalized and we in critical disability studies need to open it up.

Carlson explains that in the social model “having an impairment (a particular biological, physiological, psychological condition or trait) is distinct from being disabled because the latter reflects the interaction between the individual and his or her [their] environment”. Disability is a relational term and experienced disadvantages are a direct result of “social inequalities, barriers (physical and ideological) to opportunities, negative stereotypes and prejudices, discrimination, insufficient support systems, and general societal attitudes” (p. 5). Constructed fabrications of people with CIDs have resulted in pitying, fearful and knowing gazes that control society’s viewpoints so that, “much apparent progress through history has covered so little real change” (p. 279).

Art and disability advocate, founder and president of Cool Arts in Kelowna, British Columbia, Sara Lige (2011) contends that people with CIDs are arguably some of the most marginalized members of our society, experiencing exclusion from contemporary art structures of art education, art criticism, and art exhibition in gallery settings (p. ii). Lige maintains that, “Within the context of the arts community, artists with intellectual and developmental disabilities are not traditionally accepted as legitimate artists outside the disability arts movement. However, even within the realm of ‘disability arts’, artists with intellectual and developmental disabilities (IDD) have been neglected thus, it seems imperative that work be done to establish and authenticate their legitimacy as artists” (pp. 165-166). Alice Fox and Hannah Macpherson (2015), inclusive art researchers from the United Kingdom state that, “People with learning disabilities<sup>3</sup> tend to be undervalued members of society, are much more likely to live in poverty, and are more likely to suffer hate crime than their non-disabled counterparts... Many people with learning disabilities do not have access to any regular creative leisure activity outside their residential environment, despite the proven benefits of such activities for health, well-being and resilience” (p. 15). There are few studies that rely on the narrative input of participants working at art studios who support people with CIDs.

---

<sup>2</sup> Carlson (2010) discusses, the idea that, “[D]isability constitutes a blemish on the rosy face of medical science and societal well-being explains many of the practices associated with it, ranging from involuntary sterilization, institutionalization, and forced rehabilitation to social marginalization, euthanasia, and ‘mercy killing’” (p. 5).

<sup>3</sup> Learning Disabilities is the term used for people with Cognitive and Intellectual Disabilities in the United Kingdom.

Disability rights activists Dianne Pothier and Richard Devlin (2006) believe that “citizenship is not just an issue of individual *status*; it is also a *practice* that locates individuals in the larger community”. They affirm that:

Citizenship is more substantive: it is about the capacity to participate fully in all the institutions of society – not just those that fit the conventional definitions of the political, but also the social and cultural. As such, the substantive approach raises questions of access and participation, exclusion and inclusion, rights and obligations, legitimate governance and democracy, liberty and equality, public and private, marginalization and belonging, social recognition and redistribution of resources, structure and agency, identity and personhood, and self and other (p. 1).

Pothier and Devlin’s idea of citizenship through participation in society was applied to this study which critically examines social aspects of citizenship through existing social policies that marginalize people with disabilities who want to be artists. This study is important to critical disability studies because it can provide data and data analysis to the field of the creative arts and add to the body of knowledge that works to change social policies and dismantle policy barriers about arts funding for people with CIDs. Disability theorist Tobin Siebers (2008) states that “the presence of disabled people [sic] in any discussion changes not only the culture of the discussion but also the nature of the arguments in the discussion” (p. 4). This dissertation credits the art abilities and knowledge of people with CIDs.

Using arts-based and narrative methodologies, the study offers a unique multi-methods approach to inquiry; methods included: face-to face interviews, participant observations, surveying of accessibility and mentor/artist relationships, instruction with materials/media, creation of artwork, and inclusive art practices. This study is distinctive in the way that it actively employs the visual arts as a methodology to create and support data collection. By exploring a range of participant, volunteer, parent, instructor, administrator, and gallery owner viewpoints and examining best practices to support artists exercised in an art studio setting, the study demonstrates key components of a successfully run art studio to transfer to other studio environments to support other artists with CIDs<sup>4</sup>. This topic was carried out for the direct benefit of participants and their families to enhance artists’ life experiences in the arts and to commend participants’ knowledge of arts practices. The findings of an external reviewer of the program at

---

<sup>4</sup> Art environments should include those that support people with Autism, Down’s Syndrome, Alzheimer’s and Dementia.

Creative Village Studio (hence forth known as CVS) provide insights for the instructors and managers at Community Living. For the critical disability studies researcher, the benefits were to contribute to art creation theory for people with CIDs, to engage with artists discussing their art making process in order to gain knowledge, and to give back knowledge to the community who would advocate for social policies to support successful arts practices in the future.

To answer the question, “Why bother with this study?” I offer the views of Art researchers Fox and Macpherson (2015) who contend that the, “lives of people with learning disabilities [CIDs] tend to be characterized by a high degree of compliance with the goals and agendas of others, and for some their basic human rights are not being met” (p. 16). By “[t]alking about the role of art in their lives and the role of their lives in that art world may seem irrelevant, unrealistic or simply naïve, but to take this view risks perpetuating the social position that people with learning disabilities [CIDs] often find themselves in, and ignores the role of culture as a producer of personal and social change” (p. 16). Fox and Macpherson believe that:

Art can be just one piece of a socio-political-cultural jigsaw that needs to be put together in order to enhance the lives of people both with and without learning disabilities [CIDs]. Social services and health professionals who encounter the artwork can be helped to see the humanity and communication capacities of people they work alongside. Public audience encounters with Inclusive Art can help challenge stigma and oppression and raise awareness often creative contributions that people with intellectual disabilities can make to society (p. 16).

Studio programs like CVS can provide what Fox and Macpherson (2015) declare is, “a release from controlled environments encountered in residential supported living and day care facilities” (p. 17). I realize that arts activities alone cannot achieve a better world for people with intellectual disabilities as many other factors like social policy are involved but helping individuals realize their potential is a beginning to the realization of cultural rights as a profound part of human rights. I have witnessed art as a pathway to communication and realization of cultural rights in my work as an art educator of 27 years working with high school students who have communicated their life experiences and their personal views through their work. This life experience that has informed the writing of this dissertation.

## **Organization**

Since this is a multi-methods project, knowledge created through art is embedded throughout the dissertation. The reader is invited into each chapter with my artwork

accompanied by my artist's statement. The reader can draw their own conclusions as they look at the work and relate to the topic presented, but these artist's statements help to guide them through my thinking as a researcher and motivation behind each artwork. Artworks are visual representations of the thought processes and learning while investigating the literature and study data collected regarding the topic of each chapter.

*Chapter One: Introduction Preparing the Canvas*, introduces the reader to the dissertation providing the purpose of the study, the contribution that the study will make to critical disability studies, an outline of the organization of the dissertation, and a discussion about terminology and language. A photograph of a painting, *Replanting the Forest*, (See Illustration 1) an artwork I created at the proposal phase of this dissertation launches the chapter.

*Chapter Two: Weaving a Tapestry: Methodology and Methods*, outlines the multi-methods approach taken with this study forming a kind of bricolage (Bricolage is explained in *Multiple-Methods: A Bricolage* section.). The study uses arts-informed methods such as sketchbook journaling and a/r/tography as a way to unify multiple roles as an artist, a researcher and a teacher, as well as crip theory, that situates the researcher's positionality living with a disability indicated by the first piece in the mixed media *BS Series* (See Illustration 3). Narrative inquiry would see crip theory as a way of helping to explain the researcher's positionality and a/r/tography would see crip theory as a part of the researcher's experience living with a disability. The narrative framework of Gabriela Spector-Mersel is outlined so that the reader can gain an in-depth understanding of how the interviews are conceived of and analysed. My positionality and the story of how I came to choose this topic for my dissertation including Paulo Freire's theories of creating praxis are elucidated.

*Chapter Three: The Need for Flexible Embodiment of Social Policy for People with CIDs* outlines the social policies currently available for artists with CIDs in Ontario. The chapter begins with a sculptural artwork entitled *Flexible Embodiment* (2016), (See Illustration 14) woven with postal elastics to form a pliable textile poncho that will fit practically any wearer. This chapter explores the birth of Community Living, sheltered workshops, and organized activities in the community as social policy designed to support people with CIDs as forms of citizenship. It also outlines the personal and employment (ODSP) supports available for people with CIDs providing much detail about the *Passport Program* an individualized funding policy

that several of the participants obtain to pay for the CVS program to attain aspects of cultural citizenship.

*Chapter Four: Being an Artist: Studio Process and the Resonance of Art Practice* opens with an image of *Coffee Talk* (See Illustrations 15-16) an exhibition of handmade books featuring a page of each CVS participant's artwork in the study, accompanied by photographic portrait and brief artists' statements written with their input. These graphic collages of their work are placed in seven hand fabricated *Elbum* books to credit their art creation and art experiences. The artist's pages can be viewed privately within the *Elbum* books or removed from their pages to be mounted alongside their physical artworks in a formal exhibition setting. The chapter focuses on the inclusion of biography in the historical Fine Art exhibition sphere examining historical definitions of Art Brut, Outsider Art, Naïve Art and how society often labels the art of people with CIDs, what contemporary galleries want from their exhibiting artists through an historical examination of curatorial practice and what curatorial practice with a Disability Studies bent can look like. The chapter ends with practical applications of *Eight Studio Habits of Mind* (Project Zero, 2003) and a look at studio art facilitation.

*Chapter Five: What? What Do Participants Say and What Does it Mean?* discusses the story of how CVS began as a social policy extension for people with CIDs, the findings of the interviews using the artists', volunteers', parents', instructors', key facilitator's and a gallery owner's storied responses to interview questions. It draws conclusions from these findings examining why artists enjoy coming to the studio and the supports necessary to ensure their success. The introductory artwork to this chapter, *Fly on the Wall*, (2020) and *Fly on a Bench* are egg tempera paintings communicating the researcher's felt challenges as an artist, an art teacher of 27 years and a researcher engaging in a study within the CVS setting to let the studio processes unfold without leaving a mark (See Illustrations 18-19). Throughout *Chapter 5*, the text is punctuated with portraits of the artists, volunteers, parents and instructors drawn by artist Evelyn van Duffelen, colorist<sup>5</sup> at CVS and me as an artist and Visual Arts and Special Education educator which is fully explored in *Chapter Two: The Researcher's Story* section. Working inclusively, I created rapid contour line portraits of the participants from either their likeness in the studio setting or from videotaped stills after the interviews. Evelyn completed the drawings

---

<sup>5</sup> A colourist is an artist or designer who uses color in a special or skillful way.

with her preferred medium of pencil crayon. Either photographs or video stills are also included in the dissertation to aid the reader's understanding of the topic under discussion.

*Chapter Six: So What? Now What?* begins with the artwork, *Rhizomatic Engagement* (See Illustration 23) and summarizes the key research findings or new understandings gathered from the interviews, the artwork and the fieldnotes. It provides questions for further research including the critique of social policies surrounding people with CIDs and how they support or do not support individuals wanting to be artists in Ontario as a form of cultural citizenship.

The *Appendices* contain the required ethical approval notices, letters of information, consent forms, interview questions, social policy support documents, some samples of screen shots of graphically designed individual artists' statements and art imagery. *Coffee Talk* created as an exhibition of participant-artists' artworks that are physically printed and mounted in a series of seven hand-made books posted in the accompanying PowerPoint presentation for the viewer/reader.

To facilitate reading of this interdisciplinary dissertation and to frame each topic, a review of relevant literature from experts in each field was embedded throughout the text. These broad ranging yet related topics include adult art education, a/r/tography, art education, art exhibition, art history, book making, contemporary art, critical disability studies, disability supports, narrative methodology, social policy surrounding cognitive and intellectual disabilities, and studio art practice.

### **Language & Terminology**

In the introduction of a peer-reviewed *Journal of Literary & Cultural Disability Studies*, critical disability studies theorist Lucy Burke (2008) queries the use of the term *cognitive impairment* warning us that "any talk of representation within contemporary literary and cultural studies is circumscribed by an implicit recognition of the powers and dangers of so-called descriptive language" (p. 1). Burke notes that in the field of cultural disability studies, critical suspicion of the uses of language in "ways in which particular models and tropes articulate the boundaries between typicality and atypicality, health and illness, normalcy and disability" (p. i) is essential. One term does not fit all. She believes that perhaps *cognitive difference* or *cognitive disability* is more appropriate (p. ii) when referring to people with intellectual disabilities. We have a political and ethical obligation to recognize the very fact that this kind of terminology is never adequate (p. 1). In this dissertation clarification of language and terminology is necessary.

In her book, *The Faces of Intellectual Disability*, Licia Carlson (2010) situates her references to terminology in her work. Carlson (2010) uses the term, “intellectual disability” to refer to the general conditions traditionally associated with “mental retardation”. She prefers this general term because it reflects the recent shift both professional and political away from former dehumanizing terms. She employs the term “mental retardation” when specifically speaking about the category specifically (in the context of specific arguments, professional use, or historical period) or when referring to historically defined conditions from the past, (e.g., idiocy, feeble-mindedness, mental deficiency). She believes that the phrase “persons with intellectual disabilities,” as opposed to “the intellectually disabled” is better when speaking about actual individuals. The reader should understand Carlson does not take these terms to be self-evident “natural kinds” or unproblematic terms (xv). These terms are a construct that finds their meanings in social and cultural contexts.

Before disability studies scholars named and differentiated a medical model of disability and the social model of disability, education theorist Jane Mercer developed labeling theory in her influential book, *Labeling the Mentally Retarded* (1973) that distinguished between clinical and social system perspectives on *mental retardation* [sic] (Taylor, 2006, xv).

From a social system perspective, the term mental retardate [sic] does not describe individual pathology but rather refers to the label applied to a person because he [sic] occupies the position of mental retardate [sic] in some social system (Mercer, 1973, pp. 27-28).

Mercer refers to “mental retardation” perceived from a clinical viewpoint — a pathological condition that could be objectively diagnosed by trained professionals using standardized instruments. From a social system perspective, it was a social role played by individuals in a specific social system in which they participated (Taylor, 2006, xv). Stating the thesis of her book Mercer (1973) writes, “Persons have no names and belong to no class until we put them in one. Whom we call mentally retarded [sic], and where to draw the line between the mentally retarded [sic] and the normal, depends upon our interest and the purpose of our classifications (p. i)”<sup>6</sup> It is important to note that labelling occurred in the service of normativity and neoliberal articulations of independence and productivity (Wendell, 1998).

---

<sup>6</sup> When I began to work with children and teens with CIDs in the late 1980s and early 1990s labeling was the norm in education and recreation settings. The term mentally retarded slowly changed to mentally handicapped then mentally challenged in this period.

Illustration 2 is a sketchbook drawing that displays my thinking about language. It depicts the prefix *dis* in relationship to the word *ability* → d-i-s-a-b-i-l-i-t-y, applied to people with atypical appearances or stances who might be categorized or labelled from a normative stance. I

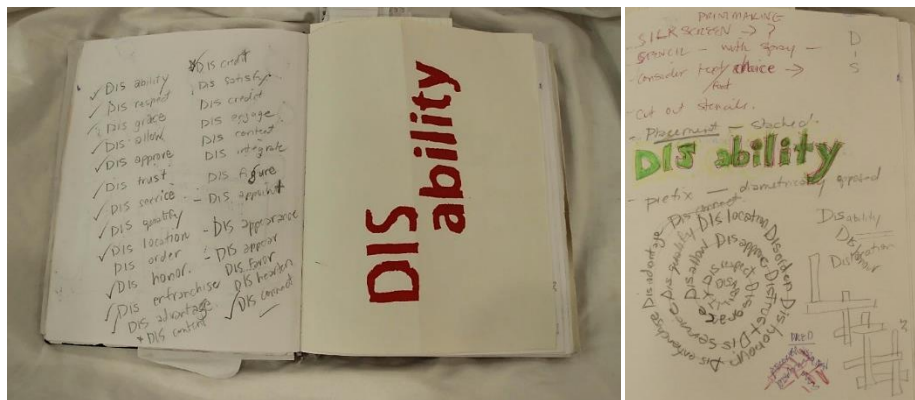


Illustration 2: Yarmol, C. (2018). *Thinking About Language*. [Sketchbook Drawing on paper with pencil and silkscreen ink in right, 3 pages, 8 ½" x 11"].

considered how normative misconceptions about disability and impairment are rendered through language. The prefix ‘dis’ has negative connotations creating a diametrically opposed signification of a term. Some examples are — appear → disappear; appoint → disappoint; approve → disapprove; content → discontent; engage → disengage; favour → disfavour; grace → disgrace; honour → dishonour; qualify → disqualify; service → disservice. This notation prompted me to consider the barriers people with CIDs have encountered in their lives.

Like Licia Carlson, I will use the phrase person(s) with cognitive and intellectual disabilities (henceforth CIDs) or person/people/individual(s) with CIDs as opposed to intellectually disabled people. Although cognitive disabilities and intellectual disabilities are related, the terms refer to different effects and conditions in terms of the medical model of disability. For example, in order to obtain supports at CVS and to acquire provincial funding to participate in courses or studio time, an official doctor’s note is required<sup>7</sup>. This fact is a reminder of the gulf between academia’s theories and the lived experience of individuals that the field studies.

Diagnosis and labelling of people through the *Diagnostic and Statistical Manual of Mental Disorders DSM-5*, (American Psychiatric Association, 1980) reflects a persistence of the medical model of disability which sanctions doctors to act as gatekeepers for access to

<sup>7</sup> Due to the studio’s location in the heart of the Inslington community in west end Toronto, the facilitator of the program also invites “walk-ins” or members of the public to encourage community membership on a pay-as-you go or self-funded basis.

governmental financial supports as well as programs for people with disabilities. The DSM is an example of what philosopher Michel Foucault (1980) would call unitary body of knowledge. The *DSM-5* provides a diagnostic nosology that becomes fully encoded and taken up by medical, educational, economic governmental and social systems. The Canadian Association of Community Living (CACL) uses the terms ‘intellectual disabilities’ and ‘developmental disabilities’ or the acronym IDD. They define intellectual disabilities as, “a group of disorders defined by diminished cognitive and adaptive development” (2017). A variety of medical conditions affect cognitive ability, defined as a “broad concept encompassing various intellectual or cognitive deficits, including intellectual disability, deficits too mild to properly qualify as intellectual disability, various specific conditions (such as a specific learning disability), and problems acquired later in life through acquired brain injuries or neurodegenerative diseases like dementia which may appear at any age” (Crawford, 2008)<sup>8</sup>.

Measures of the medical model are applied at a local level—in the relationship between the studio staff and artists (also known as clients) as the staff at Community Living are obliged by the agency’s funding body or by government rules to attach a diagnostic label to the artist/client. This mighty, authoritative and privileged classification system inserts itself into their relationship often effecting the art facilitator or a social worker’s thinking, their connection with the artist/client, and the artist/client’s self-definition.

---

<sup>8</sup> CVS supports people with a range of cognitive and intellectual disabilities defined by the DSM 5 including: autism, Down Syndrome, Asperger syndrome, traumatic brain injury (TBI), dementia, attention deficit disorder (ADD), dyslexia (difficulty reading), dyscalculia (difficulty with math), and learning disabilities in general.

## Chapter Two: Weaving a Tapestry: Methodology and the Methods



Illustration 3: Yarmol, C. (2018). *BS Series: 2.7, Felt It!* [Sculpture with dyed felted fleece, 10" x 8"].

*BS* or Blood Sugar (other colloquial meanings also implied) is a crip art series that communicates aspects of living with Diabetes Mellitus (Type 1/Juvenile Diabetes), a hidden health impairment lasting over a lifespan. Through the balance of administering of insulin ingestion of food and exercise I attempt to maintain a blood glucose level between 6-10 mmol/L (According to medical measurements normal fasting blood glucose is 3.6 mmol/l and 6 mmol/l.) to help reduce complications from the disease. *2.7—Felt It!* (See Illustration 3), and *2.4 —Felt*

*It!* (See Illustration 6) are kaleidoscopic coloured sculptures with felted fleece<sup>9</sup>, of rare occurrences when I experience low glucose levels. When I close my eyes, beautiful, bright psychedelic flashes of light emerge from the darkness. I depict them as stunning deep hues of navy, purple, pink, red and bright orange that sparkle in my field of vision. As alluring as the visual show is, something is very wrong. Starbursts gradually fade after rest and ingestion of food that elevates blood glucose. Through visual appearance and haptic touch, viewers can have a sensory understanding of the experience.

Life's circumstances sometimes cause a fluctuation in glucose levels. Presentation of high and low blood glucose differs dramatically between individuals. The sketches entitled, 2.7 (Illustration 3), and 2.4, (Illustration 9) are executed with aquarelle and watercolour paint on paper, 8 ½" x 11" a rather fluid medium to represent low blood sugar. Illustration 5, 2.6, representing low blood sugar is a monoprint created with aquarelle crayons on paper.

In contrast to portrayals of low glucose are the rare high glucose levels evident in the mono print *Hi, High* (See Illustration 11) and *The Forest on High Morning*, (See Illustration 12) a digital photograph illustrates my experiences of blood sugar levels from 12– 30 plus mmol/l. A general feeling of unwellness slowly arises with a headache, lack of appetite, fatigue, increased thirst and urination, and irritability. The headache creates a sensation that one is amid a heavy fog; it takes hours after injecting insulin to relieve the sluggish sensation.

Susan Wendell (1989) asserts that in North American, Anglo-Saxon culture, we idealize the body (p.104). Alison Kafer (1998) states, "One of the most pervasive understandings of the body is that it is something that can and should be controlled" through hard work. "If one has the right, positive attitude, determination and resources" one can control one's impairment; Wendell calls this faulty belief, *the myth of control* (1989). The disabled [sic] or the impaired become, 'the other' who symbolize failure of control and the threat of pain, limitation, dependency, and death (Wendell, 1989, p. 104). This artwork is a visual representation of what a social-medical model of disability would consider my failure 'to control my own body' every moment of the day. Daily, I live in the liminal spaces as these occurrences of high or low blood glucose levels happen infrequently, but I exaggerate them here as whenever I utter, that, "I am a diabetic" the interlocutor assumes the worst. The *BS Series* title also indicates assumptions made about the status of my impairment and my health the moment I claim my existence as a diabetic entity; thus, I am crippling diabetes.

---

<sup>9</sup> *Felting* is an ancient form of textile art. The process to create felt includes layering combed or carded fibers of sheep or emu fleece followed by adding hot water, soap and then intense agitation to bind the raw fibres together creating a more stable fabric composition.



Illustration 4: Yarmol, C. (2017). *BS Series: 2.7*. [Painting with aquarelles and water colour paint on paper, 8 ½" x 11"].

### Multiple-Methods: A Bricolage

This study employed a multiple-methods (multi-methods) approach to research as no single method alone can answer the innumerable questions that teem around inquiries in the field of disability studies. Newly inhabited research methods were required. Qualitative researcher Norman Denzin (1994) sees the qualitative researcher as a well-read, knowledgeable, kind of *bricoleur* who is thoroughly informed about interpretive paradigms. The idea of a *bricoleur*<sup>10</sup> suits the particular socio-political and art bents of this study. The multi-methods *bricoleur* understands that research is an interactive process that is shaped by their gaze, filtered by intersectional understandings including personal history, biography, gender, social class, race, ethnicity, and from the people in the setting. A multi-methods researcher is adept at performing a great number of diverse tasks, ranging

from interviewing to observing, to interpreting personal and historical documents, to intensive self-reflection and introspection (p. 2); they communicate narratives that are framed within specific storytelling traditions often defined as paradigms (Guba, 1990, p. 70). The resulting labour is a “bricolage or a complex, dense, reflexive, collage-like creation that represents the researcher’s images, understandings, and interpretations of the world or phenomenon under analysis” (Denzin and Lincoln, 2006, p. 3) connecting parts to the whole, stressing the meaningful relationships that operate in the situations and social worlds studied (Weinstein & Weinstein, 1991, p. 164).

This dissertation was laterally designed as a series of interrelated studies conducted to address one programmatic aim (Morse and Niehaus, 2009, p. 147), the operationalization of studio practices for people with CIDs giving the research its theoretical thrust. In response to the feedback from the artists participating in the study, the researcher freely altered the direction of the study after the research process had started. The inductive approach is based on learning from experience meant

---

<sup>10</sup> Art bricolage originating from the French words *bricoler*, meaning ‘to putter about’ or ‘do-it-yourself’, and related to *bricoleur*, a jack-of-all-trades (Merriam-Webster, 2019), refers to the creation of an artwork from any materials that come to hand. Applied to an art context, artists used a wide range of non-traditional found materials. Bricolage became popular early in the twentieth century when resources were scarce. Political aspects were taken on in the 1960s in Italian Arte Povera whose intent was to bypass commercialism in the art world and to assert the value of the ordinary and the ‘everyday’ (Tate, n.d.).

to generate meanings from the data set(s) collected, to identify patterns and relationships, to build a theoretical contribution (Inductive Reasoning, 2017) from the observations at the end of the research process. This multi-methods approach applied narrative inquiry, and arts-informed inquiry, including a/r/tography to best capture the rich, multifaceted, lived art experiences of the participants to address the questions posed and achieve the stated study objectives. Crip art was used to capture the researcher's positionality with respect to the inquiry under study. The qualitative methodologies used and the rationale for each design choice, the sources, methods of data collection, analysis methods are outlined below each sub-heading so the reader can easily gain an understanding of the researcher's theoretical groundings.

### **Art-informed methodologies**

Arts-informed researchers Ardra Cole and Gary Knowles (2008) discuss a dominant, paradigmatic view of "Knowledge" within academic settings where it remains carefully defined and controlled; academy and community are kept separated (p. 60). Cole and Knowles (2008) insist that the dominant paradigm of positivism historically has governed the way research is defined, conducted, and communicated consciously and unconsciously and thus defined what society accepts as knowledge. Generated by research, knowledge ascertained by intellectuals, researchers and theorists is propositional,



Illustration 5: Yarmol, C. (2019). *BS Series: 2.6*. [Monoprint with aquarelle crayons on paper, 6" x 6"].

generalizable and remains the purview of the academy where it can be carefully defined and controlled and held until its effects are determined and passed on for consumption. This positivist paradigm does not reflect actual meaning-making moments in society when life is lived and knowledge is made through everyday experiences such as, "kitchen table conversations and yarnin' at the wharf or transit station or coffee shop or tavern, in the imaginative spaces created between the lines of a good book or an encounter with an evocative photograph, in an embodied

response to a musical composition or interpretive dance”<sup>11</sup>. Society holds fast to the idea of defining “Knowledge” as beyond the realm of the everyday (p. 60). Arts-informed research is linked to a broader commitment to recognise individuals in societies as, “knowledge makers engaged in the act of knowledge advancement” (p. 60), to acknowledge “the multiple dimensions that make up the human condition including the physical, emotional, spiritual, social, cultural—and the myriad ways of engaging in the world—oral, literal, visual, embodied” (p. 60). Often arts-based research tries to make the explicit attempt to make a difference through research in the lives of ordinary citizens and in the thinking and decisions of policymakers, politicians, legislators, and other key decision makers (p. 60). Disability arts researchers Fox and Macpherson (2015) believe that, “Arts practice as a form of research is valuable in exploring the material, performative, embodied, ephemeral, habitual and no-conceptual aspects of what it is to be human. It is also useful for actively making forms of meaning and knowledge through art” (p. 146).

Artist, education, art researcher Sandra Weber (2008) outlines how and why arts-related visual images can be used in research suggesting that they are interlinked. According to Weber images:

- a. can be used to capture the ineffable, the hard-to-put-into-words aspects of knowledge that might otherwise remain hidden or are ignored providing an essential “all-at-once-ness” (Eisner, 1995, p. 1) that language and numbers cannot not capture (Weber, 2008, p. 44);
- b. make us pay attention to things in new ways engaging us making the ordinary seem extraordinary, compelling us to consider new ways of seeing or doing things (p. 44).
- c. are likely to be memorable influencing the ways we think, act eliciting both emotional and intellectual responses; they make an immediate impact on the reader/ viewer/ community (p. 45).
- d. can be used to communicate more holistically, incorporating multiple layers, and evoking stories or questions possessing an “orality,” (Ong, 1982 cited in Weber 2008, p. 45) or a narrative quality that provokes and reconstructs ideas (p. 45).
- e. enhance empathic understanding and generalizability by helping us adopt someone else’s point of view and comparing it with our own (p. 45). Through metaphor and symbol, artistic images can elegantly and eloquently communicate theory with facility (pp. 45-46).

---

<sup>11</sup> The idea for the artwork *Coffee Talk* a book, and a future show emanates from Cole and Knowles (2008) understanding that deep ‘Knowledge’ can be ascertained from everyday experiences and conversations. Much can be and has been learned about the lives of people with CIDs from conversations at the studio over coffee and tea.

- f. encourage embodied knowledge helping researchers to keep their own bodies and the bodies of those they study in mind (p. 46).
- g. can be more accessible than most forms of academic discourse. By using shared cultural codes and popular images, visual expressions make accessible the communication of research to a broad audience (p. 46).
- h. facilitate reflexivity in research design as they reveal much about the person who produces them as they do about the people or objects who are figured within them (p. 46).
- i. provoke action for social justice because although they seem personal by the very nature of their provenance and creation, are also social (p. 46).
- j. can provoke critical questions and encourage individual and collective action (pp. 46-47).

*The Right to Be an Artist* used a multi-methods approach with a strong focus on art making and imagery to credit the knowledge of artists with CIDs and the researcher's perceptions of the theory, the questioning of the status quo and queries under study. The imagery used fulfilled Sandra Weber's claims about imagery as a form knowledge-making in research.

#### **A/r/tography.**

Due to my background as an artist, a researcher, a teacher and my key inquiry questions, I can easily relate to a/r/tography, a research methodology developed by Rita Irwin, Stephanie Springgay, as a kind of "living inquiry," that is ripe for research (Wilson, 2003). This arts-informed practice-based methodology brings together various aspects of my multi-methods dissertation: art making, interdisciplinary theory and practical applications for people with CIDs in an art studio. Drawing its influence from the work of many artists, poets and scholars, a/r/tographical practice has re-writing and re-creating as its purpose (2008, p. 903). Arts and education-focused a/r/tography looks to the processes of action research which entails planning, acting, observing, and reflecting without prescribing a concrete plan or method. This process was key to this study as I was uncertain as to what my study participants would share in their narrative interviews. The analysis of their narratives brought about more questions and furthered opportunities for deepening the research. A/r/tography "asks questions, enacts interventions, gathers information, and analyzes learned information before posing more questions and enacts more living inquiry" (Irwin, 2012, p. 2). Like Aristotle's three concepts of knowledge: *theoria*, *praxis*, and *poesis*, a/r/tography integrates knowing, doing, and making (Irwin and de Cosson, 2004, p. 27) merging artistic understanding with the continual process of life-long

learning/researching and teaching being continuously committed to inquiry over time (Irwin, 2008, p. 3).



Illustration 6: Yarmol, C. (2018). *BS Series: 2.4 Felt it!* [Sculpture with dyed felted fleeces, 15 " x 11 " ].

Through the metaphor of crabgrass, Deleuze and Guattari (1987) describe the concept of rhizomes growing in all directions and how they “connect any point to any other point” (p. 21). These interconnected networks have multiple entry points (Wilson, 2003). Irwin et al (2006) say that by disrupting the linearity of beginnings and endings the importance of the ‘middle’ [or in media res] is emphasized (p. 71) in an “in-betweenness” is metaphorically conceived as a fold<sup>12</sup> to create spaces of transformation or new understandings rather than findings. A rhizomatic metaphor is integral to a/r/tography involving both self-inquiry and collective inquiry as artists and educators understand that relationality permeates our existence (Irwin,

2008, p. 3). Irwin asserts that, “a/r/tographers understand that who they are is embedded in what they know and do” and that theory and practice are “folded together through lived experiences and lived inquiry” (p. 2) much like narrative inquiry. I readily connect with Irwin’s point about a/r/tographic practice in the work that I do as both an educator and in the study at CVS as researcher; all of my experiences become interconnected. I cannot separate my artistic proficiency and training from my research ventures. My experience and knowledge become the medium through which decisions to observe or to more directly participate are made

Springgay, Irwin, and Wilson (2005) assert that the concepts or renderings of engagement in a/r/tography are attentive to the sensual, tactile, and unsaid aspects of artist/researcher/teachers’ lives (2005, p. 899). A/r/tography’s non-fixed renderings are labelled:

---

<sup>12</sup> Irwin cites Gilles Deleuze’s translated un/folding as dividing endlessly-fold within folds existing side by side performing the in-between spaces or relational inquiry in a/r/tography (Irwin, 2008, p. 3).

contiguity, living inquiry, metaphor and metonymy, openings, reverberations, and excess. These renderings are ways, “to move into the boundaries between theory, practice and creative activity and allow each to impact one another” (Irwin & Springgay, 2008, p. xxxi). This methodology relates to my own life and studies as it is impossible to uncouple my roles as an artist, researcher, and teacher (Illustration 7).

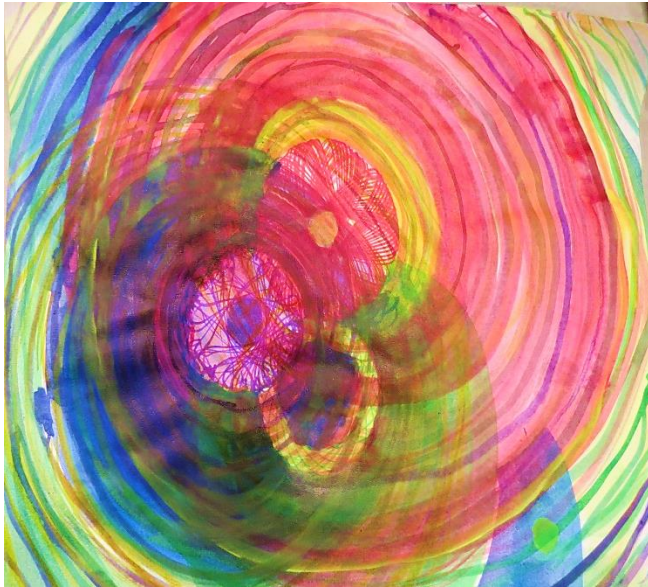


Illustration 7: Yarmol, C. (2019).  
*Artist/Researcher/Teacher: Connections*.  
[Sketchbook Drawing with coloured Sharpie  
and acrylic ink on paper), 11" x 11"].

Irwin et al (2005) state that, *contiguity* the first rendering in a/r/tography “is a coming together of art and graphy, or image and word” which is important when including both visual and written process and products of a research text (p. 900). Engaging a/r/tographic practice means to query the world through a practice of art making<sup>13</sup> and writing. Through “a process of double imaging that includes the creation of art and words that are not separate or illustrative of each other but instead, are interconnected and woven through each other to create additional meanings” that are constitutive rather than

descriptive (Springgay, Irwin, and Wilson Kind, 2005, p. 899). The roles of artist/researcher/teacher and the practices therein are also emphasized by contiguity with the understanding that living with these three roles is to live a life dialectically moving between, connecting, and not connecting with them (p. 901). It is filled with curiosity and questioning. This aspect of a/r/tographic methodology correlates with my way of working because image is an integral component of the inquiry process; notations in my sketchbook and creation of artwork based on what I am experiencing are integral to the communication of my overall understanding.

---

<sup>13</sup> Although visual imagery directs this discussion a/r/tography also comprises other art forms including music, dance, drama, film, etcetera as they are often artificiality separated.

*Living inquiry*, the second rendering in a/r/tography, is a thoughtful, enacted way of knowing and being evolving through acts of deep engagement. A/r/tography emerges from the liminal spaces of artist researcher and teacher in everyday life (2008, p. 5). Irwin et al (2005), contend that living inquiry encourages one to slow down and notice the world around and to question it. As a living practice a/r/tography is attuned to, “to memory, identity, autobiography, reflection, meditation, story telling, interpretation, and/or representation, artists/researchers/teachers” integrating knowing, doing, and making through aesthetic experiences that convey meaning rather than facts (See Illustrations 3-6, 11-12, *B.S. Series*) going hand-in-hand with narrative methodological practices. Happenings integrate the personal, political and professional aspects of one’s life (p. 903). Challenging a/r/tographic accounts can expose contradictions and assumptions of living inquiry.

*Metaphor* and *metonymy* are the third renderings. According to Irwin et al (2005), “a metonymy is a word-to-word or image-to-word, or image-to-image relationship, which emphasizes a displacement in the subject/object relation, such as part to whole encounters (p. 904) and a “metaphor is the substitution of signifiers, where one signifier takes the place of the other in the signifying chain.” Although the two signifiers are not equal; one does not absorb the other in unification (pp. 904-905). Through metaphor and metonymy, we can make our experiences comprehensible. They permit both understanding yet ambiguity of meaning at the same instance (Irwin, p. 2008, p. 5), shifting in time creating deeper insights. Doubling and redoubling aspects of metaphor and metonymy cause a movement of meaning (See Illustration 14 *Flexible Embodiment*).

*Openings*, the fourth rendering of a/r/tography, are “active and responsive requiring attentiveness to what is seen and known and to what lies beneath the surface” (Irwin et al, 2005, p. 904). Irwin (2008) considers cracks, tears, holes, losses, invitations and encounters as dynamic examples of openings (p. 5). Irwin asserts that inquiry can open-up conversation leading to relationships that reverberate with meaning (p. 5) inviting a shared participation. For an example of shared artistic partnership see the joint work of Yarmol and van Duffelen (2019) (Figures 6-7).

*Reverberations*, the fifth rendering, call attention to movement shifts meanings allowing for meaning making on deeper levels across time with others (Irwin, 2008, p. 5). Often meaning making can occur with social engagement within social networks. Irwin et al suggest that

reverberations excite slippages of meaning resisting and pushing forward new understandings (2005, p. 907).

The sixth and final rendering is *Excess*. *Excess* can represent waste and the sublime (Irwin, 2008, p. 5). It can aid the examination of fears and desires and renegotiation of everyday experiences. Irwin et al say that excess is open, pliable and constantly changing (p. 908). It questions material substances, how things come into being, philosophical nature of existence and meaning making.

As dynamic and intersubjective concepts, all of these renderings perform alongside one another with the possibility of being, “enacted through rhizomatic assemblages where meanings and understandings are interrogated and ruptured” (Irwin, 2008, p. 5) resulting in the transformation of the idea of theory as an abstract system distinct and separate from practice to become theory as practice, an embodied living space of inquiry (p. 5). Through the relational aesthetic inquiry approach of a/r/tography it is my hope that the embodied exchanges between art and text created and between and among the roles of artist/researcher/teacher in this study will enrich the viewer’s/reader’s perspectives of how people with CIDs can gain support in an art studio setting.

#### **The sketchbook as data.**

A sketchbook is an essential component of the a/r/tographic process. According to artist and art educator Lillian Gray (2017), a sketchbook is a private, safe place to work out ideas, explore possibilities, solve problems and make mistakes. Keeping a sketchbook is a commitment and a way to keep an artist’s creative muscle in shape as it can act as a place to sharpen observational skills. Drawing in the sketchbook can boost creativity allowing an artist to make random connections and juxtapose concepts. This is an idea akin to *reverberations*, the fifth rendering in a/r/tography explained in the *A/r/tography* section. Sketchbook drawing is a way to emotionally download thoughts, distil ideas and gain clarity to focus on major creative projects.

In his book *Drawing is Thinking* (2008) American graphic artist Milton Glaser concurs with Lillian Gray’s rationale taking it a step further:

Drawing can be considered a form of meditation. Meditation involves looking at the world without judgement and allowing what is in front of us to become understandable [to the artist who created the drawing]. Art, in fact, may be the best way we have to experience truth or what is real... I believe that art is a form of mediation for both maker and witness and that, like meditation, art makes us attentive. If you say that the aim of art

and meditation is to produce attentiveness and quiet the mind so that it can discard pre-existing ideas in order to see what is real, then we can say all of the arts share this. They help us to survive by encouraging attentiveness (p. 11).

Glaser believes that both the maker and the viewer become more attentive, one by creating the work, the other by experiencing it (p. 11). With Glaser's theory in mind throughout the research process, all of the artwork created for this dissertation began from concepts drawn or noted in a sketchbook including the rich discourse of interviews, goings-on at the research site, and data collection in the form of fieldnotes which support cumulative data analysis.

According to a/r/tographer, Julie Lymburner, "Arts-based journaling methods provide the opportunity to reflect in action and on action aesthetically, intellectually, and introspectively" (2004, p. 75). Lymburner further elucidates the importance of sketchbooks stating that, "visual journaling and collaging allow her to investigate relevant research questions, and to juxtapose meaningful text with image, outer phenomena with inner and negotiate a path that simultaneously accepts her role as a devoted teacher, a developing artist, and a disciplined researcher" (2002, p. 87).

A sketchbook is a place to document possible journeys to final solutions by acting as a place to research, write, brainstorm, experiment, test, analyze and refine concepts for artwork. See Illustration 8, *Being a Fly on the Wall...* for an example of a sketchbook

notation made at the research site that later became a finished artwork. In short, journaling is a way to create an artist's own inspiration from what they see. It can become a point of departure for meaningful image production in a range of media. The artwork can deepen the reader's understanding of the concepts presented. In both pre and post interviews, the artists in *The Right to Be an Artist* study continually shared details about their artwork and notes about their

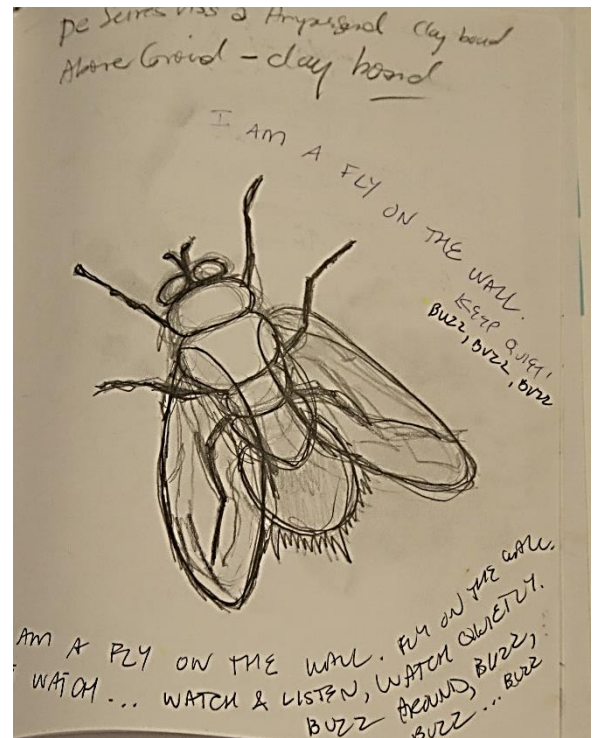


Illustration 8: Yarmol, C. (2019). *Being a Fly on the Wall...* [Drawing with pencil and black pen), 8 ½" x 11"].

discourse were documented in a sketchbook that became instrumental in cumulative data analysis.

### **Artwork.**

The artwork by the CVS artists was viewed holistically according to the intended subject matter, the material techniques applied, the selection of media used and the explanation of the artist who created the work in order to develop a recognition of the artists' unique styles. Fox and Macpherson state that, "The artwork itself is of value, for the work produced is a form of human expression where knowledge is created and meaning is made" (2015, p. 144). Creating artwork is a form of exercising participants' cultural citizenship at CVS and in the community at large. Fieldnotes were coupled with the analysis of the interviews to add further information to each participant's testimonies about their working process and their creations. In addition, the sketchbook journaling mentioned above helped to visually document the phenomena witnessed and provided visual notation leading to intellectually creative art making.

### **Narrative Methodology**

A characteristic of narrative inquiry is the identification of experience as story (Hamilton, Smith, and Worthington, 2008)<sup>14</sup>. People shape their lives through story and the story is an entry point by which the experience is made noteworthy. In their study of the potential contribution of narrative inquiry to disability studies, Smith and Sparks (2008) believe that "narratives can illuminate a great deal about the personal as they 'impart' information about their or others' 'internalized' work thereby allowing researchers to explore lived-experiences and preserve a sense of the 'individual person' in the world" (p. 18). The team also contends that "narrative inquiry bears within it the promise of fashioning a kind of scholarship that seeks to practice a deep fidelity to the possibilities of societal and individual transformation, resistance and living life differently" (p. 19). According to visual narrative inquirer Hedy Bach (2008), the philosophical underpinnings of narrative inquiry are situated in John Dewey's (1938) views of experience (p. 938). Dewey views humans not simply as "subjects" or "isolated individuals", they are originally and continually tied to their environment, organically related to it, changing it

---

<sup>14</sup> David Polkinghorne (2007) asserts that, "Narrative research is the study of stories. Stories are ubiquitous, appearing as historical accounts, as fictional novels, as fairy tales, as autobiographies, and other genres. Stories are also told by people about themselves and about others as part of their everyday conversations. In addition to the stories that appear in people's ordinary conversations, narrative researchers study stories they solicit from others: oral stories obtained through interviews and written stories through requests" (p. 417).

even as it changes them; they are deeply attached to what surrounds them. For example, after artist Judith Scott, who was diagnosed by the medical community with Down Syndrome and deafness and was institutionalized, she came to the Creative Growth Centre in Oakland, California, a studio supporting people with CIDs. No one could ever predict that she would have one woman a show entitled, *Bound and Unbound* (2014) at Brooklyn Museum's Sackler Centre for Feminist Art. Tom di Maria, former assistant director of the U.C, Berkeley Art Museum and Creative Growth Art Centre's director since 2000, was asked about Scott's success and he answered, "When you ask someone to participate in society, to tell you their story, to express themselves, and like Judith, they had been silenced or have not been asked to do this before, the results can be astonishing" (Starin, 2015). I used the paradigm outlined by narrative researcher and social work theorist Gabriela Spector-Mersel (2010) as a structure to guide the questioning strategies and analysis of the narratives presented in this multi-methods study<sup>15</sup> (Yarmol, 2013).

#### **Narrative framework of Gabriela Spector-Mersel.**

Gabriela Spector-Mersel considers narrative inquiry as a paradigm or belief system that can guide us growing out from the ontological, epistemological, and methodological assumptions of narrative inquirers Michael Connelly and Jean Clandinin (1998a). The following six major dimensions organize Spector-Mersel's (2010) narrative research paradigm: ontology, epistemology, methodology, inquiry aim, inquirer posture, and participant or narrator posture.

The *ontological* questions: "What kind of being is the human being? What is the nature of reality?" (Guba & Lincoln, 1994, p. 108) help to examine the form and nature of reality or the, "storied nature of human conduct" (Sarbin, 1986 cited in Spector-Mersel, 2010, p. 211) maintaining that social reality is primarily a narrative reality emphasizing the central place of stories in our existence (p. 211).

From an *epistemological* perspective, that is, one that questions what is the nature of the relationship between the knower or would-be knower and what can be known? (Guba and Lincoln, 1994, p. 108), the narrative paradigm shares underlying assumptions with the

---

<sup>15</sup> Segments of the text presented in the Narrative Methodology section of this dissertation have been modified from an earlier work by the author. Gabriela Spector-Mersel's framework was presented in an earlier academic work: Yarmol, C. (2013). *Listening to Voices of Exceptional Students to Inform Art Pedagogy* (Master's Thesis). Retrieved from Electronic Thesis and Dissertation Repository. (1371. <https://ir.lib.uwo.ca/etd/1371>). Due to the suitability of the framework and the author's familiarity with its effectiveness to analyse narrative data, it has been used to analyse data for this dissertation.

constructivist paradigm where we understand ourselves and our world by way of interpretative processes that are subjective and culturally rooted (Spector-Mersel, 2010, p. 212).

*Methodology* asks the question: How do we know the world or gain knowledge of it? (Spector-Mersel, 2010, p. 209). Spector-Mersel states that qualitative researchers employ an extensive array of: (1) materials that serve as data; (2) methods of collecting or producing these materials; and (3) methods of analysis and interpretation (p. 213). If social reality is a narrative reality, then narratives are the natural channel for studying it. Holding a pluralist position, Spector-Mersel believes that the researcher is not “the exclusive owner of truth but as contributing to the understanding of a kaleidoscopic reality” (2010, p. 217). Participants and alternative interpretive narrative interpretations are also possible hence the research report is always a partial version of the reality.

Spector-Mersel’s descriptions of *inquiry aims*, range from “psychological questions focusing on internal, emotional or cognitive processes on the one hand, to sociological, anthropological and historical questions on the other” (p. 215). I am using an interventionist approach to narrative in research, that is, to “endeavor to develop practices based on narratives as a tool in improving teaching, advising or mental treatment” (Spector-Mersel, 2010, p. 216). My aim is “to ‘give voice’ to marginal[ized] populations by publishing the narratives told in research” (Spector-Mersel, 2010, p. 215) knowing that I am an interpreter of their stories. Advocacy and activism are part of the narrative process as the researcher “is cast in the role of participant and facilitator in this process” (p. 215) as the narrative paradigm “maintains that researchers and the phenomena they study are inseparable” (p. 215). It considers the relationship between the “known and the knower” or “reality as it is” and the researcher “discovering” it” (p. 216). The inquirer’s voice is that of a “passionate participant” (Guba and Lincoln, 1994, p. 114) actively engaged in facilitating the “multi-voice reconstruction of his or her [their] own construction as well as those of all other participants”. As reconstructions are formed and individuals are stimulated to act on them, change is facilitated (pp. 114-115) creating what educational theorist Paolo Freire (1970) would call praxis.

In the *inquirer posture*, the inquirer is cast in the role of participant and facilitator in this constructivist inquiry process (Guba and Lincoln 1994, p. 113). Spector-Mersel suggests that an interactive voice aims at expressing the mutual influence between the researcher's and the narrators' voices, focusing on the researcher's interpretations and personal experiences (2010, p. 218). The researcher enters a process in what Clandinin and Connelly (1994) claim demands simultaneous focus, "in [multiple] directions: inward and outward, backward and forward" (p. 147) to understand how the researcher interprets the data. The researcher's experience with disability is aesthetically realized in the *BS Series* (See Illustrations 3-6, 9-12) and assists in her understanding of medical models of disability through a lens of lived experience. The aim of a constructivist inquiry is "understanding and reconstruction of the constructions that people (including the inquirer) initially hold, aiming toward consensus but still open to new interpretations as information and sophistication improve" (Guba and Lincoln, 1994, p. 113). Readers glean information from the resulting narrative text which includes both the data from the research and the researcher's interpretations.

In Spector-Mersel's *participant/narrator posture*, the narrators are at the centre of narrative inquiry, however, not as informants, but as active agents inseparable from the phenomena under inquiry. "If we wish to hear respondents' stories, then we must invite them into our work as collaborators, sharing control with them, so that together we try to understand what their stories are about" (Mishler, 1986, p. 249). Spector-Mersel concurs with Mishler's idea sharing that democratic relationships are



Illustration 9: Yarmol, C. (2017). *BS Series: 2.4*. [Painting with aquarelles and water colour on paper. 8 ½" x 11"].

developed with participants who share control over the various aspects of the inquiry with the researcher which is marked in writing the final research report (2010, p. 217)<sup>16</sup>.

Spector-Mersel's approach follows a narrative ontology that emphasizes a holistic nature in four major ways: first adopting a multidimensional and interdisciplinary lens, second treating the story as a whole unit, third focussing form and content and fourth attending to contexts (Personal communication with Kathryn Hibbert, January 14, 2013). The focus of the *Right to Be an Artist's* narrative inquiry is to gather stories from the lives of people with CIDs who want to practice as artists.

#### **Model for interpreting narrative data.**

The Spector-Mersel (2011)<sup>17</sup> model considers narrative accounts as overt texts, oral or written, recounted sequentially by a teller (instead of exchanges of questions and answers). To collect these overt texts, she encourages the use of open-ended questions such as, "Tell me about your childhood" or "Tell me the story of your life" (Spector-Mersel, 2011, p. 183) or in this case "Tell me about your experiences at Creative Village Studio". Open-ended questions allow participants to create responses that convey their cultural and social experiences (Neuman, 2000) allowing the storyteller to structure the conversation with the researcher asking follow-up questions (Gray 1998, p. 2 cited in Bell, 2005).

Examining the story as a whole, Spector-Mersel (2011) begins with an *immediate context*—time, place, audience, setting (e.g. research, studio), and direct triggers for narration (e.g. question, remark) moving to a *micro context*—the narrow circle of the narrator's life (e.g. events that occurred recently or that are expected to take place in near future, general mood, and so on); eventually leading to what she terms is a *macro context* or broad social, political, and economic conditions in the larger society (p. 173). These concepts work particularly well for the study questions involved in *The Right to Be an Artist*.

Biographical facts are chosen, filtered, and sorted, with the purpose of confirming an established *end point* (EP). An EP is the point of the story to be told (p. 174) or the "core of the

---

<sup>16</sup> The six mechanisms described are summarized from Spector-Mersel, G. (2010). Narrative Research: Time for a paradigm. *Narrative inquiry*, 20 (1), iii, 204-224. doi: 10.1075/ni.20.1.10spe and methodology are outlined in Yarmol, 2013, Master of Art Education Dissertation.

<sup>17</sup> Spector-Mersel, G. (2011). Mechanisms of Selection in Claiming Narrative Identities: A Model for Interpreting Narratives. *Qualitative Inquiry*. 17(2), 172-185. doi:10.1177/1077800410393885.

identity being claimed through the story” (p.174). It is important to note that the EP recognized at the beginning of the inquiry by the researcher may alter throughout the retelling process. Because it is a subconscious process, the participants themselves determine the overarching EP, not the interviewer, and periodically a different EP is claimed (p. 174) at the end of the narrative. For example, in this study, at the start of the interviews the selected EP was to learn specific details about the artists’ experiences of art making but other EPs emerged such as social hardships experienced at the former workshops or financial issues. The researcher treats the narrative as a whole unit carefully regarding form and content, paying attention to contexts, and employing a multidimensional interdisciplinary lens. Finally, nuances are enhanced by changing the lens or the film for what the researcher is trying to learn. It is important to note due to my inquirer’s posture; the participants’ interviews were also interpreted using an a/r/tographical<sup>18</sup> positioning employing the interviewer’s own life experience as an artist, a researcher and a teacher.

Following and then moving beyond the work of Clandinin and Connelly (1998a, 1998b, 2000), Spector-Mersel formulates six mechanisms for constructing narrative identities and story analysis: *inclusion, sharpening, omission, silencing, flattening, and “appropriate” meaning attribution*. To facilitate a swift understanding of these mechanisms, Spector-Mersel uses the metaphor of taking a photograph which also links with a/r/tography’s idea of metaphors:

The mechanisms of narrative selection might be further clarified by thinking of a camera changing its focus depending on the photographer’s purpose (the EP): Certain events enter the picture (inclusion) and others remain outside (omission and silencing). Some of the former appear at the center of the picture (sharpening), whereas others are seen only at the margins (flattening). Finally, desired nuances are enhanced by changing the lens or the film (meaning attribution). As illustrated by this image, the mechanisms of selection are by no means unique to claiming narrative identities. (2011, p. 176)

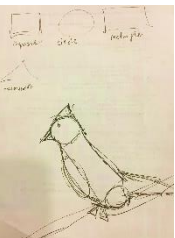

After the completion of each interview the video footage was transcribed using a stop-transcribe-start approach and film stills were used to capture the idiosyncratic nature of the descriptive narratives about the artwork to offer additional information for analysis. The use of square brackets indicated facial expressions, body language, and voice inflections observed in delivery of narrative production and the numeral in parentheses referenced the line number in the interview transcript. The utilization of various hues was added to the transcription text before


---

<sup>18</sup> An explanation of a/r/tography was provided in the previous section, *Arts-informed methodologies*.

analysis including bolded red for investigator’s key questions, red for any additional questions, blue for narrative responses, and green for fieldnotes making it easier to promptly identify various aspects of the narrative. Based on Spector-Mersel’s (2011) interpretive schemata, the following codes were employed to identify data: [INC] inclusion, [SHA] sharpening, [OMI] omission, [SIL] silencing, [FLA] flattening, [APP] for analysis. The coded interview data was globally reviewed for repetition across individual participants’ responses (Glazier, 2005, p. 4) “noting underlying patterns across example of stories” (Polkinghorne 1998, p. 177). Circling back across the individual data analysis tables helped to identify repetition across the sample to develop the overarching themes or outliers, for example, the appreciation of the support volunteers offered artist-participants. Figure 1 presents a table organizing the analysis of narrative data from interviews using Spector Mersel’s six mechanisms for constructing narrative identities and story analysis.

Figure 1: Sample Table Indicating Analysis of Coded Interview Data

<p><b>Artist-Participant’s Name:</b> Emily Parsonson  <b>Length of time at the studio, details about their working process from fieldnotes:</b>          Fieldnote(s) in green with date to indicate an observation or a conversation during the fieldwork at CVS, photographs of artwork</p>	
<p>→ has been attending CVS for approximately 6 years for one-two classes weekly; she also attends other arts-based programs in the community.          → lives with her mother within a 10 km radius of CVS. A parent drives her to the classes.          → uses bright hues to that emphasize her subject matter.          →subject matter is of naturalistic imagery including flowers, birds in brightly lit contexts.          →creates abstract compositions on some of her larger paintings and on her cards for her art business, <i>Emily Parsonson’s Productions</i>          →outgoing and has a positive attitude about learning new skills</p>	
	<p><b>July 8, 2019:</b> I sat beside Emily in card making class. She wanted me to show her how to draw a bird to make for her Auntie Carol. Together we reviewed geometric shapes, circle, rectangle, square and triangle in my sketchbook (left) which I labelled on one side of the page. We then discussed the shapes we saw on the photograph of the Blue Jay provided by the instructor; in pen, I drew the shapes directly on the body of the bird in the photograph. On the opposite sketchbook page, I created a drawing of a Blue Jay using geometric shapes we discussed and that I had drawn on the photograph. I outlined my Blue Jay image with a solid contour line. Next, I used the left-over paint on palettes at the table to demonstrate how to paint a background and the body colour of the bird. I showed Emily a blotting technique for the background and a dry-brush feathering technique for the wings to paint over the solid blue base with acrylic paint.</p> <p>Before Emily drew, we reviewed the process step by step (draw geometric shapes, trace over with contour line, apply body colour with paint, paint an additional layer with blotting technique, dry-brush feathering technique on wings). As she created her own Blue Jay, I verbally reviewed the steps in sequence encouraging Emily through the process. Unsure of the feathering and dry brush techniques, she practiced them on a piece of paper before applying paint to her good copy. She was very impressed with her results from the new techniques learned and decided to create an image of a Cardinal next. Emily remained focused throughout the entire drawing and painting process. She proudly held up her work at the end of the session for me to photograph. She immediately showed her parent who came to pick her up. A few weeks later, her mother reported that Auntie Carol had framed Emily’s artwork. * Note that this drawing and painting process was a new way for Emily to create greeting cards as she habitually painted in an abstract style.</p>
	

<p><b>OPEN ENDED QUESTIONS:</b></p> <p>Line (#) Interviewer's questions in <b>bolded red</b>. Interviewer's responses are marked in red.</p> <p>Line (#) Participant's narrative responses in are marked in blue</p>	<p><b>[INC]:</b> Certain events enter the picture</p>	<p><b>[SHA]:</b> Some events appear at the center of the picture</p>	<p><b>[OMI]:</b> Other events remain outside</p>	<p><b>[SIL]:</b> Other events remain outside</p>	<p><b>[FLA]:</b> Other events are seen only at the margins</p>	<p><b>[APP]:</b> Nuances are enhanced by changing the lens or the film</p>	<p><b>OBSERVATIONS &amp; NOTES:</b> Coding for repetition across individual participants' responses noting underlying patterns across example of stories</p>
<p><b>(80) Q5. Can you show me your art?</b></p> <p><b>Tell me a little about your art.</b></p>	<p>[Emily shared her art making process at CVS readily showing me examples of her work. ]</p> <p><b>(81) When you are at home, what for example, do you do to create art?</b></p> <p>(82) Usually Mom works for me. [Emily shows me a series of cards that she created. See example below.]</p> 	<p><b>(83)Yes.</b></p> <p>(84) I say a few things [She puts her hand on her chest and then gestures outward to indicating where her mother would sit when helping her.] what I would like to be done.</p> <p><b>(85) Yes.</b></p> <p>(86) My art, I have a greeting card business. It is fascinating how you get everything done on time. You have every art detail down because you don't want to miss anything [Emily says emphatically.]</p> <p><b>(87) Okay.</b></p> <p>(88) When Mom <u>is trying</u> to help me painting or I'm not going to say it, <i>overpainting</i>. [Emphasizes "is trying" then laughs.]</p> <p><b>(89) Oh, okay. Emily. [ Laugh.]</b></p> <p>(90) [Emily smiles broadly.]</p>	<p>Emily does not discuss the extra work she and her mother need to do to complete cards for the church bazaar or a show.</p> <p>Emily also has her own distinct style and becomes frustrated if she is not left alone to <u>create</u> on her own.</p>	<p>Emily knows that her mother does not enjoy art making but appreciates her mother's willingness to support her process. She silences the discourse that occurs in art making time at home (88).</p>	<p>She flattens any possible disagreement with her mother. Emily copes with her mother's dislike of art making with humor.</p>	<p>Emily is very proud of her artwork. She sees herself as an artist.</p>	<p>Other artists also express their pride in their work and openly share details about both the process and the subject matter.</p> <p>Emily has a positive relationship with her mother, one of her caregivers as seen in line (88). Like other artist, she feels a sense of empowerment in her art making experiences (86).</p> <p>She enjoys the classes immensely and feels confident with her own style but is always willing to learn new techniques. She requires scaffolding of learning (Fieldnote, July 8, 2019).</p>

These narratives were not the only source of data. Contextualizing the stories, triangulating them with participants' artwork, and observations recorded as fieldnotes in the studio extended the understanding of the stories. Deeper descriptions of the rationale behind these data points are outlined in the *Methods* section in this chapter. Assembling the stories alongside one another enabled a compare-and-contrast process to gather and to extract the study's findings or new understandings.

### **Positionality of the researcher.**

Both narrative inquiry and a/r/tography methods focus on the positionality of the researcher as essential considerations when shaping the initial study step up, analysing data and arriving at conclusions. In a/r/tography, the broadly conceived of and inseparable roles of artist/teacher/researcher (a/r/t) are identities existing in a contiguous relationship with one another (Irwin, 2008, p. 3) and in narrative inquiry the researcher assembles the data from their personal stance.

*Verstehen* (Weingartner, 1967, p. 7) or *philosophical hermeneutics* is deemed as an ethical consideration in narrative research. According to psychologist, narrative researcher David Polkinghorne, it is important to state the position from which a narrative inquirer situates his, her [their] interpretation (2007, p. 13). I completed the analysis and interpretation of the data of the CVS research from a philosophical hermeneutics position:

Philosophical hermeneutics, holds that the interpreter encounters a text from within his or her [their] "prejudices"; interpretation is like a conversational dialogue through which meaning is a product of interaction... The philosophical hermeneutic position holds one cannot transcend one's own historical and situated embeddedness; thus, textual interpretations are always perspectival. Narrative researchers engaging in interpretation will make different claims about their understanding of a text depending on which position they take. They need to let readers know which approach informs their interpretative claims (Polkinghorne, 2007, p. 13).

Concurring with Polkinghorne, mixed-methods researcher John Creswell (2013) explains that as they research, researchers not only need to actively collaborate with the participant conversing about their stories but need to, "be reflective about their own personal and political background, which shapes how they *restory* the account(s)" (p. 57).

Social policy and narrative inquiry researchers Jennifer Dodge, Sonia Ospina and Erica Foldy (2005) maintain that narrative inquirers do not claim to document reality but capture *individual interpretations of reality* [emphasis added] as well as shared social constructions

among a given community (p. 289). Polkinghorne (2008) asserts that narratives become creative productions that stem from the researcher's cognitive processes for recognizing patterns and similarities in texts (p. 483).

Storied responses from participant-artists are contextualized by using my a/r/tographical stances and "cognitive processes for recognizing patterns and similarities in texts" (Polkinghorne, 2007, p. 13). Clandinin and Connelly (2000) assert that, "it is imperative to do a little self-exploration before engaging in narrative research". According to narrative researcher Kathryn Hibbert, the mining of the self continues, but it is important to recognize and acknowledge that narrative is 'research with' rather than 'research on'. We must understand ourselves well to do 'research with' so that we can do the best job possible of representing the interviewees (Personal communication, 2012). It is thus imperative that I outline how I come as a researcher to this study.

### ***The researcher's story.***

I am a cisgender, heterosexual, educated, white, middle class, Canadian-born woman of Eastern European heritage with an autoimmune disability working as an artist, researcher and art educator in the public secondary school system. It is difficult to remember a time when I did not make art. I often illustrated countless stories with my sisters and collected natural objects to create sculptures. As a young child my mother was very ill with a rare form of cancer and I was often left in the care of my grand-parents, Baba and Gigi. I spent numerous hours in my Baba and Gigi's grand, picturesque sloping garden behind their house which became the first detailed subject matter of my abundant drawings only second to a copious number of life drawings of my family. Hours outside would translate into many 4" x 6" sketches drawn with black, red and blue pen or a sharpened, yellow-orange Eberhard Faber Mongol pencil applied onto rectangles of white, yellow, pink and blue recycled paper my Baba had cut and left neatly piled in a black Lucite container by her rotary dial telephone until my father came to fetch me. These visually descriptive drawings grew into a love of art when I entered nursery school and kindergarten where according to my mother, I was a prolific artist.

When I myself grew ill with an autoimmune disorder as a child, art became a way to cope with the disability. My interest in art continued through my elementary career where I won several awards and publications for drawing and followed me to high school through photography, sculpture, drawing, and painting. My mother, who healed after the removal of the

cancer, began to sell art so, there was no shortage of interesting artists at our house at any given moment.

Not only did I delight in the studio arts but, I thoroughly relished learning about art history. To me art was the key to learning about people in the society in which we lived so it was no surprise that I earned the art award in a high school of 2500 students and decided to earn a Bachelor of Fine Arts at university. But how does one connect this interest in the job market when one needs to a medical plan to pay for medication? To meet my need for a medical plan, leverage my skill in teaching others, and to complement my desire to teach art, I applied for a concurrent education program and earned a Bachelor of Education.

My interest in researching the lives of people with CIDs began in my youth when I worked for the Etobicoke Parks and Recreation department (1987-1992). The response to deinstitutionalization in the 1970-1980s, and the propagation of the *normalization-concept*,<sup>19</sup> prompted the sprouting of alternative, or “adapted,” recreation programs in the west Toronto community. Through this transitional phase of deinstitutionalization, that is, individuals moving from institutions to community placements, heavily staff-supported, segregated programs running parallel to more integrated settings existed. A “same but different” approach permeated staff training sessions, as the integration of people with CIDs into mainstream communities became operationalized. I worked as a day camp leader integrating campers into the program at day camp for two summers and as a program director of the camp for a four-month contract facilitating daily activity planning for all campers in attendance. Conventional wisdom of the time promoted integration of campers with CIDs but only offered limited supports for individual

---

<sup>19</sup>*Normalization-concept* refers to the belief that all individuals with disabilities regardless of severity were entitled “to establish and /or maintain personal behaviours which are as culturally normal as possible” (Wolfensberger, 1972, p. 28) “experiencing the rich stimulation of being involved in their community, in living with family members, and of experiencing friendships,” stressing contact with people without disabilities across all age ranges (Wehmeyer, 2013, p. 227). According to Taylor (2006), Wolfensberger’s “theory of normalization placed equal emphasis on changing society and service systems, on the one hand, and changing individuals, on the other; this is incompatible with concepts of disability culture and disability identity” (Linton, 1998 cited in Taylor, p. xxiii). Normalization became a new way to support people with CIDs: 1. for consciousness-raising to dislodge prejudices and biases general society at large hold against people who are different; 2. as a powerful organizational tool that has developed in the human services scene for consumers and advocates to marshal their strength; 3. to initially indoctrinate and train all potential human service workers...physicians, nurses, therapists, teachers, administrators, anybody in the human services embarking on their educational course; 4. as a socio-developmental model of growth...coherent and systematic ideologies to light the road for all human services: a guide (Bronston, 197, p. 492). Executive director and ombudsman of FUB, the Swedish Association for the Developmentally Disturbed, Bengte Nirje (1969) explains that the normalization principle had its basis in Scandinavian experiences from the field.

leaders with these children in their groups. Young staff members sought out clarification of their duties requiring additional daily programming tips.

In 1992, I became a program director of *New Strides Day Camp*<sup>20</sup>, a segregated day camp for participants with special needs aged 14- 21 years<sup>21</sup>, designed by medical specialists, with a staff of 3 leaders and one assistant director for 20 campers per two-week session. The program focused on engaging teenage campers who often had both CIDs and physical disabilities in an active social setting, where they were encouraged to participate in music, daily calisthenics, sports (including swimming twice a week), community volunteerism, touring around the city and creating visual arts in the community at large.

In the fall/winter session, I was employed as a program leader of *Friday Nighters*, a segregated teen recreation program run at a local, urban, community school. *Friday Nighters* was a program whose premise was to encourage teens to socialize. The program included creating art, playing board games, going on trips to see films and the like. At the same time, I also worked as a staff member at *Kingsway Club*, a segregated adult social club run in a church basement. The activities in this club included card games, crafts, social mingling, snacks and a social atmosphere that forged lasting relationships between attendees. Many of the participants had been long engaged in the Community Living social communities, adapted programs at the city level or through Arc Industries at a sheltered workshop. The experiences of working with

---

<sup>20</sup> New Strides was housed at Seneca School, a segregated day school during the year for children with intellectual disabilities operated today by the Toronto District School Board. I was responsible for hiring, training the staff, and program planning centring on activities in the community. The current normative description on-line about *New Strides Day Camp* was and “is a special needs day camp. A creative and flexible program for campers with special needs is delivered to increase independence, raise self-esteem, and improve social skills” (*New Strides Day Camp*: Toronto Parks, Forestry & Recreation, 2017). This description sees deems a hierarchical structure in play that is staff is there to support campers with special needs.

<sup>21</sup> At the time the New Strides program ran, Bengt Nirje’s normalization principle defined in the late 1960’s continued into the early 1990’s (and in some contexts continues today). The normalization principle was originally defined by Nirje (1969) as: “Making available to the mentally retarded [sic] patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society.” According to Independent Consultant, Policy and Program Development and Evaluation, Burt Perrin (2017), Nirje (1985) rephrases the normalization principle as, “Making available to all persons with intellectual disabilities or other handicaps, patterns of life and conditions of everyday living which are as close as possible to or indeed *the same as* the regular circumstances and ways of life of society” (italics in original). Nirje (1993) states that, “normal patterns of conditions of life can be viewed in terms of eight different facets or elements: 1. a normal rhythm of the day; 2. a normal rhythm of the week; 3. a normal rhythm of the year; 4. the normal experiences of the life cycle; 5. A normal respect for the individual and the right to self-determination; 6. the normal sexual patterns of one’s culture; 7. the normal economic patterns and rights of one’s society; and 8. the normal environmental patterns and standards in one’s community”. This revision had a subtle but important difference from Wolfensberger’s version in that normalization meant that human services should stop treating people with disabilities in abnormal ways (Taylor, 2006, p. xxiii).

both children, teenagers and adults with CIDs as a teenager and into early adulthood taught me the value of visual art programming for people with CIDs and introduced me to some of the injustices people with disabilities faced in society.

In addition to drawing, sculpting, photographing and painting in my spare time, I brought art into my teaching practice earning teaching qualifications in Visual Art, Drama, French and Special Education. When I began to teach high school students, my experience working with teens and adults with disabilities enhanced my ability to create learning environments for a range of students with diverse abilities in a classroom setting, which many of my teaching colleagues had only read about in educational theory in the late 1980s and early 1990s. It was these encounters that caused me to realize the power of the arts to engage participants.

### **Paolo Freire: Transformation as an inspiration**

I first came across Brazilian philosopher and educationalist Paolo Freire's theories several years after I earned my teaching degree in 1993. I was supporting a Grade 8 classroom of learners medically designated as students with learning disabilities. I began to consider how Freire's ideas and the role of *conscientização* (in Portuguese) or "learn[ing] to perceive social, political, and economic contradictions, and to take action against the oppressive elements of reality" (Freire, 2000, p. 35) might affect my role as an educator and those with whom I shared the classroom.

Freire was inspired by Critical Theorists<sup>22</sup> who grounded their theories in Marx's *Theses on Feuerback* (1924, 1994) which states, "The philosophers have only interpreted the world in different ways; the point is to change it" (p. 9). Taking up Marx's challenge, Freire wrote a book about critical pedagogy entitled, *Pedagogy of the Oppressed* (1970), with the basic premise that human society is flawed and needs to undertake radical change. Necessarily political, Freire's theories centre on power, authority and the hierarchical orders that develop in society to maintain ideological positions which benefit a few individuals at the expense of many (Diaz, n.d.). By

---

<sup>22</sup> Critical Theory's ideology was established from Marx's central economic and political notions including commodification, reification, fetishization and critique of mass culture. It also embedded Freud's concepts of the unconscious in psychoanalysis and theory of instinctual needs. According to Rush (2004) Critical Theory is, "an account of the social forces of domination that takes its theoretical activity to be practically connected to the object of its study. Critical Theory was a way to instigate social change by providing knowledge of the forces of social inequality that can, in turn, inform political action aimed at emancipation (or at least at diminishing domination and inequality)" (p. 9). Central themes and questions they raised were about: the European labour movements; capitalism in a series of acute crises; authoritarianism and the development of bureaucracy; Nazism and fascism rising; social relationships; areas of culture open to direct manipulation; the fate of Marxism in Russia and Western Europe (Held, 1990, p. 35).

confining members of society to defined roles, these ideological positions limit individual's lives and hamper their freedom.

While examining the role of education in children's lives, Freire (1970) also considered the wider nature and the purpose of education within society. He believed that education was the best prospect for the promotion of new social justice queries and the gradual metamorphosis of an unjust society. Passionate about notions of justice and rights, Freire was eager to release the potential of education to help transform people's lives but was encumbered by socio-political conditions that prevented a quicker beginning to this project (Diaz, n.d.)<sup>23</sup>.

In his appraisals of the education system, Paulo Freire (2000) critiques the oppression of what he calls the, *banking concept of education* where education becomes an act of depositing in which the students are the depositories and the teacher is the depository [sic]" (p. 72). In this model, the teacher's task "is to 'fill' the students with the content of his [sic] narration—contents which are detached from reality, disconnected from the totality that engendered them and could give them significance" (p. 71). Freire condemns this style of education system that was designed to produce passive learners destined for jobs to service capitalist mass production.

Freire (1970) claims that it is through, "dialogue in problem-posing education that the vertical patterns characteristic of banking education are broken" (p. 80). His critical pedagogy promotes dialectical thought to challenge given situations; negative and unfair aspects of education that should be removed, reformed or replaced by something better. He considers a variety of possibilities that might empower people to make positive change so that, "New terms emerge, 'teacher-student with student-teacher', a joint process where the teacher also learns from the students and grows" (p. 80) in a reciprocal 'problem-posing' fashion where people teach one another. Freire explains that banking education maintains the *submersion* of consciousness (p. 81) and problem posing education, "strives for the *emergence* of consciousness and *critical intervention* in reality" (p. 81). The theory of problem-posing education views people, "as beings in a process of becoming—as unfinished, uncompleted [sic] beings in and with a likewise unfinished reality" (p. 84). These people are aware of their incompleteness, living in a transformational character of reality and seeing education as an ongoing activity constantly remade in the praxis (p. 84).

---

<sup>23</sup> "Freire was imprisoned following the 1964 coup d'état for what the new regime considered to be subversive elements in his teaching" (Freire Institute, 2020).

Teachers can either become compliant participants in the status quo which will result in cost of the suffering and injustice that will eventually reach all or can work collectively with students to criticize the status quo. Freire declares that, “Functionally, oppression is domesticating. To no longer be prey to its force, one must emerge from it and turn upon it. This can be done only by means of the praxis: reflection and action upon the world in order to transform it” (Freire, 2000, p. 51). Freire asserts that:

Only human beings *are* praxis—the praxis which, as the reflection and action which truly transform reality, is the source of knowledge and creation (p. 100) ...And as praxis, it requires theory to illuminate it. Human activity is theory and practice; it is reflection and action ...directed at the structures to be transformed” (p. 125).

It is these words that inspire me to critically reflect on pedagogical practice and elicit change in my immediate world and watch that change multiply.

Commenting on Freire’s democratic proposals of problem-posing education, a colleague of Freire, Donaldo Macedo says that people “develop their power to perceive critically the way they exist in the world with which and in which they find themselves: they come to see the world not as a static reality but as a reality in the process of transformation” (2000, p. 12). The idea is to never settle, but move and continue with Freire’s *conscientization* that encourages individuals not to rest complacently but rise to learn, “to perceive social, political and economic contradictions and to take action against the oppressive elements of reality” (Holmes, 2002, p. 76). The idea of never settling is what thrusts me forward in a continuous mode of learning, always looking at new possibilities and at new connections. The strengths of Freire’s theories are that they offer a framework for continual re-examination and reassessment of pedagogical theory and educational practices by encouraging both creativity and innovation. They raise questions, clarify issues, identify strategies and solutions to foundational problems in education.

A drawback of Freire’s theory is that if one finds fault in everything in dogmatic ideology, the negativism can destroy morale and incite complacency. Freire’s critical pedagogy represents one application of critical theory and is rooted in his experience as an educator working in Brazilian favelas who witnessed the struggle of people living in poverty attempting to traverse their way through a rigid and traditional education system in the 1970s thus could be seen as specific to one time and one place (Diaz, 2020). Although Freire was writing about a Brazilian education system at a specific point in history, I see the basic premise of Freire’s theories as applicable today and for the future. Freire’s focus on power, authority and change in

education have caused me to reflect upon my roles especially in relation to issues of justice and emancipation in my post-graduate research in critical disability studies with people who are marginalized. It is with Freire's ideas about critical analysis, reflection and action to create praxis, that I move forward in my work as an artist, my career as an educator, my role as a researcher and beyond.

Since I was trained as an educator in the late 1980's and early 1990's my challenge has been to think outside of established, neoliberal, square-box modes of problem-solution, education-as-a-business thought founded on a historical stage of normalizing and repressive discourses. A prime example of this agenda is the public-school boards' appropriation of business theories. Subject department planning and educational goals are structured through the use of *SMART goals*<sup>24</sup> assuming that each student is a marketable product who completes their education with a set number of skills regardless of their personal biographies. These kinds of measuring sticks are not only prevalent in contemporary educational contexts but have become naturalized and hegemonic pervading all aspects of social existence and everyday life. Years as an art educator consistently writing new, topical curriculum and a desire to continually learn have helped to push outside my repressive teacher-education training to think critically and offer open spaces for my students with a range of identities. This approach has resulted in both my students' and my personal growth. For example, I began to study the work and the journals of

---

<sup>24</sup> Peter Drucker developed a *Management by Objectives* process and published it in book *The Practice of Management* (1954) instructing managers how to take methodical approach to productive work in a calm and measured manner so that workers could feel a sense of achievement. Drucker's approach was that superior and subordinate employees work collaboratively in goal setting and choosing the course of action so that they would fulfill their responsibilities as employees then measure and compare employee's actual contribution and performance with the measures set. (Rating employees as superior and subordinate itself is a neoliberal practice.) George Doran wrote the term SMART goals based on Drucker's protocol in *Management Review* (November 1981) and then Robert Rubin from Saint Louis University wrote about SMART goals in an article for *The Society for Industrial and Organizational Psychology*. To ensure that goals are clear and reachable, each one should be SMART that is: Specific (simple, sensible, significant); Measurable (meaningful, motivating); Achievable (agreed, attainable); Relevant (reasonable, realistic and resourced, results-based); and Time bound (time-based, time limited, time/cost limited, timely, time-sensitive). Rubin suggests that SMART goals should also reflect Efficacy and Feedback (Other authors have inserted this idea as Evaluated and Reviewed changing the acronym to SMARTER). Retrieved from: Emerald Works. (n.d.). *SMART Goals—Time Management Training from MindTools.com* and <https://www.mindtools.com/pages/article/smart-goals.htm>

Mexican artist Frida Kahlo after which I created the 36" high marionette depicted in Illustration 10<sup>25</sup> (See Appendix E: Process Documentation of Making a Frida Kahlo Marionette). I integrated my personal study of Frida Kahlo with a social justice project in the class with grade 10 students to challenge their thinking about disabilities and the how people with disabilities are often pathologized in the world. As a critical educator, I see education as a subversive force to encourage students' application of critical theory—in this way creating praxis and slowly altering society. In practice, this can be partially accomplished through social justice themes, engaging and embracing opportunities for community projects, teaching students to critically examine their own contemporary worldviews through viewing art and art making. I cannot escape my educational and cultural formation, but I can critique it. This positionality



Illustration 10: Yarmol, C. (2011). *Frida Kahlo Marionette*. [Sculpture: Sculpey, acrylic paint, fishing line, wood, pressboard, cotton fabric, wooden beads, silk flowers, 36 h" x 11"w x 5"d].

<sup>25</sup> I was asked by organizers of *Frida Kahlo: Her Life and Art*, (2012) at the Art Gallery of Ontario to present my marionette of Frida Kahlo to both *Family Day*, the first Sunday of each month, and the *Teacher Education* event. Organizers wanted Frida to interact with the viewers.

acknowledged, I must continue to be both outwardly and inwardly critical of re-inscription of heteronormative, neoliberal perspectives in my critical analysis and take great care to attend to intersectional specificities of any gendered, cultural, racial, and ableist norms to evade reductionist stances that I work against in my teaching and research practices.

### **Crip Theory**

To further explain my positionality as a researcher and how I relate to disability, I used crip theory that, “can function as a body of thought or a thought about bodies...which attends to how bodies and spaces are being materialized in the cultures of upward redistribution we currently inhabit” (McRuer, 2006, p. 76). Crip theory offers what prominent feminist scholar in the field of Science and Technology studies Donna Haraway (1988), claims is a way to, “partially translate



Illustration 11: Yarmol, C. (2019). *BS Series: Hi, High*. [Monprint with aquarelle crayons on paper, 6" x 6"].

knowledges among very different and power differentiated communities... a critical theory of how meanings and bodies get made, not in order to deny meanings and bodies, but in order to build meanings and bodies that have a chance for life” (p. 580). From a white, Northern, Euro-Western perspective, crip theory considers disability to be a viable, variable identity to be recognized, acknowledged and celebrated. Crip theorist Robert McRuer (2012) states that:

[C]rip theory is this critical cultural practice that has been developed in a lot of queer communities, by artists, activists, and academics, writers of all kinds, poets, painters; many different kinds of cultural workers have put into practice what I think we can call crip theory. That said, I wouldn't say there is an absolute consensus on what crip theory is. I would say that in many ways it is something that's very much about excess. Compulsory heterosexuality and compulsory able-bodiedness generate sites of containment, where disability and queerness are managed, contained, kept quiet, kept silent. And crip cultural production has been about saying, “we're not going to stand for

that,” so to speak. “We are going to generate visions of the body and desire and community that are in excess of attempts to contain and manage us. And there is not absolute consensus about what crip theory is, because that generative excess has been so incredibly varied (pp. 148-149).”

This explanation echoes the disruptive force of crip arts that puts disability at the forefront framing artistic production and practice through a disability lens seeing it as a desirable possibility (McRuer, 2006). It is with this notion of “a disability as a desirable possibility” that I created my *BS Series* (See Illustrations 3-6, 11-12). Art and disability scholar Eliza Chandler (2014) asserts that enactments of crip art and crip communities, “open up with desire for the way that disability disrupts, ways that we understand disability and how we come together in community (iii)” in order to create change.

The intention of the *BS Series* is to think about the possibilities and the limits for embodying crip identity in which I am immersed and to constructively explore how crippling can be employed to express how I come to my understanding of my disability and to disability studies in general, “as a category of analysis, a lived experience, and a source of cultural knowledge and production” (Cachia, 2016).



Illustration 12: Yarmol, C. (2019). *BS Series: The Forest on High Morning*. [Photography, digital print on paper, 8" x 11"].

At crip art's centre is the embracing of difference and building art practice in conjunction with an artist's experiences of disability as an integral part of an artist's identity and not simply an additional label denoted by the medical model. At the same instance, crip art seeks to examine the intersectionality of disability with experiences of racism, sexism, classism, homophobia, transphobia, poverty, Indigeneity and colonialism to claim multiple identities (Reid, 2016).

In *Thoughts on 'crip arts'*, critical disability studies philosopher nancy viva davis halifax (2016, February 7) poetically describes and visually illustrates crip art practice (See Illustration 13). Diverging from McRuer's explanation of crip art, I believe davis halifax captures the essence of crip art in *Thought on 'crip arts'* (2016). Key phrases that encapsulate

Illustration 13: davis halifax, n.v. (2016, February 7). *Thoughts on 'crip arts'*. [blog post]. Recounting Huronia website. [Poetry and Digital image]. Printed with permission from artist.

## Thoughts on 'crip arts'

Posted Feb 7th, 2016



Scholars have been interested in and preoccupied by the need to write and know difference differently.

However, the existing published research remains limited and is predominantly still written or expressed through the presence of "the researcher" and remains reluctant to be fully inclusive of the arts (broadly defined as: literary, visual, performing, time-based, multi-disciplinary). Yet the arts provide a significant way of articulating knowledges too often abandoned by a Western allegiance to the rational.

Through the arts, the forms that knowledge(s) can inhabit and/or be exhibited through are varied - the 26 letters of the English alphabet can be formed and reformed, spoken and whispered in ways that disorient and challenge meaning making practices. Difference, differently presented.



To further our comfort with difference Recounting Huronia (RH) embraces a crip art praxis that encompasses unruly enactments whereby sparkly cats and pyjama wearing guinea pigs find their presence in the social fabric that extends and surrounds RH.

Crip established as a colloquial abbreviation of cripple is a constant becoming. It is a movement of thought – like queer it unsettles normative expectations and is an endurance. | To crip art is to practice a form of movement that pursues forms abjured within the hegemony of normative arts practices.

The crip arts of RH have engaged members of the SP in multiple art forms: storytelling, poetry, collage, movement, theatre, dance through which they might express their life stories.

We move, are moved, from sensation, to gesture to sound to word to sensation to gesture – crip art arises from bodies that create their own norms - norms as uncertain and sometimes unsweetened difference. Our embodied beings lean into each other, entwine, combine and separate.

Crip arts practices re-situate knowledge practices as fragmented, gestural, incomplete, unpredictable and embodied. Dressed in pyjamas. Sparkly wings.

Crip arts is a handout, a cut, it nips.

Knowledges, existing outside of the bounds of the normative and objective and the rational – different knowledges undisciplining the being of embodied difference, entangled with those absented from our social fabric. dr. nancy viva davis halifax Associate Professor, York University

crip art for me are, “Difference, differently presented....” and “Crip arts is a handout, a cut, it nips” (2016, pp. 1-2).

Crip methodology acknowledges that there is no single voice that represents disability but an intricate, multi-layered, constantly fluctuating choir of voices whose common goal is to denounce *compulsory able-bodiedness* (McRuer, 2006, p. 2), unsettle normative arts practices and concepts of work produced in the art world at large while at the same instance communicating their unique experiences. This form of critical theory offers a means for resistance as it challenges and reconfigures notions of disability to lead to future possibilities. Including the voices of the study participants who communicate their realities is the first step towards lobbying for broad access to funded art studio programs as well as exercising the personal, independent (and sometimes supported) decision-making abilities for people with CIDs. The opportunity to be artists in encouraging studio environments can realize the attainment of some life goals.

### **Methods**

After successfully completing the TCP2, REB course (See Appendix D, for certificate TCP2 (REB) Ethics Process), defending my dissertation proposal, and submitting to the York University ethics committee, I received approval (See Appendix F, Ethics Approval). The study was opened to individuals with CIDs who had enrolled in studio visual art programs or make art on their own and who agreed to be interviewed. I engaged in snowball sampling, a non-probability sampling technique employed by researchers to identify potential subjects in studies when enlisting subjects of a specific or hidden population are difficult for researchers to access or to locate (Crossman, 2013). A study participant or an individual refers a friend or acquaintance to the researcher as a potential participant (See Appendix G for Snowball Sampling poster).

Due to the placement of the snowball sampling poster distributed at the Ontario Association for Developmental Disabilities (OADD) conference in the spring of 2019, interested conference attendees forwarded my poster to Community Living Toronto who considered my study and requested an ethics protocol to be completed. After completing the Community Living Toronto’s ethics protocol, I was able to introduce myself to the facilitator Harold Tomlinson at Creative Village Studio (CVS) in west Toronto. In late May-and through June of 2019, weekly studio visits to CVS began. I commenced observations of programs offered making the

acquaintance of the artists working at CVS to achieve the goal of collecting practical, philosophical, fiscal and social policy realities of people with CIDs wanting to live as artists. The visits to CVS continued through July and into the fall of 2019 when I experienced the broad range of courses offered at the studio. At the same time, I was able to post my snowball sampling poster to request interviews with willing participants at and outside of the studio. My daytime studio visits increased to 2-3 days a week in the fall until December of 2019.

A range of consent and assent forms mounted in the Appendices H to R were required for this study. Respect for persons means recognising every individual's ability to give or refuse their consent to participate. Due to the complexity of data collection, that is, narrative interviews videotaped both voice and image, watching artists work in the studio setting, inclusion of artwork, the use of names, and work included in an art show for the purpose of this study I tracked all forms collected to on an online tracking sheet I developed to ensure that I had appropriate consent (See Appendix S Checklist for Consent Forms).

All but one of the participants was able to give legal consent but signed the assent forms. The parent who was closely involved in a participant's decision-making was contacted for this participant's participation in the study<sup>26</sup>. When I started to present the letter of information and consent or assent forms to the study's participants who could give their consent, I noticed that some of the participants were having trouble reading the initial letter of consent or assent. Participants were offered the opportunity to take home the paperwork if they desired. Some opted for this choice and returned the forms after they had reviewed them with a caregiver or support worker. Since the participants had varying linguistic abilities, some chose to have the letter of information as well as the consent or assent forms verbally presented to them. After the first few participant interviews, my 27 years of teaching students with learning disabilities taught me that I needed to find a more effective way to communicate and scaffold the information to prospective participants so that they would more easily comprehend the full scope and nature of the study as well as what consent to participate meant.

---

<sup>26</sup> Decision-making capacity refers to the ability of prospective or actual participants to understand relevant information presented about a research project, and to appreciate the potential consequences of their decision to participate or not participate. This ability may vary according to the complexity of the choice being made, the circumstances surrounding the decision, or the point in time at which consent is sought. The determination of capacity to decide whether [to participate] or not to participate in research, then, is not a static determination (TCPS, 2014, p. 42).

According to the Centre for Plain Language, “a communication is in plain language if its wording, structure, and design are so clear that the intended readers can easily find what they need, understand what they find, and use that information”. The Centre’s five step guide aided me in developing a clear, effective explanation of the study’s letter of information and consent forms. I researched cases of how others facilitated this process and sought out an online exemplar for visual art research completed with people with CIDs. I found pictorial consent forms in art and disabilities studies theorist Sara Lige’s master’s thesis (2011, pp. 217-223). Using the Centre for Plain Language guidelines<sup>27</sup> and Lige’s exemplar, I produced a visual accommodation like those used in a classroom, employing both symbols and photographs for my study participants to have along side their consent or assent forms if I found that they were experiencing difficulty or becoming frustrated even after I presented the forms orally. When I offered them the plain language version (See Appendix R for Plain Language/Pictorial Consent Form Support for Letter of Information), I sensed that participants breathed a sigh of relief. Through using the plain language or pictorial version of the *Letter of Information*, the participants quickly understood the information presented and had a clear appreciation of the potential benefits and risks of participating in the study as well as what they decided to share. They weighed the potential harms and benefits of the research to themselves personally (TCPS2: CORE Module 1 Core Principles, 2014).

Core data was collected by conducting a series of interviews guided by open-ended interview questions (See Appendix T for Interview Questions) written in accordance with Spector-Mersel’s narrative framework. Key respondents were invited to tell their “personal stories” (Glazier, 2005) with the “dailiness” (Harding, p. 129) of their experiences as artists so

---

<sup>27</sup> According to the Centre for Plain Language to successful plain language texts are: 1. Identify and describe the target audience (List what people need or need to know to complete the task. Consider the characteristics of the groups that should influence design. For example, age etc.); 2. Structure the content to guide the reader through it (Organize the content so it flows logically. Break the content into short sections reflecting natural stopping points and add headings to help reader predict what follows.); 3. Write the content in plain language (Write in short but logical sentences. Pick words that the audience knows. Use strong active verbs. Present important information first. Include details that help the reader to complete a task and leave out details that will distract reader. Use transitions to connect ideas using a conversational tone.); 4. Use information design to help readers see and understand quickly (For example use headings and subheadings. Use typography including font, size, colour and bold to guide the reader’s attention. Use whitespace to organize information. Use images as signposts to make content easier to understand.); 5. Work with the target user groups to test the design and content (Test the design at multiple points so that the participants can easily understand the information. Check that the final product is useful and usable. Ask them to describe key concepts or processes in their own words.).

that they were collaborators in the research sharing control so that together an understanding of what their stories were about could be reached (Polkinghorne, 1998, p. 164). Participants' responses were videotaped, or audio taped for transcription and analysis; interviews were the first data point, artwork was the second.

Field visits to the studio were a third part of data collected. Information technology researcher Winston Tellis (1997) explains that during a field visit, unobtrusive, direct observation can provide additional information about the topic being studied that can vary dramatically from casual data collection activities, to formal protocols that measure or record behaviours (p. 12). Photographs of the artists' artwork were taken, and names were used if participants had signed the appropriate consent forms to request the reproduction of participants works for research<sup>28</sup> serving as visual data for the study. Fieldnotes were also written and sketches were produced in a sketchbook providing a consolidation of ideas for larger scale artwork.

It became clear that volunteers, and instructors played a critical role in the participants' success at CVS, as well as the input their parents who supported their creative art process. In line with a/r/tography's rendering of *openings*, the new idea of interviewing these human supports as important members of the studios became significant. I explained the rationale behind my request and many volunteers, instructors and a few parents willingly offered their time to be interviewed. Ultimately the interviews with three parents/guardians, three art instructors and the program facilitator helped broaden the understanding about the story and necessary program supports providing information that might not be otherwise realized.

As the study progressed other opportunities emerged that became seminal to understanding the importance of CVS in the lives of the artist-participants. I observed a fee-for-service<sup>29</sup> *Paint & Pizza Night* social activity, a festive holiday celebration, visited the SWACA (Supported Work & Community Activities, formerly a sheltered workshop) location in west-end Toronto mentioned by numerous participants and got a tour of *Windfall* or *Brands For Canada* a location that provides volunteer work placements for people with CIDs. All significant in developing an awareness of the lives of people with CIDs and how art making fits into their

---

<sup>28</sup> Formal ethical approval was sought before embarking on research.

<sup>29</sup> Participants sign up and pay for an individual event or a class that they select.

lives. There was a general interest, kindness and a marked openness to the study on the part of the staff at these locations.

Through the study, participants excitedly made me aware of *Art from the Heart* held at Joshua Creek Heritage Art Centre, Oakville, Ontario, an exhibit where CVS participants' work is mounted annually through the months of January-March. I explored the location's offerings by joining a *Wednesday-Open-Printmaking* workshop at the art studio where I learned about a mono-printing aquarelle technique (See Illustrations 5 and 11.) and about the philanthropy of 90-year-old owner and founder Sybil Rampen. Sybil hosts six to ten artists with CIDs from Oakville Community Living in a free Monday art class from September to June. I observed volunteers supporting these artists for several hours as Sybil prepared and presented her lesson plans in a card-making workshop. The visit was capped off with a videotaped interview with Sybil where I learned about her motivation, ideology and methods of teaching artists with CIDs. On January 19, 2020, I attended the *Art from the Heart* at Joshua Creek in Oakville, Ontario opening where many CVS participants' artworks were displayed. These experiences deepened my understanding of a variety of potential supports required for artists with CIDs. Accounts of these visits will be noted in Chapter Five: *What? What Do Participants Say?* Interviews were transcribed and analyzed with Gabriela Spector-Mersel's (2011) narrative framework to code and categorize essential meanings of participants' responses/data to arrive at prevailing themes.

Regular attendance at the research site enabled me to view artists creating artwork and to make inquiries about their art making ideas and processes noting observations in fieldnotes. Artwork was photographed and collected for the creation of *Coffee Talk*, (See Appendices A-C.) a series of coffee table exhibition-style books displaying profiles of CVS artists' work accompanied by artists' statements created with the artists. The facilitator was instrumental in pointing out the progression of some individuals' work created when I was not at the studio.

### **Limitations of study.**

This study gives a view into the workings of a small urban studio in Toronto that provides support for people with CIDs; it is reflective of the needs of the greater CID sphere speaking to issues of value, ability, voice and identity. The study does not establish causal connections among art studios supporting people with CIDs and impacts noted but connective evidence is strong. There are far too many variables such as instructors' art experience, nature of projects, artists' background, and type of disability to permit a causal connection. What this

small sample of results does not show is the number of artists who want to attend CVS but cannot due to funding, accessibility, distance or family situation. Other studies would have to be done to locate this population.

### Chapter Three: Flexible Embodiment in Social Policy for People with Cognitive and Intellectual Disabilities



Illustration 14: Yarmol, C. (2016). *Flexible Embodiment*. [Sculpture with postal elastics, acrylic and wire mannequin form, magnetic handbag clasp, 54" long is 14" across and is 5" inches in width].

This work was inspired by the readings of feminist critical disability theorists Margrit Shildrick (2015), Judith Butler (1993), and Susan Wendell (1996) who all address questions of embodiment. These philosophers posit that many of society's social constructions and policies are organized with unacknowledged ablest assumptions about neglecting the basic human needs of what many people require to participate fully in the societies in which they live (Wendell, 1996, p. 39).

I created a makeshift loom and hand-wove together individual, stretchy postal elastics from a 20-pound cache I found in my mother's basement. The medium of postal elastics living as common, singleton objects seems so apparently weightless, however when hand-woven together, the resulting textile transforms into a strong, weighty yet pliable fabric that can be a metaphor for change.

The woven poncho is a representation of Shildrick, Butler, and Wendell's conceptions of flexible embodiment that can be applied to an examination of policy making. Blanket policy making should be adaptable to the needs of the individual. A variety of policy solutions, even non-traditional options, are possible. Due to its mailable, stretchy material and the addition of a magnetic clasp in lieu of a zipper or buttons, the poncho can be adjusted and manipulated by anyone who desires to wear it; it BECOMES any form that it needs to be.

We require new "models of identity that incorporate difference" (Lindgren, 2004, p. 159). A re-examination of assumptions can begin the conversation about how to actively engage all people in society by considering how to accommodate for their needs.

## What is Disability Policy?

According to political scientist and public policy scholar Michael Prince (2004), the phrase, “disability policy,” is described as, “a convenient and recognizable, though still inadequate way, to characterize interventions that seek to enable people with impairments to live in ways that are personally satisfying and socially useful... policies usually address methods and processes that is, what interventions, usually treatments including rehabilitation and training, are available or desirable”. He argues that disability policy analysis should necessitate describing and explaining the goals, instruments, and processes of these interventions (p. 62). Health policy experts, Daniel Fox and David Willis (1989) state that from a *disability perspective*, disability policy and disability policymaking should also be about enabling people to function in and contribute to society (p. 3) in their own ways without judgement. Policy should more explicitly address, “what individuals should be enabled to do for themselves and for others” (p. 3)<sup>30</sup>. Prince (2004) underscores that policy analysis should investigate and scrutinize the impact of *all programs* (emphasis added) on the aspirations and capacities of people with disabilities, their families and related networks (p. 63) suggesting that the dearth of disability policy reform is due to “...public attitudes and the lack of information; the relative powerlessness of the disability community; the constraints of economic thinking and public finances; federal-provincial jurisdictional issues; and the absence of robust accountability mechanisms for disability policy within Canada's welfare state” (p. 59). Prince notes that policy is often based on the knowledge derived from data; “if there is little to no data, there do not seem to be problems to address therefore, little is known about public resources devoted to fostering the full inclusion and equal opportunities of people with disabilities” (p. 67).

This chapter focuses on the history of the Canadian Association for Community Living, an organization who in collaboration and shared leadership with provincial-territorial associations and with other national partners and disability organizations worked and continues to work to advance shared agendas for inclusion (CACL, 2017). These agendas include: policy

---

<sup>30</sup> In *Love's Labor* (1999), philosopher Eva Kittay writes about her experience with her daughter Sesha who was born with cerebral palsy, a profound cognitive disability and an inability to speak. Kittay expresses that in Sesha's large, wide, luminous eyes there is an unmistakable joy in living when someone she loves walks into a room or she hears the opening bars of a Beethoven concerto. Kittay declares that life with Sesha has convinced her that, “we cannot understand the demands of social organization if we cannot take the fact of dependency as one of the circumstances of justice”. Dependency is central to our existence as social creatures (Kittay cited in Garisto Pfaff, 2016). Who is to judge “the contribution” Sesha makes in her mother's life and in the lives of those she encounters?

direction; the creation and dismantling of sheltered workshops as social policy; Supported Work & Community Activities (SWACA); *Windfall* (now known as *Brands for Canada*); federal disability policies that apply to income security; provincial disability policies of Ontario including Disability Supports Program (ODSP) that through financial provisions enables individuals to live in the community as citizens and the *Passport Initiative* that directly supports aspects of cultural citizenship for people with CIDs. ODSP and *Passport* are explored in detail as these policies were mentioned most frequently during the interviews with the study's participants in relationship to their artistic endeavors at CVS studio. Critiques of the social policies are embedded after the explanation of each policy.

### **The History of Community Living**

The chapter begins with a history of an organization who has advocated to uphold the rights of people with intellectual disabilities since 1958, the Canadian Association Community Living (CACL). According to the CACL website, "The CACL national organization is family-based, governed by a board of directors with representation from across Canada, activated through a national network of volunteers, and supported through a national staff team. It has representation from across Canada through a national federation of 13 provincial/territorial associations and over 300 local associations" (CACL, 2017) and offers numerous informational supports regarding human rights and social policies on its online educational websites for families, service providers and others wanting to learn about intellectual disabilities <sup>31</sup>.

Community Living's humble beginnings began in Ontario in the late 1940's. On September 29, 1948 the *Toronto Star* newspaper published a letter to the editor from Mrs. Victoria Glover, the grandmother of an eight-year-old boy with an intellectual disability left in her care.

Sir: May I say a few words on behalf of our backward children, and their bewildered mothers. There is no school for such children, no place where they could get a little training, to be of some use in the world, only Orillia [Huron Regional Center], which is always full. If these children can be taught something at Orillia, why cannot a day school be put at their disposal? I am sure their mothers would gladly pay for their transportation to and from school. After all, they are paying taxes for other, more fortunate children's schooling. I think it is time something was done for parents who, from a sense of faith and hope in a merciful providence want to keep them at home, living a normal life.

---

<sup>31</sup> CACL's national organizations include the Canadian Association for Community Living (CACL National), CACL Foundation, Institutes for Research and Development on Inclusion and Society (IRIS), Inclusive Education Canada (IEC), and Ready, Willing & Able (RWA).

These are real parents only asking a little aid and encouragement to shoulder their own heavy burden. God bless them and may the Ontario government help them and their children, who might still be made something of, living a normal life and with the perfect love, understanding and guidance of such parents (Community Living Toronto: Since 1948, 2008).

More than seventy people responded and attended a meeting on November 8, 1948 at the Carleton Street United Church (Supports & Services Fact Sheet side two, n.d.) to seek educational and learning options for their family members in lieu of placing them into institutions. A Parents' Council for Retarded Children was formed (Community Living Toronto: Since 1948, 2008). This Council not only organized parties and nursery classes in church halls and private homes but appealed to the provincial government for financial assistance to find alternatives to institutional care. In 1950, the parents began a preschool in church basements and homes but their appeals to begin classes in school after hours were turned down as any child with an I.Q. under 50 was considered "ineducable" and ineligible for provincial education (Community Living Toronto: Since 1948, 2008). In 1955, a meeting in Toronto was held where representatives of provincial associations from across the country to form The Canadian Association for Retarded Children (Clare, 1958). Mrs. Victoria Glover's letter turned the tide starting an entire movement of like-minded allies across Ontario and then across the nation. Since that time, Community Living Toronto continually strives to assist and better the lives of people with CIDs. View Appendix U: The Activism of Community Living Organizations for a glimpse of their continual advocacy for new legislation, supports for day to day life and supported community-based activities.

### **Sheltered Workshops as Social Policy**

As definitions of social inclusion grew, sheltered workshops emerged. According to disability historian John Ravescroft (2019), sheltered workshops were first opened for many graduates of schools for the blind in the United States who were vocationally trained but were unable to secure employment due to societal misconceptions of the abilities of blind and visually impaired persons as 'unemployable'. Sheltered workshops first opened in the 1870s in the Maritime Association for the Blind in the Maritime provinces of Canada providing segregated work for adults with disabilities who were also perceived as incapable of competing in the open labour market (p. 417). Furthermore, disability and workplace theorist Dustin Galer (2012) states that the pressures created by the deinstitutionalization movement of the 1960's and 1970s helped to give rise to additional sheltered workshops around the country. Galer (2014) states

that, “Parents and families of people with disabilities formed the vanguard of a developing movement during the 1960s in Canada that challenged the longstanding exclusion of disabled people [sic] from opportunities to live and work in mainstream society”. Families as social reformers sought to transform both social attitudes and former institutional practices urging society that people with disabilities could participate in communities and in paid work (p. 27). These workshops that were run by not-for-profit organizations funded by the MCSS were first regarded solely as a transitional part of the rehabilitation process for people with CIDs who had been deinstitutionalized and then in the 1970s to mid-1980s became a vital part of the Canadian welfare state as they continued to provide employment for people with physical impairments, intellectual disabilities, or mental health issues who were shut out of the work in competitive labour markets (Galer, 2014). Although these sheltered workshops were meant as a temporary measure, many parents saw them as a safe place for their children to learn productive employment skills as well as to participate in social activities outside of the family home (Gillmore, 2018) and workshops quickly became “day centers” (Galer, 2014). The nature of sheltered work was conventionally unskilled and non-marketable, and thus people in workshops gained little actual competitive work experience. Workers were compensated with “symbolic” stipends instead of actual wages (Galer, 2014), far lower than minimum wage as they were exempt from Ontario's *Employment Standards Act (ESA)*; they did not need to follow employment laws, including minimum wage regulations.

As ideas of community inclusion for people with CIDs evolved, sheltered workshops first built by local Community Living Associations (Kyle, 2019) began to close. In 2015, approximately 75 sheltered workshops were operational in Ontario when the MCSS announced that it would stop funding the workshops and work with local agencies on transition plans to offer new workplace options for people who had laboured in workshops for decades. As of December 2017, 35 agencies were still operating workshops.

On November 22, 2017 the *Fair Workplaces, Better Jobs Act*, (2017) was passed to address this changing workplace environment and came into force on January 1, 2018. This legislation made significant changes to both the *Employment Standards Act, 2000*, the *Labour Relations Act*, (1995), and the *Occupational Health and Safety Act*, (1990) removing the exemption of sheltered workshops from the *ESA*. Employment Standard Act was in full force

and the minimum wage was \$15/per hour (Government of Ontario, October 21, 2019).<sup>32</sup> By January 2019, the objective was to organize those formerly in the sheltered workshop spaces to paid work, volunteer work or recreational activity environments depending on participants' needs and abilities (Gillmore, 2018).

Community Living organizations were responsible for creating their own transition plans about how to dismantle sheltered workshops. Unfortunately, these plans were sent directly to the Ministry and many clients were unaware of the changes (Gillmore, 2018). The absence of communication caused much social and emotional upheaval as clients become lonely and depressed believing that there was a total cessation of routine and social networks; they became scared that they no longer had support. Some individual's families claim that they were never consulted about the changes, arguing that sheltered workshops helped people, especially those with severe disabilities, stay in the community by giving the participants purpose and social relationships (Gillmore, 2018) but others argued that "workers missed out on opportunities in the community including real employment and legitimate wages" (Welsh, 29 November 2015).

Chris Beesley, CEO of Community Living Ontario said that unfortunately many people became the victims of the Ministry's good intentions since communication about the changes between individuals who ran the workshops and the participants was not optimal. Lack of government funding and tight enforcement of rules in social assistance programs created more barriers (Gillmore, 2018). According to Beesley, changes to the *Employment Standards Act* like increases in minimum wage, vacation pay, and workers' benefits also impacted agencies who work with people with disabilities as funding to those agencies did not increase. Families who needed to hire individuals for respite services have not been given any exemptions for required developmental services aspects for their family members meaning that family members had and still have to provide programming or find support assistance on their own. Support organizations want clients to have stable, full-time work but no additional funding has been given for people with disabilities to get workplace supports. These changes impact those who have CIDs (Gillmore, 2018).

---

<sup>32</sup> When Bill 47 (2018) came into effect it amended the Employment Standards Act (2000) minimum wage remained at \$14 per hour (instead of increasing to \$15 per hour on January 1, 2019). Annual adjustments to the minimum wage tied to inflation would restart as of October 1, 2020.

Premier Doug Ford's government, sworn into office on June 29<sup>th</sup>, 2018, enacted Bill 47 *Making Ontario Open for Business Act* (2018), which came into force November 21, 2018. The sheltered workshops or "persons performing work in a simulated job or working environment if the primary purpose is the individual's rehabilitation" was scheduled to end on January 1, 2019 but Bill 47 removed this date specifying that the exemption would end upon proclamation. The government's intended long-term policy direction on this file is not yet clear. The dismantling of sheltered workshops and the belief that people need to live and be included in their communities is what helped to cultivate the CVS studio.

Critically viewed, sheltered workshops were a step to involve people with disabilities into the world but as time progressed their effect segregated and marginalized people with disabilities Galer (2014) contends that reliance on sheltered work pointed to greater social and economic problems in Canadian society who valued independence created by employment. A segment of the population was designated as "unemployable" due to their physical and mental abilities and these workers were effectively denied the right to full citizenship under the pretense of "protection". Stipends and the therapeutic or training regimens meant to facilitate individuals with disabilities joining the mainstream workforce have become incompatible with contemporary rights dialogues and encouraging integration, inclusion and cooperation. From an international perspective, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) "recognized the right of persons with disabilities to work, on an equal basis with others; this includes the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities" (WHO, 2011, p. 235). The sheltered workshops era has ended, and new activity centres are taking shape like Supported Work and Community Activity (SWACA) programs.

## Visit to supported work & community activities (SWACA).



Figure 2: Image of Exterior Community Living SWACA program, 288 Judson Avenue, Unit 17, Retrieved from <https://www.google.com/maps/>

I was invited to Supported Work and Community Activity or SWACA (also known as, “Judson” by its participants) the former location of a sheltered workshop (See Figure 2, Exterior view). The building, a large box-like complex located in an industrial neighborhood in west Toronto at 288 Judson Street, Unit # 17 was approximately about 170 000 square feet. The old warehouse had a concrete floor and painted concrete walls with a high metal-beamed ceiling. There were two entrances: one on the left with a ramp and 36" wide door for participants and led to a hallway by a kitchen/cafeteria area and one on the right led to a series of box-like shared offices with doors (See Figure 3 Sketchbook Plan of SWACA Space). These offices held several desks, telephones and computers and were designed for the use of program supervisors. Nearby a single accessible washroom often used by staff stood in between the offices and the cafeteria space where a few people sat at tables talking or playing games. Just beyond these offices on the left-hand side was a small room large enough for enough people to sit comfortably in the chairs and sofas that lined the perimeter of the room. It was quiet in here; parallel to this ‘quiet room’ were other sets of offices with glass windows so whoever was working inside could see outwards to the program’s participants and participants could see inside the office. There were wide doors to accessible multi-stalled women’s and men’s washrooms on either side of the hallways and the office doors looked out onto the sprawling workshop space.

In front of the support workers' offices was an expansive space occasionally partitioned by cloth-covered half walls. A bank of approximately 10 computers was set up along one wall of one of these partitions. Many sofas were placed on the perimeter of the room. Approximately 10 circular tables surrounded by four or more chairs were arranged in the middle of the room. There was a ping-pong table with paddles and a ball. There was also a tray of plastic beads and a variety of dried beans with empty plastic containers on the ping-pong table. I was told that the bead-bean packages were for SWACA participants who enjoyed counting and sorting items. A few staff members had desks paired with stationary chairs dotted around the large space. The back of the space had a large partition wall with a singular door. Behind it were two service bay doors leading to a loading docks which were no longer used. Within the warehouse space, two



Figure 3: Yarmol, C. (2019). Sketchbook Plan of SWACA Space, Judson location, [Pencil on cartridge paper, 5" x 7"].

small offices with large window and large tables stood on the east wall. There was no one on this side of wall.

When I first arrived about seven people came directly to introduce themselves and offered their hands for me to shake. They asked me about the purpose of my visit. It was difficult to count the number of participants in the program as people were milling around from room to room, but I believe that there were between 40 to 50 people present. Some were on the internet, some were playing games, others were socializing with one another, one individual was involved in counting beads, and some were drawing on white cartridge paper with pencils. As I

walked around the space, more SWACA participants enthusiastically greeted me and began to follow me telling me about the specific dramas occurring at the program. Other people simply milled around in search of tasks to occupy them. At this location, I recognized six participants I had seen at CVS. I was informed that many people were out in the community at programs like CVS with a SWACA worker.

I was told that often there was scheduled programming offered either from outside providers like Drama programs, or by the staff working at the location. The day I visited, a yoga instructor from outside the centre offered meditation classes was present. I participated in an hour-long meditation class with approximately 10 participants in the small quiet room I previously mentioned. At the end of the mediation, the instructor congratulated the participants for their successful attempts to stay focused and to quietly mediate.

The staff was very pleasant, positive and welcoming. I could see that the staff was doing their best with the given location and resources but, the environment was quite gray due to the vast areas of concrete flooring and beige dividers that held a few colourful posters and messages. The staff assured me that the space had been designed for another purpose before Bill 148 and that the SWACA program was moving to a more welcoming and centrally located venue in the new year. Often the participants are escorted to programs in the community like CVS or *Windfall* (now known as *Brands for Canada*), which I also visited, but essentially those who have grand-parented ODSP funding were targeted to attend the SWACA program. There were not enough support staff to take all individuals out into the community, so this location was their program destination. I would describe this physical space as cold, bleak, and depressing; due to its intended purpose as a warehouse, it is the opposite of comforting. I had read much about institutionalized settings in the recent past and thought about warehousing people, keeping them in a pen-like setting. Some of the current SWACA participants were housed in institutionalized environments for a portion of their lives. Seeing this location helped me to better understand participants' desires to go out into community programs like CVS, yearnings to stay at home or parents' urgency to find their adult children engaging programming.

### **Brands for Canada a.k.a. Windfall.**

According to reporter Tom Godfrey (17 November 2014), *Windfall*<sup>33</sup> (as CVS participants refer to it) now known as *Brands for Canada (BFC)*, is a non-profit agency in on Connell Court in Toronto that provides supports for people who are marginalized, in transition or new Canadians. Three times a month, job seekers are provided with day-long workshops about key areas such as first impressions training, confidence building, networking, interviewing skills, etiquette tips, grooming, health and wellness, credit and budgeting at *Windfall Basics*<sup>34</sup> (Houlberg, 2018, July 30)<sup>35</sup>. After taking a workshop, attendees can each choose six items of new work attire, personal care products and a cell phone with a prepaid card from Rogers Uptown Wireless to help in their job search.

A large section of *BFC*'s 8,000-square-foot warehouse contains racks of new surplus clothing and other gear donated by major retailers due to changing stock, seasons or style. "*Brands for Canada* reports to have received clothing and other items from 200 donors and processed 900,000 items in 2016" (Houlberg, 30 July 2018). This clothing is sorted by participants learning job training skills or volunteer groups like members of Community Living Toronto and distributed through social service agencies, public schools and a network of men's and women's shelters across Toronto. Since several of my study's artist-participants mentioned *Windfall (BFC)*, I visited the location to see it in operation. Caroline Chester, a manager of the SWACA, brought me to the site and introduced me to the participants who were volunteering there that day.

As soon as I stepped into the warehouse portion of the facility, I saw Quyen Ngo, a participant in my study; he was both very surprised and excited to see me as he ran over and gregariously greeted me. He was puzzled as to why I was there and not at CVS. He and the

---

<sup>33</sup> Brands for Canada incorporated in 1992 by the founders of Second Harvest, one of Canada's largest foodbanks. Brands for Canada Ontario (formerly known as *Toronto Windfall Clothing Support Service*) provides new donated clothing and other items for basic needs at no charge to people living in poverty. Brands for Canada (BFC) reports that 1 in 7 Canadians live below the poverty line and most new unsold goods end up in landfills.

<sup>34</sup> The program is now known as "Suitable Impressions" (Houlberg, 2018, July 30).

<sup>35</sup> "In 2016, BFC states that it had 450 Suitable Impressions participants. BFC's Community Living Toronto program provides training to adults with developmental challenges. In 2016, this program had 36 participants". It runs two children's programs: *School Backpacks* and United Heart providing new backpacks full of new school supplies to children living in poverty in partnership with Toronto District School Board and Peel District School Board. Boxes filled with new clothing and personal care items are also delivered (Houlberg, 2018). Retrieved from *Brands for Canada*. <https://www.charityintelligence.ca/charity-details/106-brands-for-canada>

other volunteers were hard at work folding clothing and dividing it into various piles according to size. The venue was quiet, and everyone seemed to be focused on their tasks. Several workers verbally directed the volunteers with their tasks and supported them if they requested assistance or clarification of a specific task. The encounter at *BFC* illustrates that since sheltered workshops no longer operate, a few new programs offering volunteer opportunities for people with CIDs have emerged in their place. In the next section, I move from Toronto specific programs to provide a brief overview of additional programs supported by provincial and federal government.

### **Supports Available for People with Cognitive and Intellectual Disabilities**

The Canadian Association for Community Living (CACL) asserts that disability-related supports need to be acknowledged and available “so that people can live meaningful lives and contribute as full citizens” (CACL, 2017). Their benchmarks for achievement are:

- a. Canadians with intellectual disabilities have access to needed disability-related supports;
- b. disability-related supports are portable, flexible, and individualized;
- c. entitlement and access to disability-related supports is not means-tested<sup>36</sup>;
- d. increased investment by governments in disability supports and capacity of communities (CACL website, 2017).

A basket of programs most closely affecting Canadians with disabilities includes personal supports, employment programs, and income security (Tremain, 2014, p. 31). A deeper focus on both ODSP an income program to support daily living expenses so that recipients can live and participate in their communities as cultural citizens and the *Passport Initiative*, a reimbursement program whose main goals is to, “help adults with a developmental disability be involved in their communities and live as independently as possible by providing funding for community participation services and supports, activities of daily living and person-directed planning” (Developmental Services Ontario: Passport program: Funding for community participation services and supports, 2020, p. 1) are presented after brief descriptions of federal income and provincial personal supports. The *Passport Initiative* can directly pertain to cultural citizenship

---

<sup>36</sup> If a benefit is means tested, only certain people will be eligible for it (Josephson, 2018). The government agency that administers the benefit will have to determine the means cut-off and figure out a way to verify recipients’ means. Retrieved from <https://smartasset.com/insights/what-does-means-tested-mean>.

by supporting artists with disabilities<sup>37</sup> if engaging in art creation, arts activities or other active involvement in their communities is how recipients elect to use their individualized funding.

### **Federal supports.**

Programs in the federal sector largely focus on income security for people with CIDs or supports for families who have children with CIDs. Such federal programs include: *Employment Insurance, The Canada Pension Plan (CPP) Retirement Pension, Old Age Security (GIS), Canada Child Tax Benefit (CCTB); Canada Student Loans and Canada Student Grants; Working Income Tax Benefit; Goods and Services Tax / Harmonized Sales Tax (GST/HST) credit; Registered Disability Savings Plan (RDSP)* (See Appendix V: Federal Supports for People with Disabilities for detailed descriptions of these federal social policy programs). The savings plans offered through Canadian social policy like the RDSP<sup>38</sup>, introduced on December 1, 2008, has been discussed as a progressive policy that would allow people with disabilities to have savings that do not preclude their ability to collect disability benefits, however, RDSP has also been criticized for not recognizing that many people with disabilities have difficulty simply providing for their day to day living expenses and may have difficulty retaining supplementary funds for saving. According to a study by Pettinicchio and Maroto (2020), “Disability benefits programs place limits on assets, while mounting housing and health-care costs and limited access to credit makes saving money almost impossible for people with disabilities”. Many of these programs skew to families of middle-class or upper middle-class incomes.

An additional social policy called *The Opportunities Fund* is for those individuals who have little or no labour force attachment in order to prepare for, obtain and keep jobs or to become self-employed (Tremain, 2014, p. 10). This policy focuses on enhancing people with CIDs’ employability helping to finance skills for employment, wage subsidies, work experience,

---

<sup>37</sup> The terms ‘developmental services’ or ‘developmental service systems’ refer to government-funded services and supports provided to people with disabilities. The terms ‘people with intellectual disabilities’, ‘developmental disabilities’ or ‘people who have been labelled with an intellectual disability’ are employed when referring to people with disabilities who are recipients of these government services.

<sup>38</sup> According to Canada Revenue Agency (2008), the RDSP “is a savings plan that is intended to help parents and others save for the long-term financial security of a person who is eligible for the disability tax credit (DTC). Contributions to an RDSP are not tax deductible and can be made until the end of the year in which the beneficiary turns 59. Contributions that are withdrawn are not included as income to the beneficiary when they are paid out of an RDSP. However, the Canada disability savings grant (grant), the Canada disability savings bond (bond), investment income earned in the plan, and the proceeds from rollovers are included in the beneficiary’s income for tax purposes when they are paid out of the RDSP”.

self-employment, enhanced employment assistance, employer awareness, and community coordination (Funding: Opportunities Fund for Persons with Disabilities, 2010). Although these federal social policies may be useful for financial security purposes, they are not necessarily key to the discussion of Canadian social policies available to support artists with CIDs to attain substantive citizenship. The available provincial policies discussed in this dissertation apply directly to aspects of cultural citizenship for people with CIDs as many of these policies help to support the physical participation in activities out in the community at large.

**Provincial personal supports.**

There is a patchwork of social policies offering personal support(s) (Keshen and Blake, 2006, p. 9) for individuals with disabilities in their everyday lives: three major Ministries offer programs: *Special Services at Home* (SSAH) governed by the *Ministry of Community and Social Services Act*<sup>39</sup> and delivered by Ministry of Community and Social Services; *Assistive Devices Program* (ADP), administered by the Ministry of Health and Long-Term Care<sup>40</sup>; and the *Passport Initiative*, administered through Ministry of Community and Social Services.

*Special Services at Home* (SSAH) is a discretionary program designed to support families who are caring for a child in their home who has a physical or an intellectual disability or an adult who has an intellectual disability. Receipt of these supports are reliant on needs and what the family is already receiving in the community. Families can apply for funding to pay for staff

---

<sup>39</sup> Ministry of Community and Social Services Act, R.S.O. 1990, c. M.20, online: *Ministry of Community and Social Services*. Retrieved from <http://www.ontario.ca/laws/statute/90m20>. The *Special Services at Home* is designed to support families who are caring for a child in their home who has a physical or an intellectual disability or an adult who has an intellectual disability. The money for this program can help families pay for staff support who teach new skills and abilities, teach daily living activities or provide respite care. The funds granted are dependent upon the type and amount of service the child needs, the help available in the community, the other support(s) the family is receiving. It is important to note that both children and adults who receive funding from a residential program are not eligible for *Special Services at Home* funding. Retrieved from <http://www.children.gov.on.ca/htdocs/English/specialneeds/specialservices.aspx>.

<sup>40</sup> Ministry of Health and Long-Term Care Act, R.S.P. 1990 c. M. 26, online: Ministry of Health and Long-Term Care <http://www.ontario.ca/laws/view>. The following summarized description is more fully outlined on the *Community Living: Funding and Services* website. Retrieved from <http://www.communitylivingontario.ca/families-individuals/funding-services>. According to the Community Living website the *Assistive Devices Program* (ADP) covers over 8 000 different pieces, “provides funding to Ontario residents who have long-term physical disabilities” and require devices in order to increase to their independence for example: prostheses; wheelchairs/mobility aids and specialized seating systems monitors and test strips for insulin-dependent diabetics (through an agreement with the Canadian Diabetes Association), insulin pumps and supplies for children, hearing aids, respiratory equipment and visual and communication aids. In order to be eligible for the Assistive Devices Program which only pays a portion of the material cost an individual must be a resident of Ontario; have a valid Ontario health card; have a physical disability for six months or longer. Retrieved from Ministry of Health and Long-Term Care <http://www.health.gov.on.ca/en/public/programs/adp/> & Assistive Devices Program- Public MOHLT, n.d.

to help their child to learn new skills and abilities, such as improving their communications skills and becoming more independent, to teach daily living activities or to provide respite care. Individuals who receive funding from a residential program are not eligible for *Special Services at Home* funding (Government of Ontario, Ministry of Children and Youth Services, 2020) <sup>41</sup>.

A fixed, pre-determined funding formula is established by a SSAH social security officer, based on the paper application from the applicant and accompanying medical documentation from a physician or psychological assessment. If needs alter, for example if the individual requires a walker or a wheelchair and necessitates learning how to properly and safely use the equipment, a completely new application must be made. According to the *World Health Report on Disability*, “Unmet rehabilitation needs can limit activities, restrict participation, cause deterioration in health, increase dependence on others for assistance, and decrease quality of life” (2011, p. 95). Attendant services are under-funded so applicants often receive nowhere near the number of hours of service they require, particularly individuals who cannot afford to purchase additional private services. Necessary services, such as assistance with activities of daily living, like bathing, toileting, and food preparation, could take up the entire available, allotted attendant time leaving little time to shop or participate in job interviews or training programs or lessons actually requested by the family or the recipient. Disability lawyers Petricone and Montigny (2011), contend that until the number of attendant services hours a person can access is increased substantially, it will be impossible for many people who require these services to engage in employment, or other activities outside their homes (p. 19). The policy needs to be made more flexible: minor adjustments to the original application should be permitted to capture the changing daily needs of the recipient; the provision of adequate funding of attendants to cover needs of home activities and respite care and a view of pre-determined funding as needs may vary greatly from individual to individual.

---

<sup>41</sup> SSAH can help families pay for staff support to teach new skills, daily living activities or provide respite for families caring for a child or an adult with a physical or intellectual disability (Government of Ontario, M., 2016). A person is eligible for this service if she/he/they: live(s) at home with her/his/their family in Ontario or they are not living at home with the family, are not being helped by other residential services and, need more support than most families can provide (2016); a medical statement or psychological assessment describing the disability and an explanation of why services are required as well as overall cost must be attached to the application form (SSAH, 2016). *Special Services at Home* information retrieved from Ministry of Community and Social Services Act, R.S.O. 1990, c. M.20. Retrieved from <http://www.ontario.ca/laws/statute/90m20> and *Special Services at Home* funding. Retrieved from <http://www.children.gov.on.ca/htdocs/English/specialneeds/specialservices.aspx>.

The *Assistive Devices Program (ADP)*, under the Ministry of Health and Long-Term Care is available for Ontario residents who have a valid Ontario health card, and have a disability requiring equipment or supplies for six months or longer (Assistive Devices Program, Health Care Professionals, Ontario Ministry of Health and Long-Term Care, 2020). ADP covers over 8,000 different pieces which increase people's means through physical equipment purchases to fully participate in society. The available equipment includes items such as: prostheses; wheelchairs/mobility aids, insulin pumps etcetera. According to WHO's *World Report on Disability* (2011), even if a person qualifies for funding to help purchase an assistive device, many people with low incomes find it extremely difficult to maintain their assistive devices (pp. 106-108). Petricone and Montigny (2011) maintain that, "Financial assistance to cover the cost of maintenance and repairs is not always readily available. Repairs on wheelchairs, for instance, can be extremely expensive; even replacing a tire can cost more than most people on ODSP benefits have available. Therefore, it cannot be assumed that a person who uses an assistive device will always have access to a fully functional assistive device" (p. 19).

#### **Employment programs/ODSP.**

Shelley Tremain (Lecture, January 6, 2016), defines income security as "income supplementation or programs that boost low income or earnings and income replacement or programs that replace lost income as a result of unemployment, sickness, disability or retirement". Artists with disabilities would be applying for the *Ontario Disability Support Program (ODSP)*<sup>42</sup>, which attempts to meet the "unique needs of people with disabilities who are in financial need, or who want and are able to work and need support" (Tremain, 2014, p. 9)<sup>43</sup>. ODSP is entitlement program, meaning that if a person meets the eligibility criteria, they are entitled to receive income support. To qualify for ODSP a person must be:

At least 18 years old, be an Ontario resident, and be in financial need and meet the program's definition of a person with a disability or be a member of a prescribed class. Ontarians 65 years or older who are not eligible for *Old Age Security* may also qualify for

---

<sup>42</sup> Up to six months prior to turning 18, a person with developmental disabilities can apply for ODSP.

<sup>43</sup> The *Opportunities Fund* is an additional government program. It focuses on the labour market participation of persons with disabilities to enhance their employability helping to finance skills for employment, wage subsidies, work experience, self-employment, enhanced employment assistance, employer awareness community coordination (Funding: Opportunities Fund for Persons with Disabilities, OF, 2010) to assist Canadians with disabilities to reach their full potential. It lends support for local, regional and national projects that assist persons with disabilities who have little or no labour force attachment to prepare for, obtain and keep jobs or to become self-employed (Tremain, 2014, p. 10).

ODSP supports if they are in financial need” (Eligibility for ODSP income support, 2015)<sup>44</sup>.

According to disability advocates Stapleton, Procyk, and Kochen (2011), ODSP pays benefits specifically designed for [persons with] low income; the program provides benefits to people who have never worked; and ODSP encourages workforce participation and does not cancel benefits due to participation in the workforce (p. 9) but does claw back income supports as explained below.

There are two major parts to ODSP: Income support and employment supports. Income support provides financial assistance each month “to help with costs of basic needs, like food, clothing and shelter<sup>45</sup>. Income support also includes benefits, like drug coverage and vision care, for clients and their eligible family members” (MCSS: ODSP, 2020)<sup>46</sup>. Employment supports include help: preparing for work, finding a job that is right, and keeping a job. According to ODSP regulations:

You can earn up to \$200 a month without having your income support reduced. If you earn more than \$200 a month, only 50 per cent of your net earnings (or business profits, if you are self-employed) over \$200 are deducted from your income support payment. If you’re attending a secondary or post-secondary school full-time, we [the Ministry of Community, Children and Social Services] won’t deduct any your earnings from your ODSP income support...ODSP will give you \$100 each month you work or when your business makes a profit. This is called the Work-Related Benefit (WRB) (p. 9).

It is important to note that the funding a person is receiving through ODSP policy calculation and what his/her/[their] family earns from work, may reduce his/her [their] income support<sup>47</sup>.

---

<sup>44</sup> Ontario Disability Support Program Act, 1997, S.O. 1997, c. 25, Sched. B. (2014, July 24). Retrieved from [http://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/income\\_support/IS\\_Eligibility.aspx](http://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/income_support/IS_Eligibility.aspx).

<sup>45</sup> For example, a single individual renting or owning a residence in the community can receive a maximum of \$1,151 per month for basic needs and shelter. This amount is based on rates in effect September 1, 2017 (Simmons, 2017). Accessed from Marc Leroux as Litigation Guardian of Briana Leroux: Responding Motion Record of The Defendant, Her Majesty the Queen in Right of The Province of Ontario, No.: CV-17-573091-00CP (Ontario Superior Court of Justice December 15, 2017). Retrieved from <https://kmlaw.ca/wp-content/uploads/2018/03/Responding-Motion-Record.pdf>

<sup>46</sup> Government of Ontario. (2019) Ontario Disability Support Program. Retrieved from <https://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/index.aspx>. ODSP needs testing determining each recipient’s monthly cash benefit amount based on the gap between their budgeted expenses and their current income or resources. To determine ODSP eligibility is part of the ODSP process (Stapleton, J., Procyk, S, and Kochen, L., 2011, May).

<sup>47</sup> As of September 1, 2013, you can earn up to \$200 a month without having your income support reduced. If you have earnings, you will see this change in your October 2013 payment. If you earn more than \$200 a month, half of your earnings above \$200 are exempt meaning that half of your earnings do not affect your eligibility or the amount of money you get for Income Support. You can also claim some of your childcare and disability-related work costs as deductions from your earnings before they reduce your Income Support

ODSP is calculated based on the *benefit unit*, which means that benefits payments are made on behalf of the families rather than individuals. However, the family's labour efforts to care for the person with the disability are not always fully recognized from a financial viewpoint<sup>48</sup>. According to the CACL (2013), families are “the fundamental unit of our society and that families provide an essential bridge to the realization of citizenship and full inclusion of their family members with disabilities” (p. 4). If the government is going to provide funding calculated on a *benefit unit* income security also needs to be provided for family caregivers. In *Assuring Income Security and Equality for Canadians Intellectual Disabilities and their Families* (2013) a report submitted to the House of Commons Standing Committee on Finance the CACL recommends that:

1. The Canada Pension Plan be enhanced through expanding the drop-out provisions and allowing for contributions to CPP for those who stay out of the labour market to care for a family member with disability-related needs.
2. A Family Tax Benefit be developed that provides a refundable tax benefit to families providing support to a family member with a disability.
3. The Canada Labour Code be amended to include family leave provisions for those who must leave their job temporarily to care for a family member with disability-related needs.
4. Employment Insurance and Compassionate Care Leave be revised to provide coverage to family members who must leave their job temporarily to care for a family member with disability-related needs.
5. Explore options to ensure that caregivers who, because of their caregiving responsibilities, do not have the fiscal capacity to contribute to CPP or other investment mechanisms and do not benefit from the measures outlined (p. 5).

Benefits are calculated based on “the family size, age of dependants, geographic location, and the individual circumstances of the benefit unit” (Ontario Disability Support Program – Income Support Directives 6.1 Basic Needs Calculation, 2008).

People with disabilities do not have economic independence from spouses or other family members before being eligible for benefits because the family's income is considered prior to releasing any ODSP funding. This residual approach to disability policy makes a recipient completely dependent on family members limiting his/her/their potential to independently

---

(Ministry of Community and Social Services Treatment of income: When you work and earn money, Government of Ontario, 2013). Retrieved from: How earnings affect your Income Support: [http://www.mcscs.gov.on.ca/en/mcss/programs/social/odsp/income\\_support/odsp\\_workearn.aspx](http://www.mcscs.gov.on.ca/en/mcss/programs/social/odsp/income_support/odsp_workearn.aspx).

participate in cultural activities in Canadian society. This policy can be seen as an embodiment of “a regime of dis-citizenship” (Devlin and Pothier, 2006, p. 1) because a person with a disability is not considered as a separate entity. The earnings of family members should not even be factored into the ODSP policy equation. The current model disregards the possibility that other family members may have disabilities of varying degrees and may be experiencing difficulties making ends meet. Other family members are likely tending to their own financial issues; they might be encumbered by the costs of the disability limiting their own financial security (Dignity, Adequacy, Inclusion: Rethinking the Ontario Disability Support Program, 2011, p. 8)<sup>49</sup>.

Sociology professors David Pettinicchio and Michelle Maroto (2020) claim that, “Disability benefits programs place limits on assets, while mounting housing and health-care costs and limited access to credit makes saving money almost impossible for people with disabilities”. Using 1999 to 2012 Canadian Survey of Financial Security data, Maroto and Pettinicchio (2020) studied the reported financial data of 33,000 Canadians for disparities in non-housing assets, which include household savings, stocks, and pensions, across households with and without disabilities. They found that households where a respondent or their spouse reported a disability held 25 percent less in non-housing assets after accounting for key employment, education, and demographic factors (Pettinicchio and Maroto, 2020). Their study demonstrated a more complicated relationship between disability, employment, and assets, these direct effects were further strengthened by disability's indirect effects on assets through its relationship with employment income and the family’s financial situation.

Critically analysing ODSP, Stapleton, Procyj and Kochen (2011) declare that, “Eighty-nine percent of Ontario Disability Support Program (ODSP) recipients are unemployed. This extremely high unemployment is in part due to ODSP earning rules and administrative practices that create barriers to employment” (p. 5). The ODSP policy of clawing-back 50% of employment income is punitive, considering all barriers stacked in front of people including attendant services, assistive devices, or special transportation services. Disability researcher in public policy, human rights and social inclusion Cameron Crawford (2013b) expands upon some

---

<sup>49</sup> For other programs provided by the federal government available to people with disabilities please see Appendix V.

barriers that people with CIDs face.<sup>50</sup> Often individuals with CIDs are likely to be dealing with more than one disability and may experience difficulty with a range of basic educational and cognitive tasks (p. 20). For example, Crawford states that, “Approximately 88.8% of people with intellectual disabilities require some level of help from others with everyday activities [including] meal preparation; everyday housework; heavy household chores; getting to appointments/errands; personal finances; child care because of the respondent’s disability; personal care; nursing care/ medical treatment at home; and moving about at home” (p. 6). Crawford maintains that, “More than half (56.4%) of people with intellectual disabilities and other disabilities, (60.6%) need aids or devices to assist with mobility, agility, communication, learning, pain management and so on” (p. 7). When supporting employment skills, he advises accounting for “the possible confusion that people with intellectual disabilities may be experiencing in carrying out everyday tasks, in following instructions and the possible difficulties they may be experiencing in social interactions and communication with others” (p. 21).

Many of the people on ODSP are already earning very low wages without benefits or may be receiving benefits from other programs to make ends meet. Petricone and Montigny (2011) claim that ODSP rules assume that people should exhaust, or greatly reduce, other sources of income before accessing benefits. It is conceived as a ‘system of last resort,’ rather than a vital part of income security for people with disabilities in Ontario (p. 19)<sup>51</sup>. Crawford (2013b) asserts that, “Many [people with CIDs] are also discouraged because of concern about losing some or all of their present income or other disability benefits, such as drug plan or housing” (p. 20). Instead, ODSP recipients “should keep 100% of any earned income at least up

---

<sup>50</sup> Disability social policy theorist Cameron Crawford’s research focuses on issues of disability, employment, and public policy. Crawford (2013b) states that many people with CIDs have a much lower education level than that of others with disabilities, “with less than a third attaining a high school graduation certificate or higher... Job accommodations and other supportive measures need to be framed with a view to addressing multiple needs, including agility, spoken communication and emotional/psychiatric issues in addition to cognitive issues experienced by people with intellectual disabilities” (p. 20). He contends that people with CIDs sometimes require accommodations in employment, education and training such as modified job design or modified hours or days of work, human support in the workplace, a range of technical supports and accessible transportation” (p. 20). Crawford elucidates that, “A disproportionate number of people with CIDs not in the labour force are discouraged from seeking employment because of inaccessible information about available jobs, employment-related discrimination, worry about being isolated by co-workers and inadequate training” (p. 20).

<sup>51</sup> Poverty line defined here as the income required to provide for the necessities of life using recent and realistic price calculations; it has been suggested that a sum of between \$500 to \$700 should be the portion of employment income recipients of ODSP should be able to retain before 'claw-back' begins.

to the point that their total income from all sources reaches the ‘poverty line’... A staggered claw-back could be applied to income in excess of a basic poverty line income, although even then individuals should be able to retain a reasonable portion of their income” (Petricone and Montigny, 2011, p. 35)<sup>52</sup>.

To qualify for ODSP, an applicant must disclose his/her/their assets: The prescribed asset limits for a benefit unit are \$40,000 for a single recipient, \$50,000 for a couple and \$500 for each dependant other than a spouse. A number of assets are exempt including but not limited to a person's interest in a principal residence, one motor vehicle, a prepaid funeral, the cash surrender value of life insurance policies, all funds held in a Registered Disability Savings Plan, tools of the trade, student loans, and a loan used for the purchase of an exempt asset, a principal residence or an asset necessary for the health or welfare of a member of the benefit unit (Government of Ontario: Ontario Disability Support Program - Income Support | 4.1 - Definition and Treatment of Assets, 2017)<sup>53</sup>. The next section discusses how artists with disabilities arts organizations banded together to advocate for the withdrawal of government claw backs when artists earn income from their artwork while on ODSP.

#### **ODSP & Arts Grants Coalition.**

The MCSS’s ODSP had restrictive earning regulations that mounted barriers for artists with disabilities who required ODSP for daily economic support. The MCSS clawed back ODSP funds if artists earned a profit from the sale of their work, as this money was considered as income. Ontario Arts Council and disability groups joined forces to advocate for policy reform. One Toronto-based, not-for-profit, disability organization called Tangled Art +

---

<sup>52</sup> If an individual has periods of wellness (due to mental health issues for example) and could go off ODSP, it is difficult to get back on it again. An individual could apply *for rapid reinstatement* a process that if an individual meets with ODSP’s definition of a person with a disability and the individual qualifies financially for ODSP income support, and when the individual started getting ODSP income support, they either: a) were not given a medical review date, or b) were given a medical review date, but they left ODSP before they had the review. They require a medical review before they get back on ODSP (Ministry of, Children, Community and Social Services: As an Ontario Disability Support Program recipient: Coming back to the program, 2018, March 22). Retrieved from [https://www.mcscs.gov.on.ca/en/mcscs/programs/social/odsp/client/coming\\_back.aspx](https://www.mcscs.gov.on.ca/en/mcscs/programs/social/odsp/client/coming_back.aspx).

<sup>53</sup> Necessities of living and items such as furniture, clothing and household effects, which are considered necessary for the reasonable functioning of the household, are exempt as assets. ODSP staff may approve an accumulation of assets that is greater than the prescribed asset limit in order to purchase items or services necessary for the health of a member of the benefit unit or for disability related items and services up to a maximum of the sum of the prescribed asset limit plus the amount needed for the items and services. With the Director's approval, the allowable asset level for a benefit unit may be increased to permit the purchase of an item that is necessary for the health of a member of the benefit unit or for disability related items or services (Government of Ontario: Ontario Disability Support Program - Income Support | 4.1 - Definition and Treatment of Assets, 2017).

Disability is dedicated to the advancement of artists with disabilities, and to enhancing access to arts and culture for all. In 2014, Tangled Art + Disability's annual report communicated that:

[A] major problem that disability artists have been dealing with for years is how to receive arts funding (or receive commissions/sell their work) without it affecting their ODSP income. Until this grossly unjust situation is worked out, arts councils can fund disabled artists differently in ways that won't affect their ODSP, e.g. recognizing a collective, rather than an individual as a fundable entity (p. 14).

Due to this inequity, the ODSP and Arts Grants Coalition (OAGC) made up from a variety of arts organizations<sup>54</sup> joined forces in June 2015. Representatives from these associations communicated with Ministry of Community and Social Services (MCSS) Minister's office in 2016, then met with officials from MCSS and MTCS in September 2017 with the goal of getting arts grants exempted for artists with disabilities who get benefits from Ontario Works (OW)<sup>55</sup> and Ontario Disability Support Program (ODSP). After an announcement by (MCSS) on December 13, 2017, Arts grants<sup>56</sup> are now exempt as income and assets in both ODSP and OW. Recipients will no longer have funds deducted from their monthly benefits and will not have to risk becoming ineligible for continuing support from these income sources. They can create art without fear of losing their monthly income and access to prescription drugs, medical supplies, dental, and vision care. This change reduces the administrative burden as the disincentive to apply for arts grants has been removed

---

<sup>54</sup> The OAGC is made up artist representatives on ODSP from ACTRA Toronto, the Canadian Actors' Equity Association, CARFAC Ontario, the Income Security Advocacy Centre (ISAC), the Media Arts Network of Ontario (MANO-RAMO), the Ontario Arts Council, the ODSP Action Coalition, ReelAbilities Toronto, Tangled Art + Disability, the Toronto Arts Council, and Workman Arts.

<sup>55</sup> According to the Ministry of Children, Community and Social Services website, the goal of *Ontario Works* (OW) is to help people in financial need offering financial assistance including income support to help with the costs of basic needs, like food, clothing and shelter as well as health benefits for clients and their families. OW helps clients to find, prepare for and keep a job including workshops on resume writing and interviewing, job counselling, job-specific training and access to basic education, so clients can finish high school or improve their language skills. Clients must agree "to participate in employment assistance activities in order to receive financial assistance" although there is some emergency assistance available. Eligibility includes "living in Ontario, live in a house hold that does not have sufficient financial resources to meet basic living expenses and be willing to make reasonable efforts to find, prepare for and keep a job (unless you have specific circumstances that temporarily prevent you from doing so, such as an illness or caregiving responsibilities)". Members of the household must also agree to participate in employment assistance activities (Ontario Works, 2020).

<sup>56</sup> The providers allotting funding of arts grants available to artists in Ontario are: The Canada Council for the Arts; The Ontario Arts Council; The Toronto Arts Council; The London Arts Council, The City of Mississauga, The City of Ottawa and The City of Windsor. This list is not an exhaustive one. The ODSP and OW exemption applies to arts grants from these agencies and ones like it (Government of Ontario: Ontario Disability Support Program - Income Support | 4.1 - Definition and Treatment of Assets, 2017).

(ODSP & Arts Grants Pamphlet, 2018, p. 10). Artists can get a grant for: creation, production, and/or presentation of works, professional development activities, promotion, residency or travel, creative research, networking and building market opportunities, commissioning, other activities necessary for the development or creation of art, accessibility expenses during the duration of their project (pp. 9-10). Any tools an artist needs for employment or for his/her/their own business are exempt from the artist's asset limit<sup>57</sup>.

Allowance for living costs included in arts grants are counted as an asset and cannot be exempted however, the new rules now allow a pro-rating of grant funds over the duration of the arts grant. This pro-rating results in regular monthly benefits lowered over the entire period that the arts grant is intended to cover for living expenses. The recipient must report the funds for living expenses to his/her/their caseworker through a *Notification Letter* from the funding agency (ODSP & Arts Grants Pamphlet, 2018, p. 10).

To support the potential grant recipients, a plain language pamphlet entitled, *The ODSP and Arts Grants* was published (Ontario Arts & Toronto Arts Council, 2018). The definition of a professional artist is outlined in this pamphlet.

Professional artists: have completed basic training in their artistic discipline or field, either through formal study or by teaching themselves; are recognized as professional practicing artists by other artists working in the same field; have a history of public presentation or publication of their work; and spend a significant amount of time practicing their art (p. 7).

It is important to note that in this definition, a recognized professional can be *self-taught* not requiring formal education. This understanding helps open the door for people with CIDs and their advocates to gain access to grant funding.

In the late 1990's the government through the MCSS received feedback from the intellectual disability community claiming that they could not find access to help for themselves or their family members and that funding was insufficient. No single organization offered families guidance. These families felt frustrated that they had to continuously repeating their

---

<sup>57</sup> ODSP regards self-employment differently from employment income as only half of your self employment income will be deducted from your ODSP entitlement. You can have up to \$20,000 in assets. Most business expenses are exempt and will not be deducted from ODSP inventory and raw material. There are no deductions from your monthly ODSP benefit for the first \$200 in net income, but 50% of any net income above \$200 is deducted. As well, the \$100 "Work Related Benefit" is added to your monthly ODSP when you have net earnings. Net self-employment income is usually reviewed and calculated once per year and averaged over the year (ODSP & Arts Grants Pamphlet, 2018, pp. 14-15).

personal stories numerous times before they could get any support. The Ministry released a policy called *Making Services Work for People* (1997) a framework to find solutions to these issues (Contact Hamilton, 2018, October 29). To address family's voiced frustrations, the MCSS launched the *Passport Initiative* in 2006. Its goal was to provide direct funding to adults with developmental disabilities so they could gain access to community programs, develop work and daily life skills, hire support workers and live independently (Jaczek, 2017, February 14). There is a tension felt here, that is that people with CIDs are often interdependent with families whom they rely on for numerous daily supports however, they also need to be recognized as individuals with specific needs for financial supports to engage in cultural citizenship. As a social policy, the *Passport Initiative* provides some financial access for individuals with CIDs to engage in activities that promote cultural citizenship. Individualized funding through the *Passport Initiative* is described in detail in the next section.

### **The Passport Initiative and How it Works**

The second major support for artists with disabilities is the *Passport Program*. I focus on the *Passport Program* in some detail because through my research I found that “the *Passport Program* has become the sole mechanism for direct funding for [young] adults with developmental disabilities” (SSAH & *Passport* Coalition, 2012) to buy supports and services to help them to become more involved in their communities<sup>58</sup>. This section summarizes the ‘why, for whom, when, what, where, and how of the *Passport Initiative*. My critical analysis of the *Passport Program* will be embedded at the end of the policy’s explanation.

#### **For whom is the Passport Program designed?**

Under a new law called, *The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (2008) the Ontario government introduced the Developmental Services Ontario (DSO) offices in July 2011 to ensure: a single regional access point to avoid confusion about where to go for services; a clear and consistent way for determining who is eligible for services; the application of the same assessment tool across Ontario for everyone to determine the needs individuals; and a seamless transfer of information

---

<sup>58</sup> On July 15, 2005, MCSS announced \$9.4 million in additional funding for a program called *Passport to Community Living* (“Passport”). When first introduced in 2005, the *Passport Program* served 1,700 people, and was targeted towards providing funding for young adults with a developmental disability who were no longer eligible for school supports and who would benefit from meaningful activities in the community. This included young adults who had recently left school, and those who were typically not eligible for ODSP employment supports (Simmons, 2017, p. 11).

from one DSO office to another (DSO Welcome Package, 2018, p. 4). Barbara Redvers, DSO Service Navigator, and Megan Hart, *Passport Coordinator* (2019) explain that the *Passport Program* is for Ontarians with a developmental disability<sup>59</sup> as defined by a psychological assessment.<sup>60</sup> Individuals may complete a standard assessment and application package for the *Passport Program* at their local DSO when they are 16 years of age however, are not eligible for MCSS funded services, until they are 18-years-old or older. This application is due to the need for support to participate in the community after they have left secondary school and are living on their own, with family or independently in a supportive living arrangement (Government of Ontario/Help with daily living, 2016).

According to the *Passport Guidelines* (2014), the program attempts to, “recognize that the individual’s family is his or her [their] primary support network. It is meant to be fair and equitable based on a funding formula” yet, *Respite Services: Passport Initiative* (2017) states that priority will be given to applicants who are living at home with their families (Respite Services-The Passport Initiative, 2017). The *Passport Program* favours individuals with close family support to organize the paperwork possibly overlooking those individuals who no longer have the assistance of a parent and who need the funding the most. There are a series of documents available online that attempt to simplify how to fill out the *Passport* paperwork for example *PassportONE: How to Submit Your Expense Claim* (Family Services Toronto, 2019)<sup>61</sup> gives a step by step guideline however due to the complexity of the process, a parent or caregiver might be needed to fill out and submit the forms. This is problematic as there are many people with CIDs who live in group homes or without the direct intensive support of their families<sup>62</sup>.

---

<sup>59</sup> For the purposes of this Act, a person has a developmental disability if the person has the prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations that originated before the person reached 18 years of age. The disabilities are likely to be life-long in nature and affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity (SIPDDA, 2008, 3. a). At the intake interview proof of age, proof of Ontario residency, a detailed psychological assessment about the disability” (Developmental Services Ontario Welcome Package, 2013).

<sup>60</sup> When applying for the *Passport Program* an assessment that was completed by a doctor, school, hospital or another organization must be presented. The DSO office will review it to make sure you are eligible by reviewing your significant limitations in cognitive and adaptive functions. If no psychological assessment is available the DSO office will help a potential client find out how and where to get one (DSO Welcome Package, p. 5).

<sup>61</sup> Retrieved from <http://passportfundinghnr.ca/wp-content/uploads/2017/02/2019-PassportOne-Tip-sheet-FINAL-1.pdf> for a step-by-step guideline for *Passport* funding reimbursements.

<sup>62</sup> *PassportONE* created by the Ontario government and *Passport* agencies to improve the *Passport* Service experience by making invoice processing and reimbursements faster and more efficient. This new approach includes consolidating the back office financial functions associated with *Passport* into a newly created agency called *PassportONE*. Invoices and receipts can be submitted at any time during a fiscal year and reimbursements

Prioritizing support for individuals living with their families over those in group homes discriminates against those living in group homes as they are at a disadvantage and should be given priority as they might not have any other means of support to attain their goals.

The aspect of personal choice inherent in the directives of the *Passport Initiative* offers enormous potential for an individual wanting to develop or to strengthen his or her skills as an artist. Payment for courses, studio time or supports could be readily designated. There are direct funding options available for many programs inside Community Living programs. But if other programs outside of these programs are selected, it is the responsibility of the applicant to select the services which meet their goals and then pay these service providers directly then submit expenses through a series of *Passport* forms.<sup>63</sup> It is extremely challenging to navigate the paperwork and to determine the services providers *Passport* administrators agree to fund. The MCSS has attempted to provide some examples of how to fill out paperwork required (See Appendix Z). There are detailed instructions about how to properly submit expenses with visual examples and prompts to support applicants. For example, these instructions state:

Ensure the forms are complete – incomplete forms will delay payment; attach as many invoices and receipts as you have to one POS form; submit your forms at any time of the month; allow 30 business days for payment from the date the expenses are received in our office; do not submit more than once per month (less often is okay); do not send the same forms more than once” (Passport Information Package: New Clients, 2017 & Family Services Ontario, 2017, p. 8).

Individuals and their families submit their invoices and receipts for expenses from admissible services and supports on required forms (e.g. Support Worker expenses forms), according to a reimbursement schedule,<sup>64</sup> to support expenditures (See Appendix Z). Recipients must be willing to manage their own funding by signing a formal funding agreement before monies are released. The tracking forms required to complete for repayment of funds can be

---

will be processed faster. *Passport* agencies can spend more time helping clients find needed services and supports. *PassportONE* is being implemented across the province in four phases that began in May 2018. Families can use My Direct Plan (MDP) an online expense management application designed to help manage direct funding. When *PassportONE* processes *Passport* payments, the MDP application will automatically file invoices electronically with *PassportONE*. Retrieved from *PassportONE*. Family Service Toronto. (2020). <https://familyservicetoronto.org/our-services/programs-and-services/passportone/>

<sup>63</sup> There are strict guidelines for submitting the forms for reimbursement; payment processing [details]; and [instructions] for keeping track of your expenses (*Passport Program* Information Package, 2017, p. 5):

<sup>64</sup> Guide to Self-Directed *Passport* funding, (August 2013), online: Contact Hamilton, *Passport* Agency for the communities of Brant, Haldimand, Norfolk, Hamilton, Niagara Six Nations of the Grand River Mississaugas of the New Credit First Nation. Retrieved from: <http://contacthamilton.com/main/wp-content/uploads/2013/10/2014-08-11-Guide-to-SELF-DIRECTED-Passport-Funding.pdf>.

overwhelming. Parent of an adult-child with a disability, Laura Parsonson (Personal communication, 2017) referred to the complexity of the process, which she said becomes “challenging for a caregiver without an intellectual disability” so it is difficult to imagine a person with a CID successfully completing this process given all the administrative barriers. I believe that this is a reason why priority for funding is given to those who are living at home with their families and because family members are likely assisting with the *Passport* paperwork relieving pressure from the service offices. A participant can opt to pay an assistant or broker of the allocated funding to manage the paperwork. *Passport Information Package: New Clients* (2017) advertises, “Did you know you can use up to 10% of your *Passport* funds to hire someone to manage your direct funding? (p. 5). This phrase is telling of the complexity and accessibility of a *Passport* application process so convoluted that access of a paid ‘account manager’ can be hired.

According to a Roehrer Institute report (1993), individualized funding programs have eligibility rules that often act to keep people out rather than ensure that they receive the assistance they need (p. 48). According to Barbara Simmons, Director of the Community Supports Policy Branch, Social Policy Development Division, at the Ministry of Community and Social Services, budget limitations force a rationalizing that disallows funding as the *Passport* is a discretionary program, meaning the province has the discretion to allocate funding amongst applicants (2017, p. 19). Access to services or supports is limited due to overall funding, which leads to limited availability of spaces and funds (p. 36)<sup>65</sup>.

### **Why is Passport funding provided?**

According to the *Passport Program’s* guidelines (2014) the key goals of the *Passport Initiative* are to foster independence through community participation, teach daily living skills, increase opportunities for participation in the community, promote social inclusion and broaden social relationships, ease transition from school to life as an adult and support families and caregivers of an adult with a developmental disability<sup>66</sup> (*Passport Program: Guidelines for Adults*

---

<sup>65</sup> In 2017 *Passport* supported approximately 25,000 people and their families in Ontario (Simmons, 2017, p. 19). There were 66,484 individuals with developmental disabilities in Ontario in 2011 (Lin, 2011).

<sup>66</sup> According to *Participation and Activity Limitation Survey* (PALS) a national post-censal survey conducted by Statistic Canada and funded by Social Development Canada that gathers information about Canadian adults and children whose everyday activities may be limited because of a health-related condition or problem, the main support providers for people with disabilities are family 83.1%, friends 13.5 %, organizations 13.4%, employees 10.7% or other 4.2%. This indicates that programs like the *Passport Initiative* are necessary to provide life skills, leisure programs to support people with disabilities, respite for family members providing individuals a sense of

with a Developmental Disability and their Caregivers Ontario Developmental Services, 2014) by taking a break from their caregiving responsibilities through the hiring of a support worker (MCSS: Help with Daily Living, 2018, March 8).

There is a focus on creation of, “their own life plans” also known as *person-directed planning* to reach an individual’s distinct goals. “These plans can help them make the most out of funding and outline ways they can participate in community activities” (MCSS, 2018). According to MCSS, the foundational values and beliefs of person-directed planning are:

- Inclusion — everyone wants to be a participating member of their community;
- Citizenship — rights and responsibilities, valued roles, and choosing from a range of opportunities that enable one to learn, explore and participate;
- Self-determination — everyone wants to have choice and control over their life;
- Community as a First Resource — much of what we want in our life can be found in community —opportunities for jobs, volunteering, recreation, relationships and experiences. Your community is rich in possibilities;
- Contribution and participation — building on the gifts and talents that we all have will lead each of us to discover our own unique way to contribute and participate in community.

At the heart of all the planning approaches is the belief that every single individual has their own life to lead - a life that is right for them. As a result, everyone's plan will be different (MCSS: Creating Good Life in Community: A Guide on Person-Directed Planning, 2018). According to the Individualized Funding Coalition for Ontario’s, *Creating a Good Life in Community: A Guide on Person-Directed Planning*, “ ‘Being in community’ is not just about where we live-it is about our human need to belong and participate with others in families, neighbourhoods, networks and groups. The community is many different things to each person” (Dingwall, Kemp, Fowke, 2006, p. 5). This explanation splendidly describes how individualized funding through programs like *Passport* can foster cultural citizenship.

An issue with this person-directed planning directive is that the idea of, “community as a first resource” and the idea of “your community is rich in possibilities” could be challenging notions. Without the intensive support of worker and additional costs, opportunities for community engagement can be limited. Laura Parsonson (Personal communication, November

---

human dignity. This ongoing survey helps government agencies to respond to new data needs that have emerged since the last surveys in 2001 and 2006. Retrieved from Government of Canada, S. C. (2012, April 13). *Participation and Activity Limitation Survey*. Retrieved from <https://www.statcan.gc.ca/eng/survey/household/participation/participation>.

17, 2019) parent-participant of artist-participant Emily Parsonson discussed enrolling Emily in a local, community-run pottery class that Emily really wanted to attend. Laura recalls that she had to obtain special approval from the course registrar and the class instructor who she had to independently contact. The course registrar required that due to Emily's intellectual disability, Laura had to seek out and pay a support worker. Laura said that Emily had a marvellous experience but that the 10-week course was quite costly. Due to prohibitive costs, enrolment in one class outside of designated service agencies' offerings could cause a reduction in enrolment in a *Passport* recipient's other desired activities over the duration of that community class.

### **When is the Passport Initiative accessed?**

The *Passport Initiative* is targeted at young adults, but an applicant is not eligible until age 18 years of age in order to smoothly transition from school life to adult services in the community. As mentioned, its goals are to encourage independence, to foster social, emotional and community participation skills and to promote continuing education and personal development (Power, Lord and deFranco, 2013, pp. 152-153). According to the Education Act, S22(1), there is a "secondary school alternative curriculum [that is] is non-credit bearing. The students complete their secondary schooling and transition out in June of the calendar year in which they turn 21 years of age" (Leadership and Learning Department, Toronto District School Board 2018). Although legally students need to be enrolled in secondary school until 18 years of age, many caregivers choose the option of alternative curriculum so that their adult children can still gain access to educational programming and qualify for the *Passport Initiative* whose eligibility begins at age 18 years. Since secondary school systems already have a three-year socio-educational system in place to support people with CIDs from 18 to 21 years of age, the movement of the starting age of *Passport Program* eligibility to 21 years could offer greater coverage to those who are currently waitlisted<sup>67</sup>. The documentation about the *Passport Program* does not list an upper age limit for accessing the funding even after "transition" into adult services.

Eligibility does not guarantee access. The number of people requiring funding is greater than the current *Passport* budget permits so many individuals who meet the age, and other eligibility requirements cannot get funding. They are consequently placed on a service registry list until funding becomes available at an indeterminate date. Approximately \$810 million

---

<sup>67</sup> Those who are not enrolled in a high school program could be still be eligible at age 18 years of age.

dollars in new funding has been given since 2014 to improve developmental services (Monsebraaten, 2017)<sup>68</sup>. There are no other publicly available funding options for individuals beyond the transition years so that they can gain access to services like the art classes; individuals must pay privately for these opportunities or draw partial funding from their ODSP income.

Applicants or their families are encouraged to communicate with the DSO any changes to their circumstances (*The Passport Program: Questions and Answers*, 2016) so that prioritization for funding can be re-established by the designated accessor in their region. When reviewing the *Passport Program* Assessor's Rubric (See Appendix X) one can see that, deterioration of behavioural, medical, personal, or unpaid caregivers' situations are the key considerations in determining priority of *Passport* funding. Those individuals who continuously wait for services might never get them even though *Passport* funding could make them more active members of their cultural communities.

Approval for *Passport* funding renews every April 1st, and runs for twelve months from April 1, of the current year until March 31, of the next year. All invoices must be submitted by the 10<sup>th</sup> of each month because the approved funding amount renews every April 1<sup>st</sup>. This funding is provided for a three-year period and then it can be renewed. If funds are not used in that year they cannot be carried over until the next year. Invoices take 30 business days after the payment from the date received in the *Passport* office. The prepayment of services may prevent some individuals from enrolling in classes because they may not have the necessary funds in their accounts (York Support Services Network, 2011) to pay for services paid in advance or at the time of purchase of services.

### **What does Passport Initiative provide?**

With the *Passport* funding, recipients can participate in a range of activities from art classes, to gym memberships<sup>69</sup> because *Passport* does not precisely stipulate specific service

---

<sup>68</sup> The annual amount given to developmental services is \$2 billion dollars (Monsebraaten, 2017, April 23). Retrieved from *\$110 M lawsuit targets Ontario waitlists for developmentally delayed adults. The Toronto Star.* <https://www.thestar.com/news/gta/2017/04/23/110m-lawsuit-targets-ontario-wait-lists-for-developmentally-delayed-adults.html>

<sup>69</sup> There are a range of services available including art classes, cooking classes, support workers, activities of daily living, transportation to and from activities, life skill development like learning to ride the TTC or buy groceries, swimming lessons, gym memberships, day programs, parks and recreation programs, camps, respite, person-directed planning, administration of *Passport* funds (Family Service Toronto, 2017, p. 4) as well as hiring of a support

providers. It permits payment of services to a wide range of community operators, developmental services agencies, private service and support providers, adult education providers, and personal support workers (*Passport Guidelines*, 2014) to tailor the plan to specific needs, values and choices of the individual making it flexible and person-directed. Appendix Y outlines what the *Passport Program* will cover in the areas of community participation and activities of daily living, caregiver respite, person-directed planning and administration of the *Passport* funding in order to meet the monthly deadline (*Passport Funding: What Can I Use It For?*, 2014). *Passport* funding is not considered income; it will not affect ODSP benefits (York Support Services Network, 2011).

The amount of *Passport* funding determined is based on the information that a person or family provides during the application process including the kind and amount of service one requires and the type of support they may already be receiving. These considerations are matched against a funding table to arrive at the amount of *Passport* funding a person will ultimately receive. “There are four categories of backing: Low/Minimal (up to \$6,250). Most individuals receive a maximum of \$5000.00 (York Support Services Network, 2011); Medium/Moderate (\$6,251 to \$12,500); High/Significant (\$12,501 to \$18,750) and Exceptional (\$18,751 to \$25,000)” (*Passport Questions and Answers*, 2006)<sup>70</sup>. Funding amounts are determined by a *Passport* Coordinator aided by an automated tool. There is a list of *Inadmissible Expenses*<sup>71</sup> provided by the *Passport* documentation in the footnotes. Although the

---

worker to provide assistance with community participation and activities of daily living out-of-pocket expenses like meal costs and admission tickets (Ministry of Community and Social Services/ Help with daily living, 2016).

<sup>70</sup> The level of the approved funding is not dependent on the applicant’s choice of direct funding or transfer payment agency community participation supports, but instead upon the applicant’s capacities and support requirements.

<sup>71</sup> *Inadmissible Expenses* that *Passport* funding may not be used to purchase the following types of services and supports: Indirect respite services and supports (e.g., cleaning, meal preparation, snow removal, care of other family members); tuition for post-secondary education/degree programs that are eligible for government student assistance programs such as the Ontario Student Assistance Plan; supports that are available through an on-campus accessibility office; items for which the individual receives an allowance from the Ontario Disability Support Program (e.g. drug benefits, medical aids); housing and home maintenance (e.g. rent, home purchase or mortgage payments, repairs, renovations or modifications, housekeeping, yard work); groceries, food, and restaurant meals for the individual with a developmental disability; clothing; household items and electronics (e.g. furniture, appliances, televisions, computers); telephone/telecommunications (e.g. home telephone and internet service, cell phone and service); holiday travel (e.g. personal or family vacations, accommodation, transportation, travel insurance); dental care and services; fees for therapies/specialized services (e.g. speech and language, physiotherapy, occupational therapies, nursing, massage); personal goods and services (e.g. toiletries, spa treatments, aesthetic and cosmetic services); assistive devices and specialized equipment; vehicle purchase and/or modifications, leases and rentals (*Passport Program Guidelines for Adults with a Developmental Disability and their Caregivers*, 2014, p. 11). Note: In exceptional cases, the *Passport* agency may allow expenses that are not normally covered under the program (*Passport Tips Sheet*, n.d.).

*Passport* documents state that there is “no coverage for household items and electronics,” my experience with participants enrolled in the Photography class at CVS is that they have had the cost of their single lens reflex cameras covered by *Passport* funding.

### **Where can one apply for Passport Funding?**

Almost 370 non-profit agencies deliver developmental services and employ more than 18,000 staff. Under the authority of SIPDDA, those wishing to apply for adult developmental services and supports such as, “person-directed planning services and supports” or “caregiver respite services and supports” (Opportunities and Action: Transforming Supports in Ontario for People who have a Developmental Disability - Executive Summary, May 2006)<sup>72</sup> or the like, must contact their respective regional DSO organization. There are nine regional offices around the province<sup>73</sup>. A critique about the location of the Developmental Services Offices is that they may be distant from, and not easily accessible for, individuals with mobility issues. Numerous lengthy interviews must be undergone in person, rather than remotely, with no guaranteed access to funding. People with CIDs or behavioural issues may find it difficult to undergo this process.

### **How to gain access to the Passport Initiatives, assess service and support needs.**

There is no single resource that states all of details and processes about the *Passport Initiative*<sup>74</sup>. A series of MCSS websites do include *Passport* in their title but, one must follow a trail of links to learn about the various aspects of the program in order to glean the whole picture. One example is the *Exemplars [for] Submitting Expenses Passport Forms* (See Appendix Z). The *Passport Program Guidelines for Adults with a Developmental Disability and Their Caregivers* (2014) is an online booklet written in plain language that attempts to assist the understanding of the basics of the program, but other regional agencies have uploaded pdfs for, “Frequently Asked Questions” to answer specific questions.

If an individual is eligible for services through *Passport*, an assessor or a service navigator meets the applicant, or other respondents, to give basic instructions about the

---

<sup>72</sup> *Passport* is the coordination program and is divided into 11 agencies that support clients with forms, referrals, information on local services etc. *PassportONE* is an administrative funding program that processes invoices for all *Passport* recipients in the province (Redvers & Hart, 2019).

<sup>73</sup> To locate a Developmental Services Ontario office to begin the *Passport Initiative Process* go to: Find your local DSO, online: Developmental Services Ontario <https://www.dsontario.ca/agencies>.

<sup>74</sup> The Respite Services: The Passport Initiative Website. Retrieved from: <http://www.respiteservices.com/Halton/index.aspx?ArticleID=386&lang=en-CA%CB%83> and <https://www.respiteservices.com/Ottawa/index.aspx?ArticleID=1382&lang=en->, several regional Community Living web pages (<http://www.communitylivingnorthgrenville.ca/index.php?/resources/funding>) as well as the actual “Application for *Passport*”. Retrieved from <http://www.class.on.ca/pdfs/PassportFormPDF.pdf>.

completion of the Application for Developmental Services and Supports (ADSS) package and organizes two more interviews the first to gain an applicant's demographic and lifestyle information and the second to ask a respondent who has known the applicant for at least six months to comment on disability support needs and finances<sup>75</sup> ((DSO Central East Region, 2020). The person with the CID's testimony of his/her/their functional ability is not fully recognized. Psychology professors Kelly Coons and Shelley Watson (2013) claim that individuals with CIDs disabilities are the experts on their own experiences (p. 14) but that have been largely omitted from the disability discourse (Kitchin, 2000, p. 45). Decisions are typically made *for* individuals with disabilities, rather than *with* them resulting in a sense of disempowerment of a vulnerable population (Coons and Watson, 2013, p. 14). In the process outlined, the *Passport Program* claims to promote the applicant's independence yet in the same instance denies that independence with the addition of lengthy interviews with two adults without a disability active in the life of applicant to ensure eligibility of funding<sup>76</sup>.

---

<sup>75</sup> The first interview takes between two to four hours to complete and is used for the assessor to gain information about the applicant's demographic information, lifestyle, personality, caregiver circumstances, requested supports, medical and behaviour needs. The second meeting takes about two to three hours, where the DSO agency asks for a respondent, who has known the applicant for at least 6 months, to speak about his or her health, disability, support needs and finances.

<sup>76</sup> A *Support Intensity Scale (SIS)* ®<sup>76</sup> is used as a tool to identify the pattern and intensity of required supports to participate in everyday life activities. It is also used to record any exceptional medical and behavioural support needs in an individual (DSO Welcome Package, 2018). The assessor then meets with two individuals active in the life of the applicant. This second meeting is repeated every five years to gauge any significant circumstantial change in recipient's situation (Spindel, 2013, p. 4). The assessor produces an *Assessor Summary Report (ASR)* which is used for planning for the applicant when he or she is approved for funding and services as funding becomes available. It is at this stage that successful and unsuccessful applicant are determined. The local *Passport* designated agency will determine the level of eligible funding according to the four funding bands: the desired and/or available services and support; the manner in which services and supports will be funded; the priority for resources; and, the *Passport Program* waitlist reporting to the regional office. The province claims that, "priority service is its objective" thus an automated priority service tool that assesses each applicant's specific situation assesses their level of risk according to behavioural, medical and personal, as well as the life circumstances of the caregiver. The system produces a numerical score that summarizes a person's risk level in relation to other applicants across the province (Passport funding website, 2017). This multi-step process leaves many eligible applicants on waitlists. A recent newspaper article *Ontario Suit Alleges People With Developmental Disabilities Denied Services* outlines problems with the current support systems for people with CIDs and their families: "The Developmental Services Ontario waitlists are indeterminate and administered in an ad-hoc, inconsistent and unreasonable manner, denying eligible recipients statutory benefits which are necessary for their basic daily human needs and safety," the Marc Leroux of Timmins, Ontario class-action lawsuit against the Ontario government alleges. "Adults may spend years on the DSO waitlists, requiring family members or other caregivers to provide necessary services or supports, or going without such services. This practice damages the persons directly in need of such services, as well as their family and caregivers." (Loriggio, 2017, April 24). Retrieved from <https://www.theglobeandmail.com/news/national/ontario-suit-alleges-people-with-developmental-disabilities-denied-services/article34796765/>. "Funding allotted for deinstitutionalization in the 1980's was to have followed these individuals into the community. The result is that transfer payment agencies like Associations for Community Living and other developmental services providers are struggling to retain staff, maintain any degree of quality

According to reporter Rob Ferguson (2017), there are now 24,000 people receiving support under the Ministry's *Passport Program* but there are still currently about 11,000 families on the waitlist due to insufficient *Passport* funds. Regarding waiting lists, Community and Social Services Minister Helena Jaczek (Toronto Star, Ferguson, 2017) assures the public that, "what we do is we ensure that priority cases receive *Passport* funding first". For example, "in addition to having a developmental disability, a person may also be medically fragile, have mental health issues or be subject to a precarious living situation" (The *Passport Program* Questions and Answers, 2016). The assessment practice reflected in the table (See Appendix X: *Passport Program* Assessor's Rubric) creates a social assistance system that distinguishes between persons with 'severe' disabilities, and those with 'not severe' disabilities, which seems logical given the limited amount of funding available, but borders on being contrary to human rights laws, violating the basic elements of our Human Rights legislation and the UN Convention on the Rights of Persons with Disabilities (2006)<sup>77</sup>. The assessor's comparison based on application completion and interview of potential *Passport* recipients does not necessarily consider how an individual's need may change based on the environmental level of support promoting a hierarchy of disability. It positions some impairments as more or less disabling than others, perpetuating social exclusion, stigma and lack of program access. The criteria of having a substantial developmental disability should be enough for access to the support.

A critique of the DSO is that it places a level of bureaucracy between families and the Ministry<sup>78</sup>, just one more assessment hurdle that "families need to jump through before they can obtain any amount of funding for their loved ones – if indeed funding is even available"

---

services, meet the needs of individuals with complex needs, and try to address union contracts with funding that does not stretch far enough" (Spindle, 2013, p. 5).

<sup>77</sup> There are eight guiding principles that underlie the Convention and each one of its specific articles: 1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; 2. Non-discrimination; 3. Full and effective participation and inclusion in society; 4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; 5. Equality of opportunity; 6. Accessibility; 7. Equality between men and women; 8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

<sup>78</sup> "An October 23, 2013 Freedom of Information request yielded data that actual expenditures for Developmental Services Organizations (DSO's) is in excess of \$12,000,000.009" (Correspondence: Cate Parker, FOI Unit, MCSS/MCYS, October 23, 2013 cited in Spindel, 2013) has been spent on this administration in lieu of funding going to individuals.

(Spindel, 2013, p. 4). Some of these administrative practices seem redundant and do not necessarily seem to support families.

Often, people receiving the *Passport Initiative* may not have the funding available to pay expenses outright and wait for lengthy processing times to receive reimbursement funds. A study by the Roeher Institute (1993), showed bureaucratic delays indicating that, “the governments are often late in transferring funds, leaving consumers responsible for the interim period during which the service providers must be paid. Consumers actually end up subsidizing the government—a burden few can afford” (pp. 65-66). Many people with CIDs are, “living alone or with unrelated others, [and] the vast majority of people with intellectual disabilities are in low-income households” (Crawford, 2013, p. 20) who may not be able to bear the waiting period of a fund transfer. It is only in the case that one is engaging with a community agency whose programs are limited can arrangements for direct payment for an individual’s supports can be organized.

### **Is individualized funding the answer?**

Making Canada an inclusive and accessible reality for people with CIDs, requires sweeping changes to the current funding formulas. Power, Lord and defranco (2013) assert that, as more and more countries transition from traditional service regimes to personalised support systems, this is a timely opportunity to examine the evolving area of individualized funding and planning models to support individuals and their families (p. 2)<sup>79</sup>. According to CACL’s (2013) report, submitted to The House of Commons Standing Committee on Finance, the action plan has four key areas that require revision:

1. Enhanced disability supports to enable independent living, active citizenship and full participation;
2. An enhanced Federal role in alleviating poverty of persons with disabilities and their families thus freeing up dollars at provincial/territorial levels for new investments in disability supports;
3. Labour forces inclusion measures;
4. A national social development role to promote accessibility and community inclusion and an adoption of measures to recognize the short and long-term economic impacts for family members with significant caregiving responsibilities of family members with disabilities (p. 3).

---

<sup>79</sup> Individualized funding in which planning is inherent, encompasses direct funding, meaning that funds go directly from the government to the person whereas indirect funding, goes to the person through a transfer payment agency.

To shape this long-term agenda, CACL suggests the establishment of high-level table reporting to Minister of Finance and Human Resources and Skills Development Canada (HRSDC) on income security and equality for Canadians with disabilities and their families. They recommend Federal/Provincial/Territorial (FPT) leadership by convening FPT dialogue on income security and labour force to develop a joint strategy, clearly defining roles for both levels of government. The Federal government should expand income roles including a refund on the Disability Tax Credit for low-income Canadians<sup>80</sup> reducing the total amount they pay on taxes.

Lord's (2006) findings, in his *Study of Individualized Funding in Ontario*, reflect the desire of people with CIDs to participate in citizenship roles including connecting with the community, recreation and leisure. People want to become part of the fabric of their communities, 42.6 % wanted to find meaningful activities in the community and to increase community presence. Other findings included 71.1% of participants who wanted to increase the number of relationships and develop a support network or circle of support (p. 7). From this study Lord concludes,<sup>81</sup> jurisdictions that have implemented individualized funding usually joined independent planning and facilitation with other kinds of infrastructural support networks and support for individuals with CIDs (2006, p. 1). Circles of support are key for artists working in a shared studio environment.

Costs for individualized funding are comparable to existing conventional supports and their funding models, however, studies show that quality of life outcomes are usually more positive due to emphasis on self-determination in new paradigm projects (Lord, 2006, p. 1). The Individualized Funding Coalition for Ontario (IFCO) focuses on gaining, "control and decision-making power for the funds to direct what happens with individualized funding, including how the funds will be spent; this full control may be done through the use of a contract called a

---

<sup>80</sup>The Federal Government has attempted to address some poverty and income security needs of Canadians through: Employment Insurance, CPP/QPP, Old Age Security and The Guaranteed Income Supplement, the National Child Benefit and Child Disability Benefit, The Registered Disability Savings Plan and various tax measures (CACL, 2013, p. 4).

<sup>81</sup> John Lord (2006) a study called *Moving Toward Citizenship: A study of individualized funding in Ontario*. Three questions guided the study's research approach: 1. How much individualized funding have people received for individualized support? 2. In what ways have individuals and their families utilized their individualized funding? 3. What is the experience of individuals and their families in regard to outcomes and participation? Note: In *More Choice and Control for People with Disabilities* Lord, Zupko and Hutchinson explain that a paradigm can be thought of as a set of basic beliefs that define the nature of the "world" and the boundaries and relationships within it.

‘personal support agreement’<sup>82</sup>. Their IFCO’s model promotes an infrastructure to support and focuses on relationships with a provincial community of practice that believes in shared learning, independent facilitation and planning that is separate from direct service provision, access centres which are a single point of access, and funding allocation proposing that goal achievement can be achieved through supported invoicing/financial accounting and accountability, human resource support and capacity enhancement, for example, training for families and personal assistants (p. 55). With the help of the internet as a tool, people around the province, around the country, and around the world, are communicating funding options and rallying for a reformed individualized funding program to be put into full action (Individualized Funding Coalition for Ontario, 2006)<sup>83</sup>.

One issue that has been raised with respect to individualized funding, is that there is an over-reliance on the demand-supply argument. According to the Roeher Institute (1993), individualized funding presumes that there is a marketplace of existing services. In fact, this is a myth. There are few service choices in communities so people who receive individualized funding turn to traditional services who offer limited choices rather than seek new options (pp. 55-56). Another critique of individualized funding, as it currently exists, is that there are provincially imposed restrictions on the services that can be purchased. Even though persons with disabilities are supposed to have the final say in their own service requirements, their plans rarely occur because consumers must submit service proposals to government representatives who review and accept or reject their plans (Roeher Institute, 1993, pp. 62-63). Leaving art facilities whose employees understand both art making and how to support people with CIDs up

---

<sup>82</sup> Individualized Funding Coalition of Ontario, Retrieved from <http://www.individualizedfunding.ca/>, Direct Individualized Funding that is based on the following principles: The person’s voice is honoured through any decision making process (with assistance from family and/or friends), with the person’s voice being honoured in the process; participation and contribution in community is a given – community as a first resource; dreams of the person and the strengths of the person, family and support network guide the process; facilitation and planning is a separate function in the system; relationship building and networks of people are key; funding is fully portable (funding can be moved within an area to a different agency, to another part of the province, out of province, from agency base budgets to direct, whatever is needed).

<sup>83</sup> According to Guest (1997), the public has become more interested in the form, content and operation of social security programs (p. 7). As measures of participatory citizenship, Canadians are now part of planning boards, have become advocates of various client groups such as the Council of Canadians with Disabilities (CCD) who articulate recommendations regarding how to transform Canadian society through calling for better service, more benefits and greater accountability by officials (p. 7). Advocacy is evident in the debates of the House of Commons called a *Hansard* debates which are discussions by citizens or representatives of citizens before a bill is passed into law. All this said there are still many draw backs to our social security system.

to the demands of the marketplace to emerge, might not become a reality. Nationally there are so few studios akin to CVS in existence despite a market need. An entrepreneur using the, if-you-build-it-they-will-come approach would have to understand and navigate provincial funding agencies financial and bureaucratic processes and possess knowledge of supportive art making to offer opportunities to broaden clients' cultural horizons to address issues of cultural citizenship.

In sum, the birth of the organization that we now know as Community Living began as an advocacy movement leading a charge for inclusion of people with CIDs in communities in the late 1940's. A group of like-minded caregivers lobbied for the revision of social policies to educate their children in lieu of models of institutionalization and segregation. The building of specialized schools for children who had intellectual disabilities has now largely been replaced by increasingly inclusive education options for people with CID's. As the children of the 1950s grew, so did the movement helping to develop social policies that supported them in daily living. This evolution of new understandings of what true inclusion in society meant gave rise to social policies in all aspects of life including education, employment, housing, workplace, justice, human rights, and the right to personhood. Take for example applying pressure to close government-run institutions the last of which closed in 2009 in Ontario (Brown and Radford, 2015) in favour of community-based housing options and schooling<sup>84</sup>. Financial social policies like ODSP providing a basic level of income, prescription drugs and dental care employment programs designed to encourage people receiving benefits to enter the workplace and retain employment for adults over 18 years of age with disabilities emerged. With Bill 148 The sheltered workshop model, first advocated by Community Living to teach work skills, closed in favor of community employment options (Kyle, 2019). As workshops were dismantled with Bill 47, sheltered workshops transformed into programs like SWACA or *Brands for Canada* providing daily activities in the community and social policies such as the *Passport Initiative*

---

<sup>84</sup> On March 31<sup>st</sup> 2009, more than 130 years of institutional functioning and operating ended in Ontario as the last three institutions for people with CIDS closed: Huronia Regional Centre (Ontario's first institution in 1876, the Orillia Asylum for Idiots), Rideau Regional Centre, and Southwestern Regional Centre (Brown and Radford, 2015, p. 25). At first, "institutions were intended to promote health, safety, training, and other aspects of growth and well-being, and many successes were noted. As time went on, however, overcrowding, underfunding, lack of demonstrated success, and philosophical, economic, and social changes resulted in a long decline of institutions. The philosophy of normalization, which claimed people with disabilities had the right to live in communities, became popular in the 1970s in Ontario, and resulted in the dramatic growth of community services and housing options. Community living gradually replaced the long tradition of institutional living in Ontario" (p. 7)

arose. The Community Living movement and the Community Living Association itself have grown to focus more on what each person wants by monitoring, analyzing and responding to issues of public policy that affect people who have CIDs and their families (Kyle, 2019) advocating for programs that support individualized funding.

ODSP funding makes people with CID's dependant on their families as family income is used to determine financial allowances and living accommodations over the course of a lifetime. Although ODSP offers health care and dental benefits, the funding allocated marginally covers housing and basic living expenses leaving little room for cultural participation in the community. There is also a focus on employment training and ironically, punitive measures if one does find and maintain a work. The deduction of earnings beyond the \$200 per month ODSP grant (Government of Ontario, ODSP: Information Sheet, 2018) acts as a disincentive to artists. Arts organizations have successfully lobbied for ODSP to remove some restrictive measures for artists with disabilities who receive ODSP to keep their earnings however, restrictions should be further lifted to reflect the inconsistent nature of purchasing art supplies for art making and/or earning money by selling art.

As a form of individualized funding, The *Passport Program*, if granted, can be used to gain greater cultural citizenship in the broader community but requires a convoluted, procedure-filled admission ordeal to navigate. The continuous support of a caregiver or paid community service worker must be enlisted by the recipient to manage the numerous official receipts and documentation to maintain funding. *Passport* is a move in the direction of flexible, person-centred planning, as a human right. Individuals can select art-related activities to engage in cultural activities.

Chapter Four focuses on the Fine Art exhibition sphere examining biographical references of artists, the labelling of people with CIDs' art in narrow historical definitions. A discussion about contemporary galleries' prescriptive notions of artist and their art exhibition through a historical examination of curatorial practice is presented and how a refocusing of curatorial practice through a disability lens can be achieved. Artists' ways of working in a studio setting are examined through the *Eight Studio Habits of Mind* (Project Zero, 2003) and art facilitation for people with CIDs.

**Chapter Four: Being an Artist: Studio Process and the Resonance of Art Practice**



Illustration 15: Yarmol, C. (2020). *Coffee Talk*. [Digital photograph of exteriors of 7 finished albums, 9" x 11" each, book binding cloth, matt board, Japanese paper, double-sided tape, PVA glue]



Illustration 16: Yarmol, C. (2020). *Close up of Interior of Coffee Talk Book*. [Digital photograph of interior concertina and endpapers of book #6 , 9" x 11" each, book binding cloth, matt board, Japanese paper, double-sided tape, PVA glue].

According to American author, book artist, visual theorist, and cultural critic Johanna Drucker, “The space of a book is intimate and public at the same time; it mediates between private reflection and broad communication...” (2007, p. 15) as we turn the pages. I have chosen to sculpt a succession of handmade, album-structured books using the *Elbum technique*<sup>85</sup> I learned at the Canadian Bookbinders and Book Artists Guild (CBBAG) in Toronto, Ontario as a form of exhibition of the study participants’ and my artworks (See Illustrations 15-16). The books hold pages by gripping them into a series of articulated narrow pockets forming an organized exhibition of artists’ statements and photographs of artwork. Each artist was asked about the subject matter and the content of their artworks. With the help of the help of Harold Tomlinson, the studio’s facilitator, I collected the artists’ statements from each of the participants. I edited these statements maintaining key points from the verbal exchanges about their artwork. I also photographed a selection of their artwork and created individual pages unique to each artist (See Appendix A-C). Inclusive arts practitioners Alice Fox and Hannah Macpherson say, “Self-authored artists’ statements offer another opportunity for the artist’s voice to emerge for individuals to represent themselves rather than to be, once again observed and talked about. However, supporting a learning-disabled (terminology in the United Kingdom, known as CID in North America) artist to write an artist’s statement is an art in itself, and one that needs to avoid an overly simplistic wordy, sentimental or sympathetic response. The best work in this area tends to emerge from well-established relationships” (2015, p. 41). Spending months at CVS getting to know participants has forged trusting relationships with many of the artist-participants enabling me to write the artists’ texts in cooperation with them.

Residing between each of these pages are colour copies of artwork that CVS artist Evelyn van Duffelen and I created for this project. I sketched portraits of each participant at the studio and Evelyn selected and applied the colours in her preferred medium of pencil crayon. Key phrases from the interviews with each artist are positioned below each jointly created portrait.

The advantage of the structure of these albums is that they can be enjoyed privately, or pages can be withdrawn from the central concertina spine and exhibited in a public space alongside each artists’ artworks (See concertina in Illustration 16). In the future, I hope to have an exhibit with the CVS artist’s artwork and my own artwork completed for this project.

Artist-author Audrey Niffenegger communicates the authority a book can have: “The book is an object. The book is an idea. Books inspire and are inspired by revolutions, love affairs, religions. What does it mean to make a book? To make a book is to gain power over objects. Books are potent items” (Wasserman, K., Niffenegger, A., & Drucker, J., 2007, p. 12). Niffenegger continues:

To make books is to create physical form for ideas. All artists do this, of course. But the book has been the body of human thought for many centuries, and when we make unusual books, artists’ books, we are messing with that body. This can incite strong feelings in readers. We identify with books, and when artists transgress against books it’s a serious thing (p. 13).

I agree with Niffenegger’s commentary. I believe that the creation of these handmade books is well-suited for this multi-method critical disability studies dissertation as it credits the knowledge of the artists in this study. Book creation is not only a visual way to exhibit work but a means to powerfully communicate the idea that people with CIDs can be knowledge makers.

---

<sup>85</sup> This technique was developed in France by Benjamin Elbel, a bookbinder in 2013.

## **The Art World**

Chapter Four begins with a discussion about hegemonic, Euro-Western, historical precedent of adding texts to the exhibition of artwork mounted in museums, publicly funded galleries, and commercial gallery spaces in art world. These texts written by a curator, often include artists' biographies, statements, process or style descriptions sometimes in form of gallery guides presented alongside artwork to document, offer explanation or categorize artists' artwork. The thrust to rigidly categorize and label people with CID's as well as their artwork in groupings or classifications such as *Art Brut*, *Outsider Art* or *Naïve Art* is explored in this chapter. Although these designations in neoliberal gallery spaces can intentionally or unintentionally limit and reduce artists' work and self-valuation, gallery owners and curators work in systems that consider art as commodity —providing institutions with the products to incur financial profits and renown for the institutions themselves. The chapter turns to the traditional roles of curators to individuals who consider themselves to be both critical disability theorists and gallery/museum curators who question prescriptive notions of artists disabilities specifically artists with atypical, cognitive abilities. These curators challenge the silencing of normative curatorial habits of curtailing, minimizing or erasing the artists with disabilities thoughts and voices about their work as part of the exhibitory practice. Potential ways to actively involve the voices of artists with CID's in the contemporary art exhibits are expounded. Other avenues for inclusive art exhibitions including artists' collectives and cooperatives, local gallery spaces and on-line collections are offered. The end of the chapter turns to art making in the studio-setting with a view to how artists' creative processes like the *Eight Studio Habits of Mind* (Project Zero, 2003) are iteratively enacted. A definition of *art facilitation* for people with CIDs is presented to underscore the requisite requirement for hinderance-free art making and development of personal expression.

### **Personal Biography in Art**

Art historian Colin Eisler (1987) claims that biographies of artists have been of interest in Western art since “antiquity first harped upon the uniquely privileged status of the artist” (p. 75). Eisler writes, “Anecdote is the right, not the wrong stuff of art history, beginning with Pliny [the Elder], whose telling stories about artists are found in his Natural History [about life]. The usually mythic event, ‘as told to’ some anonymous earwitness, the *bon mot* or Treppenwitz, written for or dictated by popular fantasy, all reveal how society wanted and needed its artists to be seen and heard” (p. 75). Founding editors Ulrich Thieme and Felix Becker wrote,

Allgemeines Künstlerlexikon (translation from German to English is General Dictionary of Artists), thirty-seven volumes from A (1907) to Z (1947) of Western visual artists' biographical lives in an encyclopedia adding six additional volumes for the twentieth century (p. 74)<sup>86</sup>.

Biography of the artist in public exhibitions has been deeply fixed in Western art history and is still prevalent today. The artist's biography appears in concert with the tendency to categorize artworks in particular classifications in neoliberal gallery settings. Western models of the standard discursive practices of the contemporary art world are described in Appendix W: *What Galleries Want*. The questions presented in Appendix W are typical of normative interaction and information curators, critics and gallerists would expect of potential exhibiting artists. Critical disabilities curator Amanda Cachia asserts that the gallery circuit is part of a, "Deeply elitist art world, where categories like "normal" conveniently persist" (Cachia, 2014, p. 121). Galleries' demands habitually socially and representationally exclude people with CIDs.

Artist and disability arts facilitator Jan Swinburne (2005) outlines the potential power of aesthetic expression and the proliferation of linguistic processes expected in today's art exhibition world. The non-verbal process of creating art without the use of language makes art creation a seemingly perfect activity for artists with atypical oral and written communication modes because their communication is mitigated by artistic language of elements and principles of art<sup>87</sup>. Through their aesthetic expression "a unique connection to one's self and ultimately for the artist, to others" (p. 4) providing opportunities for social connections that may otherwise be impossible. Swinburne (2005) stresses that "the process of making art is like having a conversation with one's self and letting others overhear" (p. 4).

Although visual intelligence is not dependant on linguistic communication for its production, high language proficiency has become a major force in the professional art world, particularly regarding exhibition, endorsement, and academia through artists, art critics, curators, professors and the media. The importance of language related to art creation becomes muddled

---

<sup>86</sup> Today the *Allgemeines Künstlerlexikon Online* (Artists of the World Online) is a contemporary reference work containing a database of artists. It contains biographical information on more than 1.2 million artists. It links to the database *Paintings in Museums in European Countries: Germany, Austria, Switzerland*.

<sup>87</sup> The Elements of Art/Design are considered the building blocks or ingredients of composition: texture, value, colour, shape, form, space, and line. The Principles of Art/Design are how the elements are organized in a composition: balance, rhythm/movement, unity/harmony, variety, proportion, contrast, emphasis, pattern. Retrieved from <https://www.slideshare.net/kpikuet/elements-and-principles-of-art-presentation>. Various references differ in their inclusion of the Principles of Art/Design listed above.

with the linguistic response spawned by the finished work, and its promotion —resulting in exclusivity and inequity. As language use thrusts to forefront of art exhibition, an enigmatic relationship of language and visual arts emerges in what Swinburne calls, “dancing with a paradox” (p. 4) creating additional barriers for artists with atypical linguistic modes of communication. Viewers become the interpreters of the meaning but may not understand the art-creation process or central meaning of the artwork intended by the artist, so these viewers seek clarification. Curators write and post their own ‘educated’ interpretations; the public becomes linguistically dependent on these elucidations through oral audio guides and written annotations that are quite distinct from the non-linguistic, private creative process experiences shared by the artist and the individual observer of the art.

Since curators structure their descriptions from their own positionality and may have limited experience with artistic processes, sometimes the resulting texts display a flagrant disregard for the artist’s intention or actual circumstances. An example of how an artist’s artistic process might have been misread by a curator<sup>88</sup> was in *the Carr, O’Keeffe, Kahlo: Places of Their Own Places of Their Own* exhibit at the McMichael Gallery in Kleinburg Ontario, (2001) which included the work artists Emily Carr (1871-1945, Canadian), Frida Kahlo (1907-1954, Mexican) and Georgia O’Keeffe (1887-1986, American). Referring to a text positioned beside a painted sketch by Kahlo at this show, Doctor nancy halifax [sic] (Personal communication, April 19, 2020) and I discussed how exhibition texts accompanying artwork can articulate a pathologization of an artist’s disability rather than an iterative art creation process. Halifax voices her observations:

There was a small masonite board with a rough sketch from Frida Kahlo; the writing that was beside suggested that the use of paint and the rough nature of the painting was due to her opioid addiction. From my perspective, i saw a painting done, likely at the end of a day. There are a few brushes, not yet well cleaned, a bit of oil paint remains on the palette and the beginning of an idea. What is captured is a process - and it has been reduced to pathology. This example is significant when we think about disability in the cultural world.

---

<sup>88</sup> The show *Carr, O’Keeffe, Kahlo: Places of Their Own* (2001) at the Michael Gallery in Kleinburg, Ontario was inspired by Dr Sharyn Udall’s book of the same name. Udall, S. R. (2001). *Carr, O’Keeffe, Kahlo: Places of Their Own*. Yale University Press. Dr. Udall was the guest curator.

The curator's supplementary text inscribes her estimation of Frida Kahlo's mental health to an audience who might consciously or subconsciously reinscribe their misconceptions of mental disability. I believe this dependence on written explanations in art exhibits is a result of a public who might not feel confident in their ability to view, analyse and critique what they see. They have been educated in what Paulo Freire (2000) terms a "traditional banking system of education" where they are waiting to be "fed the answer". Their *conscientização*<sup>89</sup> (p. 35) has not yet developed.

Another example surfaces in a *Diane Arbus: Photographs, 1956-1971* (2020) exhibition at the Art Gallery of Ontario, in Toronto curated by photography curator Sophie Hackett. As I walked through the exhibit, I was particularly attentive to the texts that accompanied the photographs. I noted the commentary Hackett selected to place by numerous photographs. The text written by American photographer of the New York school, a critic, and teacher David Vestal of *Infinity Magazine* positioned beside *Transvestite Showing Cleavage*, (1966) N.Y.C., [Medium: gelatin silver print, 26 x 25.3 cm. (10.2 x 10 in.)-MOMA –"New Documents" collection] read:

She [Arbus] photographs individuals who in one way or another depart from conventional behaviour or appearance, but she does emphasize their 'abnormal' or 'freak' character. Instead, she concentrates on showing with dignity, seriousness and sympathy how much they have in common with the 'normal' people around them. It would be wrong to say that Diane's people are less than normal than the rest of us. They may be more open and more direct, more vulnerable, more visibly human than most people.

Attempting to praise Arbus' photographs, Vestal's critique acts in the service of normativity revealing a cultural disdain for people who are different from a defined norm. I question, whose experiences are taken as the norm as Vestal uses the pronoun "they" about the subject of the photograph and 'less than normal than the rest of us'. Who is included and who is excluded from the group of 'the rest of us'? I wondered why the curator selected Vestal's critique rather than just leaving the photograph for the spectator to view and to come to their own conclusions or why Vestal's appraisal of the Arbus' work was not itself critiqued or situated by Hackett. A deeper discussion of the role of the curator and curatorial practice in art exhibition as it relates to

---

<sup>89</sup> The term *conscientização* or conscientization refers to learning to perceive social, political, and economic contradictions, and to take action against the oppressive elements of reality" (Freire, 2000, p. 35).

disability emerges in *The Role of The Curator & Curatorial Practice with a Disability Studies Bent* section.

### **Art Brut, Outsider, Naïve Art —Just Call it Art**

Canonical art history plays an important role in shaping the academic study, teaching, production, reception and sale of art in the art market (Dačić, 2015) by limiting the definitions of sanctioned art in society. But who decides on the kind of art that will be coveted? What about the individuals who create art beyond the constraints of cultural institutions? These were some of the questions in the mind of Jean Dubuffet when he began prospecting for marginal artworks in the summer of 1945 (Dačić, 2015).

Dubuffet started to create artwork in his early 40's after the devastation of World War II when artists started making redemptive art to restore old values (Jean Dubuffet French Painter, Printmaker and Sculptor, 2019). Dubuffet, who was irritated with the ideas of art historical canons, believed that Western culture was unfertile, stifled by convention and tradition and believed that the work of the mentally ill broke away from these limitations (Beveridge, 2001). From a contemporary critical disability studies perspective, Dubuffet's ideas may be a reinscription of the trope of "the disability artist as genius". Dubuffet's interest grew from study of Swiss psychiatrist Walter Morgenthaler's work with Adolf Wölfli who was hospitalized in 1895. Wölfli was Morgenthaler's patient from 1907 until 1919 in the Waldau Mental Asylum. Morgenthaler published, *A Mentally Ill Person as an Artist* (1921), a monograph pioneering the field of art and psychopathology. This publication was the first time a patient with a mentally illness was described as an artist and was referred to by his actual name, not his initials or number (Baumann, n.d.). Additionally, Dubuffet knew of the work of Hans Prinzhorn, a German psychiatrist and art historian who published *Artistry of the Mentally Ill*, (2013, 1973, 1922). Prinzhorn was considered the first physician to attempt a major study and aesthetic analysis of psychiatric art. Many of the artists Prinzhorn studied had artworks which were recovered from waste baskets or found on toilet paper, the insides of envelopes and sculptures made from bread of other foods (Eiss, 2013, pp. 52-53). According to Universitätsbibliothek Heidelberg (n.d.), Hans Prinzhorn identified six basic drives that give rise to image making: an expressive urge, the urge to play, an ornamental urge, an ordering tendency, a tendency to imitate, and the need for symbols. For Prinzhorn (2013), image-making for humanity in general is driven by our intense desire to leave traces:

When we cover a piece of paper with doodles, when a child arranges colourful pebbles on his mud pie, or when we plant flowers in our gardens, one quality is common to all of these quite different activities, namely the enrichment of the outer world by the addition of perceptual elements. Like the need for activity, it is a final, irreducible psychological fact – an urge in man [sic] not to be absorbed passively into his environment, but to impress on it traces of his existence beyond those of purposeful activity (p. 21).

Prinzhorne's 1922 book and the accompanying artwork was not positively received in society of the time as it, "reflected a breakdown of high culture's claim to 'civilisation', exposing the misery and turmoil at the heart of modern life... Prinzhorne granted voice to the previously marginalised: those incarcerated, those deemed insane, those suffering under poverty, those untrained, those in the 'wrong type of institution'" (Universitätsbibliothek Heidelberg, n.d.).

Art critic Roger Cardinal declared that, "Dubuffet was a guerrilla warfare man, who was challenging the unsuspecting Parisian art world with his art writing" (Ishida, 17 June 2019) and art. Dubuffet sought out the artwork of confined artists — patients in hospitals, marginalized or obscure individuals, prisoners or individuals who resisted society's conventions in all aspects of life. Art historian Lucienne Peiry (2001) says that Dubuffet termed their art, *Art Brut* or *Raw Art* that is, art that is imprecise and purely intuitive (p. 11), raw, rough art, unpolished, secret and uncooked by cultural influences, unpredictable with primitive elements created outside of the sphere of the fine art canons. Dubuffet believed that isolation ensured that artists were not exposed to conditioning by the dominant culture. These self-taught artists worked silently, clandestinely, and unreservedly creating dream-like worlds that allowed them to make a symbolic escape from confinement, producing work that was unlike artists institutionally trained [in art schools] (Peiry, 2001, p. 11). Peiry says that each artist, "developed new thematic, iconographic, stylistic and technical syntax that bears witness to an obvious inventiveness and independence" (p. 11). In a two-week summer jaunt to Switzerland (5-22 July, 1945)<sup>90</sup> Dubuffet visited asylums, and prisons, gathered creations by the patients that would become part of *Compagnie de l'Art Brut* in 1948, a collection on which he founded this movement believing that the work seemed to flow directly from the subconscious. He searched for:

[A]rtistic works such as paintings, drawings, statues, and statuettes, various objects of all sorts, owning nothing (or as little as possible) to the imitation of art that one can see in museum, salons, and galleries; but that on the contrary appeal to humanity's first origins and the most spontaneous and personal invention; works which the artists has entirely

---

<sup>90</sup> Dubuffet was invited to Switzerland by the Cultural Ambassador of French-Swiss Tourism Paul Baudry. He went on the trip with Swiss-French architect Le Corbusier and French critic-publisher Jean Paulhan (Phaidon, n.d)

derived (invention and manner of expression) from his own sources, from his own impulses and humours, without regard for the rules, without regard for current convention (Dubuffet, 1948).

Dubuffet was inspired by the artwork he found.

Armed with anti-cultural positions about art and art making Dubuffet also explored the naïve aesthetics he had unearthed in his own art. He generated free-form, simplified imagery from a flow of his thoughts sometimes in a *hourloupe* style<sup>91</sup>, with coarse textures through the explorations of unorthodox materials (Dačić, 2015) and dull colours satirizing canon-like genres of high art. Art critics felt his media and its application were akin to dirt and excrement but could be an acknowledgement of humanity's failing and a prospect to start again from the soil-up (Jean Dubuffet French Painter, Printmaker and Sculptor, 2019).

Jean Dubuffet was one of the pioneers of the avant-garde Art Informel movement. Dubuffet wrote a manifesto in 1947 dignifying art created by people labelled with mentally ill; it promoted a style free of intellectual heritage, established values and high culture (Dačić, 2015). He championed Art Brut and endeavoured to be like its creators, however, he lived with the knowledge that he could never attain the artistic freedom of these artists as he was too socially and culturally enmeshed in the contemporary system and unable to attain true uniqueness, honesty, and authenticity. The conventional wisdom of medical practitioners in institutions evolved their ideas about creative artistic expression and "actively proposed, encouraged, and supervised in art workshops, [where] Art Brut neutralized and takes flight" (Peiry, 2001, p. 262).

Art Brut raised questions about "the training of professional artists and the status of artists at the dawn of a new century, about present-day channels of artistic communication, and about art's relation to society" (Peiry, 2001, p. 264). It altered the idea of a sacred aura surrounding the act of artistic creation. With the growth of Dubuffet's collection, it was evident to him that some work did not fit into his original narrowly-defined Art Brut definition because the artists had made contact with people in everyday society and their self-awareness of their work precluded their inclusion into the category<sup>92</sup>; he placed these artists' works into a collection

---

<sup>91</sup> *Hourloupe* style developed from a chance doodle while Dubuffet was on the telephone. It appears as a tangle of clean black lines that forms cells, which are sometimes filled with unmixed color. Dubuffet thought the style evoked the way objects appear in the mind (Jean Dubuffet French Painter, Printmaker and Sculptor, 2019).

<sup>92</sup> Dubuffet moved these artworks to the Annex Collection renaming them *The Neuve Invention*. They were not characterized by the same radical distancing of mind as Art Brut but were sufficiently independent of the fine-art system to constitute a challenge to the cultural institutions.

entitled *Neuve Invention*. Unwittingly Dubuffet had created his own system of classification (Rawvision, n.d.).

Technological evolution in society such as the spread of instantaneous means of communication, the growth of mass media, and the expansion of mandatory schooling all facilitated the transmission of images and information and the idea of self-sufficient life (Peiry, 2001, p. 262) was no longer viable; the original definition of Art Brut falls into the realm of impossibility. Exhibiting Art Brut in museums and books has pushed it into a cultural system from which it was estranged or at least discounted from the mainstream due to its association with Otherness. It eventually become accepted by the critics, the public and became a categorical art marketing tool.

### **Outsider Art**

Inscribed ableism is apparent in how people with disabilities' artwork is described, defined, and categorized in the terms Outsider Art. A professor and art critic at the University of Kent, Roger Cardinal introduced the term *Outsider Art* as an English equivalent of Art Brut in 1972. In his book, *Outsider Art* (1972), Cardinal posits the question, "Can art be conceived that is not 'cultural'? Does such a rigorously different art exist (p. 7)? His definition is applied more broadly than Art Brut's in that it includes un-tutored, self-taught artists who may be inspired by vernacular culture but are working outside of the art institutions and the canonical concept of art. It also encompassed Dubuffet's categories of both Art Brut and *Neuve Invention*. "Not hooked up to galleries and certain expectations. It should be more or less inward-turning and imaginative – self-contained as it were" (Cardinal in Kits Media Tech, 2015). In an interview, Rawvision author Wilem Volkersz asked Roger Cardinal how he came up with the term Outsider Art:

Well, it all happened when I produced this book [Outsider Art]. I wanted to call it 'Art Brut', and I had studied the Dubuffet collection, and had a lot of examples from the collection and some that I'd chosen myself, but fitting into the general rubric of Art Brut...I showed the publisher what I wanted to do, and I said, 'Well, you've got Art Nouveau, and you've got Art Deco, now you've got Art Brut and everybody will get on with it.' But the publisher was very worried about this particular title and wanted something more easy [sic] to get on with for the English ear and said, 'Well, shouldn't we call it something else?' And we went through hundreds of titles: 'The Art of the Artless', I remember was one of them (Volkersz, 1998).

Thus, Outsider Art was selected simultaneously for the style and the title of Cardinal's book holding a revolutionary spirit. Cardinal said, "The critical definition of the creative Outsider is that he or she should be possessed of an expressive impulse and should then externalize that impulse in an unmonitored way which defies conventional art-historical contextualization" (Phaidon, n.d.). The public began using the term Outsider Art to describe the works of any untrained artist including Folk Art, Naïve Art, Marginal Art and Visionary Art, regardless of the definition accentuated by Dubuffet (Dačić, 2015) for artists with disabilities or suffering social exclusion, whatever the nature or aesthetic end of their work (Rawvision, n.d.). Fox and Macpherson (2015) contend that some people thought that Outsider Art was thought to be contaminated with myths of 'authenticity', 'purity' or a 'lone genius' artist.

According to the Tate Gallery (n.d.), Naïve Art or Naïf Art is characterised by childlike simplicity of execution and vision. A naïve creates simple, unaffected and unsophisticated art claimed with reference to subject matter and technical application. Naïve works are often extremely detailed, with brilliant, saturated colours applied to the substrate rather than subtle mixtures or tones; they lack the illusion of perspective with no vanishing points resulting in two-dimensional figures that appear to be "floating" (Encyclopaedia Britannica, 2019) similar to the art of the Early Medieval and Byzantine eras<sup>93</sup>. Naïve Art style results since the naïve artist often has little to no formal training in an art school or academy. The art of children, art made by people on the fringes of society such as prisoners and people with mental illness are artists included in Naïve Art's definition. Wanting to flee from insincere sophistication of art created within the traditional system, Modernists valued Naïve Art for its sheer simplicity (Tate, n.d.).

Compartmentalization of art produced by self-trained artists with disabilities continues today. Their art is often rigidly categorized and labelled as Outsider Art, Naïve Art, Art Brut and Mad Art or "artists who don't know they're artists" (Wall Street Journal cited in Rich, 2015). Delimitations of the art of 'intellectually disabled artists' have experienced a resurgence during

---

<sup>93</sup> In the Early Medieval (400s to the 900s) era and Byzantine era which corresponds to the dates of the Byzantine Empire (330 B.C.E. until 1453 C.E.) secular arts were unified by the Christian church and the sacred arts associated with it. The main characteristics of Byzantine art include: a concern for religious symbolism, abstract view of reality, non-realistic, flat, two-dimensional, floating figures, metallic background (Art Net: Byzantine Art, 2017) and meaning and emotion take precedence over the depiction of reality (Brommer, 1997, p. 217).

the past 15 years<sup>94</sup> “because for many collectors and critics, the disability is central to the work’s appeal” (Rich, 2015). This appeal is largely due to the frequent exhibitions of ‘Art Brut’ and like-styles in museums and books that pushed it into a cultural system becoming a sought-after genre.

Director Tom di Maria of Creative Growth Art Studio, in Oakland California (Rich, 2015) cautions against the use of the artist’s biographies and artist’s statements when exhibiting art. He contends that, “Strong narratives sell” and have become major marketing tools of contemporary art in capitalist markets. Making galleries, collectors, critics and the public privy to the artist’s biography can swiftly fashion an artwork into a saleable commodity;<sup>95</sup> buyers want to know if it is Art Brut, Outsider Art, Naïve Art or Mad Art making these labels central to the work’s appeal (Rich, 2015). *New York Times* reporter Nathaniel Rich (2015) advocates that biographical effacement, “contravenes a dominant trend in the contemporary art scene” but, does avoid the danger of aestheticizing the disability or exploiting the disability to sell the work. It is difficult to escape these discursive practices bent on promoting the artwork, while at the same instance Othering the artist with disabilities. When participating or holding shows, Creative Growth Studio in Oakland, California tries to de-emphasize an artist’s disability and does not participate in exhibitions carrying the name, “Outsider Art”<sup>96</sup> instead holding up the artists’ works for their originally and aesthetic merits.

Harold Tomlinson art facilitator at Creative Village Studio spoke about an invitation that CVS artists received to an Outsider Art show in upstate New York several years ago. Harold promptly declined the invitation as he did not want the CVS artists’ work to be categorized as somehow simplistic, pure or untouched art as Dubuffet or Cardinal did.

---

<sup>94</sup> Nathaniel Rich is referring to The Guggenheim, the Museum of Modern Art and the Metropolitan Museum of Art purchases of art of Henry Darger, William Edmondson Martín Ramírez and Augustin Lesage (All categorized as an Outsider artist, a Naïve artist, a Mad artist, and an Art Brut artist respectively) for their permanent collections. Rich notes that, Creative Growth artists such as John Martin have caught the attention of big businesses like Facebook who purchased 35 of Martin’s tool sculptures — cut outs of scissors, hammers and switchblades — for \$8,000 and installed them in the Menlo Park headquarters in June of 2015. They commissioned him for 20 more sculptures. Note that many of these artists’ works were not discovered until after their deaths.

<sup>95</sup> Art facilitator, Harold Tomlinson at CVS as well as Sybil Rampen owner of Joshua Creek Heritage Art Centre, mentioned the categorizations of Art Brut, Outsider Art, Art Naïve as they relate to the public’s perception of artists with CIDs.

<sup>96</sup> One notable exception that artists from the Creative Growth Studio in Oakland, California do participate, “is annual Outsider Art Fair in New York the field’s most prominent showcase” (Rich, 2015).

Tomlinson stated, “Outsider art, it is too narrow a category.” (H. Tomlinson, personal communication, September 23, 2019).

In an interview with Sybil Rampen (Personal communication, December 9, 2019), founder of Joshua Creek Heritage Art Centre, she described where her inspiration to create an art centre and an art class for people with CIDs derives. Sybil graduated from art and archaeology at University of Toronto (Line 39), spent time studying and travelling in Europe (Line 41), attended Ontario College of Art to become an art specialist and a fibre artist and then taught in the United States before deciding to embark on a historical restoration project of her family’s 1827 farm house and property (Line 43). Despite these grand life experiences, Sybil states that in, “1964, my 5th son was born and he’s Down Syndrome. And he has become my greatest teacher and my greatest influence in what I do” (Line 4). Sybil describes her weekly Monday art class with artists with CIDs:

So, every Monday for two hours we work with Community Living Oakville and we have about 6 or seven artists and they do change slowly because they go off and do other things. And every Monday, we have two sessions with 6 or 7 of them and I have 2 or 3 volunteers who are totally wonderful, so I invent [Emphasis on invent.] lessons because I have a... I am quite fortunate to have a background in art for many, many years. And I make a lesson plan which is very step, step, step, very clear and it is based on the artist within (Line 6) [Sybil begins to give examples of her lessons.]. You inherited, no, you won the lottery, so you draw your dream house —So they drew their monastery, their condo, their palace etcetera. And then you have to open the door and see the *artist within* [Sybil pauses for 3 seconds.] (Line 8). Another one [lesson] was called hats, and they do a blue sea of life [lesson], and then they did a raft [lesson], and they have an egg shape and they created an egg (Line 10). And then they all opened it [the object of focus] up and they hatched their artist within. So, it is based on the *artist within*, trying to find it...(Line 12).

Sybil bases her program on the overarching theme of the *unlocking the artist within*. Her weekly lessons begin with a primer phrase to ignite the artists’ creative sparks. Her topics permit endless possibilities by offering the artists an open opportunity to express what they imagine in their mind’s eye. Sybil says, “the magic thing is they all have *‘the pure art’* [Sybil said with emphasis.]. It is different art than any other art in existence. It is pure art and the impact of everything they do. It totals me in such a way that it makes me... [She pauses 2 seconds to choose her words.]. It humbles me” (Lines 12-14). Sybil wants to foster the potential of these “pure artists” or Naïve artists by offering them lessons with the overarching theme of “opening up or hatching” the “artist within” (Lines, 6, 8, 12, 114, 116). Sybil credits the knowledge and

commitment of her Monday artists saying that, “On Wednesdays, I teach another class [for people without disabilities] but, I base it on what I have learned on Monday with these amazing people. So right now, I am making a book about the inspiration and stuff and I am illustrating it with their [the Monday classes’] work, so well it's a tribute to them because they are also dedicated (Lines 14-15).

Like Dubuffet and others in the art world, Sybil sees the art people with CIDs in her class make as “the pure art” as she believes they have not been affected by contemporary art mechanisms; their art comes directly from inside them. I would argue that by the very act of providing instruction this “pure art” is touched by the outside world—as the artists learn and grow, often becoming more curious about the technical skills, subject matter and application of lessons taught. Sybil’s provides a venue for artists with CIDs to create art. Her lessons do what she intends, “bring out the artist [already] within”. Given the definitions of Art Brut, Outsider Art and Naïve Art, the artwork of the artists at CVS do not fall into any of these categories. Artists at CVS are made aware of art historical models, learn a range of techniques, have diverse styles, work in a community and want to sell their work to earn a profit, all characteristics which deny them the categorization of Art Brut or Outsider artists. The next section examines how the role of curator emerged in early Western societies and how the curatorial practice is slowly evolving due to demanding public audiences.

### **The Role of the Curator & Curatorial Practice with a Disability Studies Bent**

A brief description of the purveyors of Western gallery exhibits—the curators are expounded in *Curationism, How Curating Took Over the Art World and Everything Else* (2014) by David Balzer, a Toronto-based author, editor and art critic. Balzer seeks to define a curator and curation through its teleology. The root of the word curator is the Latin *cura*, meaning care; curator means essentially, caretaker. A common understanding of the term curator is found in the Oxford English dictionary, “an extension of museum and gallery practice, an act of selecting, organizing and presenting items in the vein of an arbiter-editor” (2014, p. 9). Balzer eruditely illuminates how the role of the curator has evolved through history from an organizer and arranger of public works to the collection, presentation and explanation of artwork. The term curator, “can be traced back to the Roman Empire, in which curators were bureaucrats made responsible for various departments pertaining to public works (*Curatores viarum*—responsible

for overseeing roads) (Balzer, 2014, p. 30)<sup>97</sup>. In the 16<sup>th</sup> -17<sup>th</sup> centuries exhibition of collections of things like the cabinets of curiosities, the first museums (British Library, 2019), the identity of the curator within the context of a museum or collection takes place. The curator cares for objects, and the objects, not the curator, are the focus (p. 33). Slowly through the “18<sup>th</sup> and the 19<sup>th</sup> centuries, a curator is appointed, not a free agent—but a tool of the state or the body politic as many museums developed because of political turmoil and imperialism as the ‘universal museum’ housed spoils of war.” In France of the late 19<sup>th</sup> century the “forerunners of what we now call artist-run culture” who were attuned with the market emerge as artists working in collectives and mounting artist-initiated exhibitions when they were not accepted by the Salon (Official Art Academy shows). In opposition to the academy-studio-and patron-bound practices that had become the standard (e.g. Impressionists in the 1870s -1880s), artists themselves curated their own work and the emergent dealer began to play a role (p. 37). Balzer highlights the contributions of a range of curators in Europe and North America from the 20<sup>th</sup> century who minted contemporary gallery design<sup>98</sup> and “the notion of curator who did not see himself [sic] as an artist, but is crucially informed by everything artists, did” (p. 40).

Balzer maintains that with the coming of conceptual movements in the 1960s and 1970s, artists began to put their trust in curators as managers as a, “fresh or refreshed position” (p. 48) was necessitated to demystify their art. The custodianship position of a curator becomes superseded by connoisseurship. “Curators no longer tended ground, but secured, organized and landscaped it...The curator’s new position entailed duties of ringleader, translator, mediator, diplomat, gatekeeper” (p. 44). The curator shapes and ushers forth the avant-garde (Balzer, 2014, p. 48). Balzer notes that since the 1990s, there has been a rise in curated group shows around race and ethnicity<sup>99</sup>; these shows have been a “strong facet of the curationist moment and

---

<sup>97</sup> Under Roman law, curators were bureaucrats appointed to minors as they entered into contracts or advisors for those classified as *prodigus* or prodigal (i.e. proved to be squandering their estate or their inheritance) and as lunatics [sic]. Curators of the equestrian class also supervised outlying provinces” (p. 30) of the Roman empire.

<sup>98</sup> One example of an American curator is Alfred H. Barr who imported ideas from Europe, including the notion of the white cube, or exhibiting paintings symmetrically, in one neat, eye-level horizontal line, against walls covered in light beige monk’s cloth (Balzer, 2014, p. 41).

<sup>99</sup> I agree with Balzer that art shows about race and ethnicity have been a focus of curators’ projects. I would add Indigeneity and colonialism to that list. I had the opportunity to participate with my students in a project called *Walls and Barriers—A Collaborative Project*, at the Royal Ontario Museum (henceforth the ROM) (September 24 until October 25, 2010) presented in the Canada Court atrium of the ROM which was in response to the *El Anatsui: When I Last Wrote to You about Africa* from October 2, 2010 to January 2, 2011. This show was presented by the Institute for Contemporary Culture (ICC). The 40-year retrospective of visual artist El Anatsui’s work included large shimmering metal wall sculptures created from flattened, twisted salvaged liquor-bottle caps that had been

constitute attempts to court new demographics and add value to the institution as a progressive and accepting entity” (p. 77).

Although roles of a curator have altered over time, Balzer’s description of the curator as an “impartor of value” (p. 11) holds true through Western art exhibition history. Balzer states that, “Curation has close ties to capitalism and its cultures” (p. 11) and the absence in Balzer’s novella of the art of people with disabilities in museums and galleries once again reflects a subjugation of their knowledge (Foucault, 1980) or of their very existence.

We can tell by Balzer’s omission that the system is already defective, praising and maintaining the hegemonic discourses of neo-liberal institutions. A look at how contemporary curators who are well-versed in the discourses of critical disability studies is essential to try and respond to the question about moving away from dominant exhibition practices. As curator and critical disability studies activist Amanda Cachia states:

The art world has long remained a “normate” world, replicating society in a micro-cosmic fashion. The gallery is an arbiter that reproduces the hierarchy between those who are included and those who are excluded, on multiple levels. The reality is that very few art institutions are run by disabled gallery directors, employ disabled people who are curators, educators, or gallery assistants, let alone artists who may identify with an impairment. If those governing the art world don’t include disabled people, then it comes as no surprise that they should continue to maintain the invisibility of disabled subjects as fictionalized exemplars of Otherness, which is very carefully handled with a clinical efficiency in order to keep “them” at a distance from having authority or authorship. This “normalizing” work of institutions is reinforced by the gallery’s employment of the artist, who is selected to represent what the gallery considers to be the social realities of our time (pp. 112- 113).

Cachia maintains that this seemingly natural system has failed to be challenged. If a curator’s role of modeling the viewpoints of future generations is considered important in society, then we should look to curators who celebrate difference.

So how do we move outside of these discursive contemporary art practices? Disability theorist Alison Kafer (1998) states:

Our "subjugated knowledges" or "reverse discourses" operate as forms of resistance because they positively prove the existence of people, bodies and experiences not found

---

stitched together with copper wire. While these massive sculptures recall Ghanaian traditionally woven brightly coloured, hand-woven Kente cloths, they also represent the effects of colonialism in Ghana. My grade 12 Visual Art students selected socio-political topics to critically analyse which were of relevance to them. Together with students from art classes from 10 other public, Catholic and private schools in Toronto, their 10" x 10" visual panels were suspended together in a 6-foot-high wall for visitors to examine. Students had the opportunity to have their work critiqued by artist El Anatsui, have it on display and photographed for a show catalogue sold at the ROM.

within the histories and narratives created by dominant groups in society. Our lives challenge the naturalness and rightness of the dominant discourses and categories such as race, gender, sex and disability. Resistance, then, can be understood as a contestation of the ways in which discursive practices classify and identify bodies and as a rejection of the dominant interpretation of our bodies. To posit reverse discourses based on these experiences and knowledges is an exercise of power that can result in a profound shift in the way many people regard themselves and their place in society.

I turn to contemporary curators of the twenty first century who use their curatorial practices and their positions to try to get audiences to think more critically about the status quo and disability; they attempt to do what Kafer insists, “Resist”.

Katherine Ott, critical disability theorist, historian, senior museum scholar in the Division of Medicine and Science at the Smithsonian Institution’s National Museum of American History in Washington D.C is a curator who believes it is her duty to revamp institutional collections and scrutinise them from new perspectives, “making the invisible, visible” (Ott, 2019). At a lecture I attended at the Royal Ontario Museum in Toronto entitled, *When "No" Gets in the Way*<sup>100</sup> Ott stated, “Museums are purveyors of knowledge and have an immense, untapped power but that they have resisted change” (K. Ott Lecture, 27 September, 2019). In the online descriptor articulating her presentation Ott (2019) avers:

Visitors are pushing museums to reinterpret their holdings to reflect the complexity and diversity of culture, heritage, and the past; but power never gives way easily. The need to share authority, abandon tradition, and revise the narratives and regulations that only serve a narrow demographic are often bull-dozed by institutional fear. Questioning received wisdom [sic] and navigating the nay-sayers is slow, stressful, and potentially career-ending but also necessary.

Occupying the traditional role of a curator who focuses on objects and material practice, Ott explains, “Museums collect objects and memories [which] can reside in a *mythical place* also known as *objects*. Memories spill out in the presence of [these] objects because objects connect with us in a visceral way”. By finding, researching, analysing and arranging artifacts from the past, Ott shows how these objects have caused the Othering of individuals or groups of people by members of society at large. Ott questions how to create safe spaces where visitors can use their tacit knowledge (intuition, experience, shown by doing) to feel what they know, not formal or

---

<sup>100</sup> Katherine Ott was invited to speak at the University of Toronto Museum Studies Anniversary Keynote address at the MMST50 Unconference: The Rewards of Risk (Faculty of Information, 2019).

explicit knowledge. She asserts that objects can create this space naturally communicating her belief that, “tacit knowledge in what you know generates inclusion”. Ott has been working with several objects linked with disability/Otherness and is examining how these artifacts through material culture have actively shaped and defined disability. She sees disability as being relational according to culture and social phenomenon<sup>101</sup>. Since people with disabilities often need tools to accommodate them to overcome barriers (physical, sensory, neurological), disability is bound by technology, tools and machines to shift into new registers of social interaction.

In risk taking and reinterpreting their holdings, museum curators can reflect the complexity and diversity of culture, heritage, and the past<sup>102</sup>. “Dealing with diversity means dealing with conflict and the world tries to crush difference” (Ott, 2019). She maintains that curators need to, “undo the privilege and share authority and abandon tradition, and revise the narratives and regulations that only serve a narrow demographic are often bull-dozed by institutional fear” [caused by fixed, normative stances] (Ott’s Lecture, 2019). Ott says that her objective, “Is to disrupt the status quo through material, culture and objects or the ‘stuff’ that humans are surrounded by.” Katherine Ott’s curatorial methods subvert normative practices inviting a contesting of habitual, ableist practices by inviting disability-related content into the museum space.

Exhibition curators and disability theorist, Amanda Cachia, who identifies as physically disabled, explores various ways people with disabilities are either excluded or portrayed in gallery spaces. As a curator she tries to destabilize the gallery space and its relationship to the person with a disability. She has explored activist positions and aesthetics within specific disabled community groups with the intention of “transforming reductive interpretations of the

---

<sup>101</sup> During her lecture (2019), Ott discussed a few of the objects in a show about sexuality that she curated. The following object list describes Ott’s approach to curation with objects inside and outside of the collection: “Joystick. Velcro. TV remote. Straitjacket. Communication board. White cane. Sex toy. Thorazine. Wedding ring. Wheelchair. Curb cut. Cochlear implant”. Ott believes that the experience of disability, as is all human experience, is grounded in the human body and mediated through the environment. The environment is constituted of the culture-bound material culture of its era and includes architecture, assistive devices, media, clothing, food, technology, and all the other objects that surround us. Human relationships are established and mediated through these objects. Ott has used “both the artifacts owned and used by people with disabilities and those that are used upon them or that are encountered in life” (Ott, 2014).

<sup>102</sup> *Ways of Curating* (2014) well known curator Hans Ulrich Obrist writes, “At its most basic [curating] is simply about connecting cultures, bringing their elements into proximity with each other – the task of curating is to make junctions, to allow different elements to touch (p. I)

disabled body, and to introduce audiences to ‘disability aesthetics’<sup>103</sup> rooted in her curatorial practice (Cachia, 2016). In her 2011 show, *What Can a Body Do?*<sup>104</sup> Cachia (2014) explores disability as a critical theme because she believes that, “Traditionally, disability issues in the museum or gallery are limited to providing access. Many do so by offering programs for patrons who are blind, deaf, or use wheelchairs for mobility. But this preoccupation with access, though important, has ironically obscured the possibility of disability-related *content* within exhibitions and other curatorial practice”. Cachia underscores the importance of both accessibility and exhibition content. Access is embedded in both Cachia’s curatorial practice and mounting of shows. Cachia (2012) insists that:

Access involves more than checking off a list of practical accommodations. It is a way of thinking about the world that challenges us to imagine how another body, another self, experiences it... By hanging the work at variable heights and providing audio description from multiple perspectives, Cachia asks the viewer to pay attention to the conventions of how we display and describe works of art and how we move through a gallery or experience a performance. Access is treated not as an afterthought but as a creative process intrinsic both to art practice and curatorial practice (p. 3).

Critiquing conventional curatorial practice Cachia (2017) asks, “How, precisely, can perceptions of the disabled body be liberated from binary classifications such as "normal" versus "deviant" or "ability" versus "disability" that themselves delimit bodies and constrain action? What alternative frameworks can be employed by scholars, curators, and artists in order to determine a new fate for the often-stigmatized disabled identity?” Through her curated exhibits she tries to practically respond to these queries encouraging the viewer to consider, “What disability *does* rather than simply what it *is*. Such reframing breaks binary constructs as it is focused on a type of concretized being-in-the-world, on the truths of living *inside* a disabled body” (Lindgren, K. A., Cachia, A., & George, K., 2014).

---

<sup>103</sup> Disability aesthetics is a concept coined by Tobin Siebers (2010) who centred the presence of disability in canonical art history and contemporary art as he argues that nondisabled artists see aesthetic merits of disability in art (Pablo Picasso to Francis Bacon). Siebers studied, documented, and [plotted a] historical trajectory of where disability studies and contemporary art productively intersect (Cachia, 2016).

<sup>104</sup> Cachia’s exhibition title, *What Can the Body Do?* spawned the gallery exhibit. It was inspired a longer quote by Deleuze & Guattari (2004): “We know nothing, about a body until we know what it can do, in other words, what its affects are, how they can or cannot enter into composition with other affects, with the affects of another body, either to destroy that body or to be destroyed by it, either to exchange actions and passion with it or to join with it in composing a more powerful body” (p. 284).

I attended *The Flesh of the World* exhibit curated by Amanda Cachia mounted in 2015 in Toronto at the Justina M. Barnicke Gallery, University of Toronto and University of Toronto Art Centres. The exhibit was inspired by the 2015 XVII Pan American and Parapan American Games and the work of the philosopher of phenomenology, Maurice Merleau-Ponty. Cachia asked Canadian and international artists to use the body as medium in terms of corporeal performance and potential when it is engaged in competitive sports and games as well as the body's relationship to technology to "challenge dominant culture's understanding of normativity and embodiment" (Cachia, 2015). Although Cachia's (2014) belief in participatory art opens a space where artists with disabilities can create work based on a consistent theme or their relationship to disability—a form of crip art, not everyone wants to create crip art. Cachia reports that one artist, Ryan Gander resisted participation in the 2011 show, *What Can the Body Do?* At the end of her essay Cachia's notes indicate one artist's refusal to join the exhibit. She writes:

Indeed, well-known British artist Ryan Gander cited this [...]history as the reason he didn't want his work to appear in *What Can a Body Do?* In an email dated November 17, 2011, he stated, "Sorry I can't do this show, I strongly disagree with the grouping of artists with disabilities, but thanks for the invitation and good luck with it." Among subsequent email exchanges, on November 18, 2011, he wrote, "Your show... does group disabled people together, something in the history of the world, in all sorts and parts of society, humans have again and again fought to make sure isn't forced. I'm not a disabled artist, I'm an artist that happens to use a wheelchair, in the same way I use glasses, or a car or a cup."

Gander's refusal to participate in Cachia's thematic show about disability indicates that not all artists with disabilities want to identify with a disability or participate in crip art ventures. It is unlikely that all the artists of CVS would want to be in a show that included them because of their identification with an intellectual disability. At the end of this chapter, I will offer some alternative ideas for artists to exhibit their work outside of gallery setting or predetermined themes.

Cachia (2016) does not only engage those with visible physical disabilities, but also artists with intellectual disabilities. She questions the standard notions of "artists voices in museum and biographies imagining what art practices might sound like, feel like, and look like"(p. 122). She acknowledges that society perceives people with atypical cognitive abilities' knowledge as "arrested or stymied" but that they can engage in "modes of dialogical or socially

engaged art practices in ways that express their way of knowing and understanding the world” (p. 123). Cachia strives to rupture or challenge normative assumptions by questioning, “How can the museum incorporate the voice of the developmentally disabled artist? How can disabled [sic] artists have more of a ‘say’ in the production of collaborative exhibit work about them? (2014, p. 110)”

In their move from working with objects and a material practice to one that involves collaborating directly with people, curators might want to let go of their well-trodden practices in favour of an approach that is experimental, open, and questioning, where they lean as much as the participants. In this move from curators who work at arm’s length to curators who explore variations in voice, and other modes of communication embodied by the full spectrum of their participants, developmentally disabled artists will come to be defined more by their renewed presence than their absence, their activity rather than their passivity (2014, p. 125).

Cachia examines the *don'ts* and the *dos* of curatorial practice. The following description illustrates a *don't*. In response to a large-scale, *seemingly* [sic], (emphasis added), revolutionary show (Marcus, 2011 cited in Kuppers, 2012) entitled *CREATE* (2011) co-curated by Lawrence Rinder<sup>105</sup>, and Matthew Higgs. *CREATE* was mounted at the Berkeley Art Museum with numerous artists with CIDs from selected studios including: Creative Growth in Oakland, (CA), the National Institute for Arts and Disability (NAID) in Richmond (CA), and Creativity Explored in San Francisco, (CA). The artists’<sup>106</sup> artwork hung on the walls but the curators neglected to recognize the voices of the artists relying on the institutions’ staff, catalogue essays, and monovocal texts on didactic labels posted beside the works in the gallery space (Cachia, 2014, p. 115). Disability culture activist, a community artist, and professor of English, women's studies, theatre, dance, art and Design, Petra Kuppers (2012) shared that Rinder’s catalogue essay (2011) on disability and art relied on medicalized, labelling language without an “acknowledgment of the power that medicine holds over people who are easily and often institutionalized, sectioned,

---

<sup>105</sup> Rinder was director of the Berkeley Art Museum and Pacific Film Archives (BAMPF), California, and Matthew Higgs, director of White Columns, New York.

<sup>106</sup> The artists work mounted in the *CREATE* (2011) show included: Mary Belknap, Jeremy Burleson, Attilio Crescenti, Daniel Green, Willie Harris, Carl Hendrickson, Michael Bernard Loggins, Dwight Mackintosh, John Patrick McKenzie, James Miles, Dan Miller, James Montgomery, Marlon Mullen, Bertha Otoy, Aurie Ramirez, Evelyn Reyes, Lance Rivers, Judith Scott, William Scott, and William Tyler...The exhibit was displayed first by its host institution, the Berkeley Art Museum, before it traveled throughout 2012–2013 under the auspices of Independent Curators International (ICI). The exhibition included works on paper or canvas such as paintings, drawings and prints, and multiple sculptures (2014, p. 115).

sterilized, imprisoned and physically invaded with medication”<sup>107</sup>. The artists were not invited to communicate their viewpoints and they were invisible on the website, poster, and invitation to the opening (Sherwood and Rinder, 2011). The artists are juxtaposed with ‘normal’ mainstream artists as a means of validating their work implying that they could not be autonomously presented (Cachia, 2012). Koppers (2014) believes that, “This is a politics and an approach that is out of step with social justice movements of the 21st century and needs to be called out”. I bring this example forward as it is typical of curators who are fixed in their reductive approaches to exhibition and do not credit the artists with CIDs knowledge or art making abilities.

With the support of her team<sup>108</sup> of self-identified physically disabled artist-interviewers, professor and artist Katherine Sherwood “called out” *CREATE*’s curators by directing and producing a 26-minute video with several artists including Jeremy Burlison, Daniel Green, Willie Harris, Dan Miller, Bertha Otoyá, and Aurie Ramirez who all had work mounted in the *CREATE* show. Sherwood invited these artists to communicate about their artwork and their artistic processes. This series of interviews conducted by self-identifying disabled artists [sic] as a reaction against the lack of self-representation of the interviewed artists in the large-scale exhibition “might challenge the very nature of dialogue in and of itself” (Cachia, 2014, p. 113). The film was eventually screened adjacent to the *CREATE* (2011) show’s exhibition space and ushered in some of artists’ expressive input about their work and their art making into the gallery space.

Cachia encourages artists and curators in the art world to re-examine their definitions of “participatory” art and art exhibition arguing that non-standard bodies, non-normative voices and other non-verbal cues can empower and give people with disabilities increased agency (p. 113). If a show is centred on marginalized people then the, “marginalized subjectivity should be ‘voiced’ as a way of honoring their artistic discourses, and for accepting a myriad range of

---

<sup>107</sup> Katherine Sherwood (2011, June 11) challenges Lawrence Rinder’s *CREATE* (2011) catalogue essay writing, “Throughout the essay you conflate mental illness with developmental disabilities and thus flatten the whole enterprise. You explain that in the past the two terms were confused. You provide us with a legal definition of developmental disabilities but don’t further expand it to include the wide span of conditions it encompasses such as autism, down’s syndrome, deafness, etc. None of the *CREATE* artists would warrant being in a mental institution or claim mental illness as their disability. Larry, why set up the false comparison between them and the psychiatrically disabled (Sherwood & Rinder, 2011, June 11)?” Koppers (2012) points out that the curators could have handled the *CREATE* presentation with more sensitivity and consultation within the local California based disability community.

<sup>108</sup> View Neil Marcus, Leroy Moore, Sunaura Taylor and director Katherine Sherwood’s, *CREATE: The Artists Are Present* / Azin Seraj. Retrieved from <http://www.azinseraj.com/1302/artwork/collaboration/create-the-artists-are-present/>.

embodiments or expressions” (Kuppers 2012, cited in Cachia, 2014, pp. 115-116). Cachia applauds the use of video asserting that, “the very nature of artist/curator dialogue in museums is deepened and enriched by much more variegated forms of communication amongst those typically occupying the margins”<sup>109</sup> (p. 111). Using the film *CREATE: The Artist is Present* (2011), Cachia points out how artists may express themselves:

This might mean that the voice is atypical, embellished with stuttering or non-normative utterances that can be more challenging to hear for a normative ear. It may be non-verbal, and instead include body language, hand, foot, or eye gestures, or communicatory neologisms that don’t have established definitions, signifiers, or codes yet among normative speakers (p. 116).

It is with this review of the 21<sup>st</sup> century role of an inclusive artist-curator in mind, that I facilitated the creation of CVS artists’ statements that both involved their own choices of artwork typical of their styles, and written descriptions of their work through their oral accounts. These artists’ statements may be mounted alongside a display of their artwork.

Considering the discussion of language usage in art exhibition spaces and the vision of critical theorists-curators like Cachia and Ott, I created an idea for larger mixed-media artwork that employs text as its grounding (See Illustration 17: *Here to Stay*). These photographs mark points in the creative process that germinates from a single idea and grow into a finished artwork. From textual notation in sketchbook, a maquette was created. Text was transferred with glaze through a letter-stencil to slab-rolled, low-fire clay tile-like forms. Larger tiles will be mounted on a wall. An interactive Braille version modeled in clay will be fabricated and available as an interactive segment of the work can be touched by visually impaired viewers. An audio recording of a deep voice reciting the text “Embodiment; Em body ment; I’m body ment; I’m body meant; I am a body meant”. This definitive statement will be communicated by an ASL interpreter on a video loop projected on a screen that is viewer-activated by a motion sensor. The text is an affirmation that everyone, every artist has value and is a “body meant” to

---

<sup>109</sup> It was surprising how Sunaura Taylor herself a painter well versed in art language, did not more fully engage the artists with whom she interviewed. Usually a clear, boisterous, eloquent speaker, Taylor used minimal amount of vocal, art language to draw out the artists being interviewed who seemed to have much to communicate.

be validated and recognized for their contributions to the art exhibition sphere (See Illustration 17)<sup>110</sup>.

Large gallery spaces are not the only venues for displaying artwork. When two or more artists join, they can form a collective where several artists can unite forces to exhibit work in a myriad of places like public libraries, schools, colleges, universities, schools, restaurants or the like. Studios and



Illustration 17: Yarmol, C. (2016). *Here to Stay*. [Sketchbook Drawing with felt-tip marker, 8 ½" x 14", Sculpture, low-fire clay and glaze. 4" x 10" x 1/4"].

home studios can also act as venues for art display. Today these locations promote locally based artists offering numerous opportunities to exhibit. Canadian Artists Representation/Le front des artistes canadiens (CARFAC), an organization who is a representative for the voice of Canada's professional visual artists, has a list of larger artist-run centres and collectives in Ontario.

### Studio Habits of Mind

As I consider the classes taught at CVS and the artists who create there, the *Eight Studio Habits of Mind* become apparent. The *Eight Studio Habits of Mind* are part of a framework designed by educational practitioners at *Project Zero* in Harvard University's Graduate School of Education that describe the habits and the thinking teachers intend for their students to learn during the creation process. Note that these processes are not unique to the Visual Art domain but contain a language of critical thinking that expands across every discipline. The *Eight Studio Habits of Mind* listed in Hetland, Winner, et al's, (2007) book are to: 1. develop craft, 2. engage and persist, 3. envision, 4. express, 5. observe, 6. reflect, 7. stretch and explore, and 8. understand art worlds. Looking more closely at these habits we can see that they are formalized terminology describing what artists have done for centuries. Artists spontaneously move iteratively through these "steps" and practices organically. The artists with CIDs at CVS are no exception. Examples can be seen throughout the observations in this dissertation:

---

<sup>110</sup> The clay tiles use reorientation of text to urge the viewers to query their individual conceptions about the meaning of *embodiment* as it relates to disability. I considered Kuppert's and Cachia's challenging of preconceived notions of how a body "should look" or "should act" or "should be" in society. This sketch and maquette are a preliminary work of a projected larger, finished artwork.

1. Develop craft: Technique → Learning to use tools, materials, and artistic conventions and Studio Practice → Taking care of tools, materials, works, and space;
2. Engage and Persist: Finding personally meaningful projects and sticking to them;
3. Envision: Imagining new artworks and steps to bring them to life;
4. Express: Making works that convey personal meaning and interpreting meaning in the works of others;
5. Observe: Looking closely and noticing;
6. Reflect Question and Explain: Talking about students' work and working processes;
7. Evaluate: Talking about what works well, what does not, and why, in works by self and others;
8. Stretch and Explore: Playing, trying new things, making mistakes, and learning from them;
9. Understand Art Worlds: Domain → Learning about what artists make and Communities → Learning to collaborate and understanding that artists often work in groups (Adapted from *Studio Thinking from the Start: The K–8 Art Educator's Handbook* by Hogan, Hetland, Jacquith and Winner, 2018).<sup>111</sup>

Artists at CVS practice these skills on their own to create personal work<sup>112</sup>. Many CVS artists have been engaged in their own learning journeys and sometimes require supports or art facilitation.

---

<sup>111</sup> The original terminology developed by *Project Zero* is as follows: 1. Develop Craft: Learning to use tools, materials, artistic conventions: and learning to care for tools, materials and space; 2. Engage & Persist: Learning to embrace problems of relevance within the art world and/or personal importance, to develop focus conducive to working and persevering at tasks; 3. Envision: Learning to create works that convey an idea, a feeling, or a personal meaning; 4. Observe: Learning to attend to visual contexts more closely than ordinary “looking” requires, and thereby to see things that otherwise might not be seen; 5. Reflect: Learning to think and talk with others about an aspect of one's work or working process, and learning to judge one's own work and working process and the work of others; 7. Stretch and Explore: Learning to reach beyond one's capacities, to explore playfully without a preconceived plan, and to embrace the opportunity to learn from mistakes; and 8. Understand (Arts) Community: Learning to interact as an artist with other artists e.g. in classrooms, in local arts organizations, and across the art field and within the broader society (Hetland, Winner, et al, 2007).

<sup>112</sup> It is interesting to note that The *Eight Studio Habits of Mind* (Project Zero, 2003) are innately practiced by artists in art making contexts whether they formally expressed or not. The Ontario Ministry of Education (2010) has published a circular model similar to Project Zero's iteration in the Arts curriculum. It is called *The Creative Process* to be followed in a flexible, fluid, and cyclical manner: 1. Challenging and inspiring – responding to a creative challenge from the teacher or another student and using creative ideas inspired by a stimulus; 2. Imagining and generating – generating possible solutions to the creative challenge by using brainstorming, thumbnail sketches, choreographic sketches, musical sketches, mind mapping 3. Planning and focusing – creating a plan for an artwork by choosing ideas, determining and articulating a focus, and choosing an appropriate art form; 4. Exploring and experimenting – exploring a range of elements and techniques and making artistic choices for a work; 5. Producing preliminary work – producing a preliminary version of the work – sharing the preliminary work with peers and teacher, and seeking their opinions and responses; 6. Revising and refining – refining the initial work on the basis of their own reflection and others' feedback; 7. Presenting and performing – completing the artwork and presenting it to or performing it for an audience e.g., their peers, a teacher, the public; Reflecting and evaluating – reflecting on the degree of success of the work with reference to specific aspects that went well or that could be improved and

## What is Art Facilitation?

An understanding of the meaning of *art facilitation* or support is necessary when discussing art creation by people with disabilities. Art education and disabilities education specialist theorist Doris Guay's (2006) research expands and critiques concepts of "support" by paraprofessionals, paraeducators and support workers for artists with disabilities in art studio classrooms<sup>113</sup>. In one study Guay (2006) observed paraeducators creating student artists' art for them (p. 32), hiding or covered up, minimizing or suppressed difference (p. 31) rather than adapting or differentiating instruction to meet diverse student needs. To "have the work of students [artists] with disabilities look more like teacher models or peer efforts, paraeducators commonly imposed their aesthetic ideas or did the creative work for their assigned students. Choosing iconology and design directions, adding to or changing artwork, and even substituting their own work for student work-with or without student knowledge-was common" (p. 32). She frequently witnessed art students' own mark making attempts thrown away during cleanup (p. 32). Guay concluded that authoritarian, interactive patterns of paraprofessionals that dominated many of the visual art classes she researched, resulted in defining student-artists with disabilities, "as having few ideas or experiences, little or no knowledge or ability to solve problems and no opinions" (p. 38). Art facilitators should reflect upon the extent to which they may unwittingly disempower artists through their role as "expert", through the authority of their knowledge (Foucault, 1980).

Art education and disabilities education specialist Susan Loesl's (2006) conclusions concur with Guay's as she cautions art instructors to be conscious of the kinds of marks, images, and movements that artists with disabilities make independently as sometimes paraprofessionals, "well-meaning but generally untrained"<sup>114</sup> [sic], tended to diminish learning, marginalize, and disempower [artists] students" (p. 20). These assistants will sometimes place their own hands into the artwork under the guise of 'supporting the artist'. Loesl believes that this practice may

---

using the results of this reflection as a basis for starting another arts project with feedback from peers, teachers and self-reflection at the centre (Ontario Art Curriculum, 2010, p. 17).

<sup>113</sup> Paraeducator's role in classrooms in further explored in Christina Yarmol's (2013) *Listening to Voices of Exceptional Students to Inform Art Pedagogy* (Master's Thesis). Retrieved from Electronic Thesis and Dissertation Repository. <https://ir.lib.uwo.ca/etd/1371>

<sup>114</sup> Untrained here refers to support workers without schooling in Visual Arts or how to work support people with disabilities in a Visual Art context. Guay's (2003) interviews with paraeducators revealed that training outside of the classroom for their paraeducator/paraprofessional positions was minimal or nonexistent; they provide instruction, yet, they generally have little or no formal training or preparation for their instructional or other roles (p. 25). Paraprofessionals also may require training and mentorship to better service the artists they support (p. 192).

inadvertently communicate to the artist that he/she/they cannot create or fully engage in the task presented on their own. I refer to this process as “art sabotage”.

According to practicing artist and art facilitator Jan Swinburne (2005)<sup>115</sup>, the theory of art facilitation emerged from insufficiencies of both the educational and social systems to appropriately adapt to needs of artists with disabilities and the social models which disadvantage them. There is a clear distinction between educational, therapeutic, and art facilitation models: Formal art educational systems, “impart knowledge of historical, conceptual and technical models and prepare students for professional art practices” (p. 1). The goal of art therapy “is to address clinical outcomes of relieving distress, gaining psychological insights, controlling behaviour, and the like (p. 2) while art facilitation is “a supportive and pragmatic practice” intended to support “artists for whom the other two systems are inadequate in addressing their individual requirements when pursuing artistic endeavours and to create opportunities and alternatives for artists who face barriers in the mainstream arts and arts education communities” (p. 2). Art facilitation is the focus on individuals and their art making.

Swinburne underlines that there can be overlapping features of the various models, for example, art facilitation can inform technical and historical information present in the educational model and can offer therapeutic and social benefits (p. 2) but instructors need to be conscious that the emphasis should be on art production by the artists (with CIDs) themselves.

Creative Growth Centre in Oakland, California supports artists with CIDs and is staffed by local professional art teachers and artists who have all attended art schools. Director Tom di Maria says, “No one has a social-services background or a psychiatric background. This is an important part of our philosophy: Artists should work with artists” (Di Maria cited in Rich, 2015, p. 53). The art educators assist but are under orders never to guide or instruct, unless asked to do so by an artist. This practice underlines that active communication with the artists themselves to request their need for assistance with selected tools or the application of selected media to express colours, lines, shapes, textures, or the like is essential for effective art facilitation. The artist with CID should have the option to request or refuse the support at any point in the art making process. The art instructor or manager needs to emphasize to volunteers and

---

<sup>115</sup> Jan Swinburne created the cover for Carlson, L. (2009). *The Faces of Intellectual Disability: Philosophical Reflections*. Bloomington, Ind: University Press.

paraprofessionals who come to the studio that the artists should be left to explore, discover, make mistakes, tell their own stories with media and, in short, create by themselves rather than rush to complete the artwork to some fictional, external standard. The instructors, paraprofessionals and volunteers should facilitate or make art making easier for the artist with a CID so that cultural citizenship can be experienced.

The next chapter discusses the oral and artistic data collected for the *Right to Be an Artist* bringing together the process of art making and socializing at the CVS combined with social policy realities artists with CIDs face arriving at findings in the conclusion.

## Chapter Five: What? What Do Participants Say?



Illustration 18: Yarmol, C. (2020), *Fly on the Wall*. [Egg tempera on wood panel with faux silver leaf and size, 16" x 20"].

Illustration 19: Yarmol, C. (2020), *Fly on a Bench*. [Egg tempera on wood panel, 12½" x 8"].

I agree with a/r/tography theorist Rita Irwin’s claim that, “A/r/tographers understand that who they are is embedded in what they know and do” (2006, p. 2). I was keenly aware of my artist, art educator and researcher identities throughout the research process. As a researcher, I found it challenging not to constantly share knowledge deeply embedded within these identities with the study participants. Letting the art making process naturally unfold by refraining from offering advice or sharing commentary that might interfere with instructors’ art facilitation and artists’ production of their own ideas was of paramount importance at the outset of the observation sessions. A mantra resounded, “Be a fly on the wall Yarmol!” or “Be a fly on the bench!” Refer to Illustrations 18-19 for the visual representation. This phrase is what Irwin et al (2008) would term as a metaphor — to be still and to use my senses to actively attend to what was unfolding around me.

The fly’s anatomy helps to strengthen this metaphor: the fly’s compound eye made up of various lenses makes up most of its head affording the fly with accurate three-dimensional sight. The six legs each equipped with a tarsus, a pair of claws and a fleshy, adhesive glandular pad called a pulvillus assists the fly with walking across walls and ceilings suspending itself in various locales around the studio.

I communicated to the studio’s facilitator that I would share my reflections about the studio’s processes after the research data was analysed however, if an art researcher acts simply as a stiff observer who purposefully does not respond to the artists’ queries about their work, opportunities are denied and the resulting fieldnote data and observations become less rich.

I found that I was constantly balancing on a sort of teeter-totter thus I found myself moving toward the participant-observer role creating small landscapes in my sketchbook with the excess paint left on palettes at the end of sessions. My small, painted sketches drew the CVS artists’ interests as they wanted to see what I could produce (See Illustration 20). My interactions with participants, their artwork and artistic processes resulted in increased communication and caused the effect of validating me as an artist-participant. These resulting *impressions* are represented by pigment smudging left on the panel at the base of the fly’s pulvillus.

The choice of an ancient method of egg tempera is purposeful in that pigments are very thinly applied in transparent linear washes. The layering of the egg tempera is slow and methodical building up coats of paint to avoid crumbling and cracking. The utilization of this process was also reflective of a/r/tographic processes which “builds up knowledge” through lived experience like the way I carefully approached the data collection at the research site.

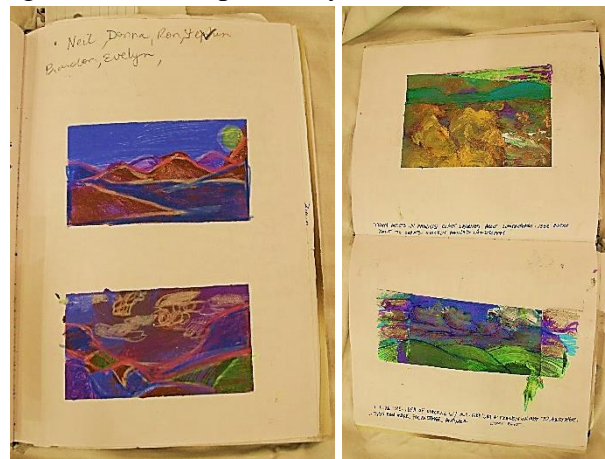


Illustration 20: Yarmol, C. (2019), *Participant-Observer Landscape*. (2019). [Acrylic paint, coloured pencil crayon on paper, 9" x 11"]. NOTE: Sketches like this one were created at CVS studio while observing the participants.

## **What?**

To remind the reader, this research examines the right to be an artist as a means of cultural citizenship and life enhancement for people over the age 21 years with CIDs in Ontario, giving a view into the workings of a small urban studio in Toronto that provides support for people with CIDs. Parents with children who have CIDs face great challenges as their children age out of the education system at age 21 years and find that there are not enough day programmes or work placements for them. This examination of everyday subjective conscious experience from individuals' perspectives strives to understand the importance of art practice in their lives and uncover what conditions are necessary to create positive art making experiences. As mentioned in the introduction, the key questions are:

How can we operationalize and support successful studio art practices for people with cognitive and intellectual disabilities to exercise their right to become artists and achieve an aspect of cultural citizenship?

How can we support people with CIDs in new contexts to enhance their lives as artists?

How can we commend or credit the knowledge visual artists with CID communicate with their artwork?

This study is reflective of the needs of the greater CID social sphere speaking to issues of value, ability, voice and identity as integral aspects of cultural citizenship.

## **How Creative Village Studio Began**

An interview with Creative Village Studio founder and facilitator Harold Tomlinson (Personal communication, November 25, 2019) revealed that the idea for CVS first started in late 1980s early 1990s when he, Karen Bell, and Charles Hackbath, while working in the Community Living Association communities, started using art as a way of teaching new skills and abilities in three different regions around the city. Harold said: "I did paintings, Charles did mosaics, and Karen did sculpture. There was no funding, so we became very creative obtaining donations or scavenging recycled materials from construction waste like tiles, plywood and 2" by 4" wood to build canvases." Harold would bring in gesso from home or purchase it from a hardware store. Due to the haphazard collection of materials he claims that there was some opposition from some people in the community (Lines 1-6). People kept saying, "You're not going to be able to do this! There is no way you can do this! [He shrugs both of his shoulders up and down quickly.] And once people say "no" to me, I make sure it gets done [Harold smiles and laughs.]" (Line 7)!

Harold said that he learned to work with individuals' strengths and needs "adapting tools for people with limited mobility using Lazy Susans,<sup>116</sup> or spatulas so that they could engage in painting and drawing" (Line 8). He also directed participants towards card making which was art on a smaller basis or on small to mid-size canvases which were easier to manipulate (Line 9). Working as a community service worker driving to different sites, Harold grew frustrated with watching people still in their pyjamas at 6 o'clock at night. Many group home residents did not know one another, were forced to live together and were constantly fighting (Lines 10-11); he saw a need to coordinate arts and crafts, painting, board game nights. The key by-product of this undertaking was that they learned social skills, getting along better through the building of relationships. Harold moved to a position as a vocational counsellor in the day programs; he and his colleagues noticed that when people exited from the day programs in the sheltered workshops within two weeks clients were back to the workshops because they felt as if they had lost their routine, supports and friends. They developed alternative art classes at SWACA so that the retired clients were 'engaged' but not formally working. Those who were not-yet-retired also started to become interested in the art classes and the classes grew (Lines 13-16, 32, 38). Harold knew that his own passion for art was shared by others in the SWACA community and the group started to receive attention from government officials (Line 18). According to reporter Leslie Ferenc (29 September 2009) some original participants in the program were Neil Clifford, Jeff Down, Patricia Habuda, Judy McLarnon, Quyen Ngo, Kirk Ross, Cara Scott, Evelyn van Duffelen, and Donna Worotyec. Their work was showcased at the Canadian Association for Community Living juried exhibit at the Ottawa School of Art, September 2008. Some of these artists are still making art at CVS today.

In 2009, The United Way hosted an opening at Dundas Square in downtown Toronto. Harold said, "I wanted to prove as well that they were 'legitimate' artists and that their work was deserving of hanging on people's walls" (Line 38). He continued, "Framing legitimizes a work. All of a sudden, you frame it and it gives the work a different stature" (Line 20). Harold took a

---

<sup>116</sup> "A rotating tray, generally circular, which is placed on the top center of a table in order to assist in moving food around to all the diners on all sides of the table" (Garden Furniture Blog, 27 September 2020). Retrieved from What's in a name? The origins of Lazy Susan - Lazy Susan. *Lazy Susan Garden Furniture Blog*. <https://www.lazysusanfurniture.co.uk/blog/garden-furniture/the-origins-of-lazy-susan/>

chance and used his own funds to frame the artwork (Line 44); all the work sold. He had kept the receipts knowing that the work would sell and that he would be reimbursed (Line 45).

At the beginning the organization would take 60 % of the profits to purchase materials and frames and the artists got 40% in their pockets but the general public, “told me [him] very quickly that they did not think that that was fair” so the percentage ended up as 50% of the profits to the house and 50% to the artists (Line 48). The artists were happy they got a cheque every time they sold an artwork.

Harold and members of Community Living Toronto submitted a grant application to the Ministry of Community and Social Services and the United Way and received \$100,000 (Line 58). After much searching for an accessible site in a community setting, a location was found in Islington Village (Lines 59-62), a short walk from Islington subway station in Toronto with access to two Toronto Transit Commission buses steps from the front door. Late in 2009, CVS studio opened (Community Living Toronto, Supporting Rights and Choices of People with Disabilities: Milestones a Snapshot, 2018). Harold communicates that today about 125 artists drop in and/or attend the studio on a weekly basis (H. Tomlinson, personal communication, October 16, 2019)

## The Studio Setting



Figure 4: *Creative Village Studio* (2019) exterior view location in the community, Retrieved from <https://www.google.com/maps>

The setting for the Creative Village Studio is a north-facing storefront on Dundas Street intersecting Burnhamthorpe Road in Islington Village. It is approximately a 10-minute walk from the Islington subway station at Islington Avenue and Bloor Street in the west end of



Figure 5: Yarmol, C. (2020). *Creative Village Studio interior view facing north*. [Digital photograph].

Toronto (See Figure 4). The facility includes moveable tables and chairs. One counter with a sink for hot beverage preparation as well as a small bar refrigerator for artists' perishable food and milk are located near the front of the studio. Nearby a multi-row card display is mounted holding the cards made by the artists of CVS. These are sold on a regular basis for \$5.00 a piece. Some small paintings rest on a shelf on top of this card display exhibiting finished paintings to the passersby. A round table is set up as a workspace near the front windows, one of which is a glass mechanic's garage door that can be elevated during the warmer summer days of the year. The open door encourages passers-by to investigate the studio space and its artists. Another counter with a sink and both upper and lower cabinets is nestled in the back of the studio which hold art supplies including, acrylic paint, palettes, paint brushes and water containers (See Figure 5 Creative Village Studio Interior view facing north). All other supplies are stored downstairs in clear plastic bins labelled for specific classes and brought upstairs for use. Several clear display cabinets, one at the front of the studio, and one at the back-right side hold sculptures made of yarn or plaster. Brightly coloured paintings completed by CVS artists dot the walls at regular intervals; new artworks are mounted quarterly or for special events. They are hung from a wire strip mounted on the wall and made available to the public for purchase. The gray tables and chairs can be collapsed as needed because the space is multipurpose, used for music and choir a few times a week as evidenced by the electric keyboard placed at one side of the studio. Painting mats are added to the tables

Toronto (See Figure 4). The facility includes moveable tables and chairs. One counter with a sink for hot beverage preparation as well as a small bar refrigerator for artists' perishable food and milk are located near the front of the studio. Nearby a multi-row card display is mounted holding the cards made by the artists of CVS. These are sold on a regular basis for \$5.00 a piece. Some small paintings rest on a shelf on top of this card display exhibiting finished paintings to the passersby. A round table is set up as a workspace near the front windows, one of which is a glass mechanic's garage door that can be elevated during the warmer summer days of the year. The open door encourages passers-by to investigate the studio space and its artists. Another counter with a sink and both upper and

before a class and aprons are provided for the artists. CVS offers a small class setting, one to five and up to one to ten teacher-to-student ratios with individualized instruction available through volunteers and students from local college social service training programs.

### **Data Collection**

As per Spector-Mersel's (2011) narrative framework, I asked a range of open-ended interview questions to begin the investigation (See Appendix T Interview Questions for Artist-Participants). The initial end points (EP) (Spector-Mersel, 2011, p. 174) of the narratives was to be able to operationalize studio practices to support artists with CIDs but often the EP altered throughout the retelling process resulting in interviews which focussed on how participants' days were spent, families, issues experienced, financial concerns and/or how art was important to them.

Although the interviews began with by guiding questions, over time they became more like conversations with the artists about their working process and their resulting artwork. The art making histories of artists who had been at CVS for many years unfolded as they referred to their past successes. Artists were excited to convey their artistic successes, but everyone could not fully impart them due to memory loss or communication difficulties; a resounding, "ask Harold about that" often emerged thus additional questions were posed of facilitator Harold Tomlinson on an ad hoc basis. Harold was instrumental in filling the historical gaps to grasp interviewed artists' triumphs.

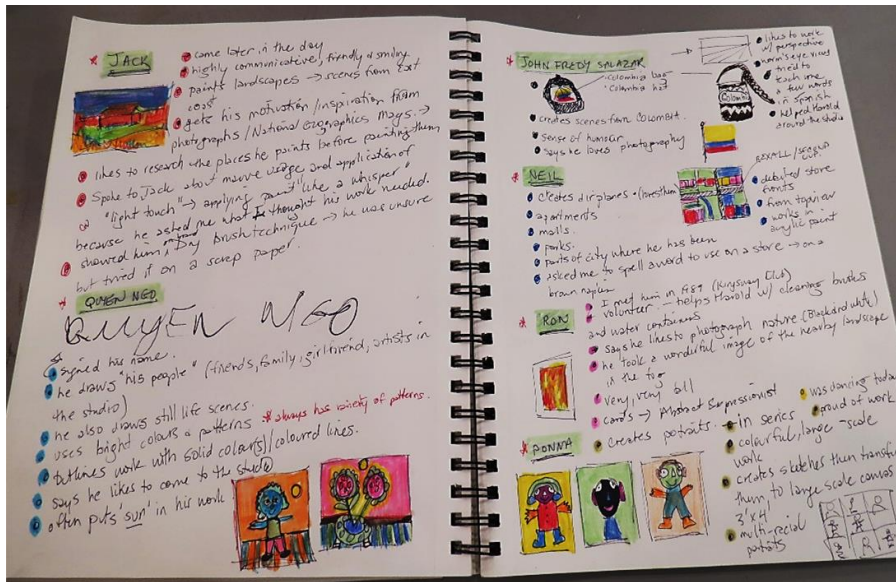


Illustration 21: Yarmol, C. (2019). *Meeting the Artists*. [Drawing with pen, coloured pencil crayon & aquarelle crayon), 8 ½" x 14"].

Both pre and post interviews the artists continually shared details about their artwork as I observed their art creation processes in the studio. Excited Quyen points to his artwork, “Look at this background behind people!” [He points to thickly applied green paint spotting the background with two figures in the foreground.] (Q. Ngo,

Fieldnote, October 3, 2019). The recording of frequent exchanges with artist-participants in my sketchbook became instrumental in enriching cumulative data and its analysis (See Illustration 21 *Meeting the Artists*). Interviews hold a wealth of information about the artists who create at CVS; the results offer an insight into how people with CIDs think, create and feel about art making. A description of the themes embedded in the narratives coupled with fieldnotes/sketches/artwork collected over the course of an eight-month period craft the overarching themes of artists interviewed at CVS. *Specific Findings CVS Artists* section describes how more specific themes emerge outlining how the number of years and time spent enrolled in the studio at CVS have influenced artists’ confidence levels and style of artwork. View Appendix A: *Tiled Images of Book Covers, Their Endpapers & Book’s Contents* and Appendix C: *Sample Book Pages with Quotes & Artists’ Statements* for glimpse of the artist’s work and artist’s statements compiled during the data collection process.

The duration of the interviews with artists was 9 to 25 minutes depending upon the answers to the questions. Out of sixteen artists working at CVS, eight identified as male and eight as female. Four artists from the program’s inception 11 years ago still create art in studio either daily or multiple times a week. Six participants have been coming to the studio for six to nine years attending one or more programs a week. Five participants have been coming for three

to five years and participate in one or more one or more programs weekly along with other programs offered out in the community including, part time work, volunteering, sports, SWACA (Supported Work & Community Activities), cooking, dance, theatre or social groups. The youngest participant has been coming for almost two years. At the time of the study, she participated in three classes weekly.

Communicating the on-the-ground, tactile and visceral quality of the artwork produced in the studio is a monumental task in a written dissertation, thus, I have included images of the participants' artwork interspersed in the text to help the reader understand their viewpoints and the rationale behind the findings. Given Glaser's theory of connectedness through artwork that is, "...A reader might not understand connections immediately because they are not overt. However, connections are made by that part of the mind that is susceptible to ambiguity, to imagery that is not literal" (2008, p. 13). The reader can make connections by examining the imagery presented.

To underline the studio-based nature of this project, I have collaborated with CVS artist colourist Evelyn van Duffelen (Figure 6) to create 23 small scale, gesture line vignette portraits of each of the study's participants. Critical theorist and art curator Amanda Cachia (2014) states that inclusive art should, "include disabled [sic] participants in the role of agent, maker, leader, or even active speaker" (p. 111). In this project Evelyn, an active maker of the portraits, contributed her skill as a colourist; there is a marked difference between coloured portraits and uncoloured (Compare Figure 6 with uncoloured Figure 66). Inclusive arts researchers in the UK, Alice Fox and Hannah Macpherson (2015) define *inclusive arts* as a term that presupposes exclusion but, in our world, it must be thus named as today, artists with CIDs are often excluded from everyday forms of arts practice and inclusive arts "engages with the productivity of difference and the challenges of communication" (p. 2). Inclusive arts, "is collaborative processes [that is] intended to support a mutually beneficial two-way creative exchange that enables all the artists involved to learn (and unlearn) from each other" considering the creative contribution that each participant can make (p. 7). It explores the valuable and skilful contribution that learning-disabled artists (artists with CIDs) can bring to the arts and be celebrated. This aesthetic of exchange places the non-disabled artist in the more radical role of collaborator and proposes a shift away from the traditional notion of "worthy helper" (p. 2) placing "greater emphasis on collaboration, communication, exchange, relationships and the

creative talent of collaborators” (p. 7). The emphasis in inclusive arts is on the entire humanity of the producers of work (not just their differences), and on the potential of collaboration and creative exchange with people from diverse backgrounds as well as with the critical contemporary art world (p. 11). Cait Mitchell, social activist and one of the former CVS instructors concurs with the notions inclusive art’s purpose by asserting that, “Collective creation challenges assumptions, builds bridges, strengthens relationships, and can help identify priorities and assist with finding new possibilities and opportunities for growth” (Mitchell, n.d.).

Working collaboratively with Evelyn afforded me the opportunity of how I could learn from a CVS artist. I drew quick, black and white portraits of each participant at the studio or shortly after my visits there. These drawn portraits were then given to Evelyn who breathed life into them through her choice of dynamic, bright, energetic colours and solid application of her



Figure 6: van Duffelen, E. and Yarmol, C. (2019), *Evelyn on Different Days*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

preferred medium of pencil crayon. I appreciate Evelyn's devotion to and application of her favoured medium. I asked her to teach me how she applied the pencil crayon and attempted her technique finding that I could only last a short while pressing as firmly yet as gently as Evelyn does on the paper's surface. When I was not at the studio, Harold said that Evelyn would ask if I had left any more drawings for her to complete. Extra copies were even made for Evelyn to work on at the studio or at home at her leisure. I respected her dedication to the project completion.

This chapter of the dissertation is punctuated with the artwork resulting from the collaborative project between two artists, van Duffelen and Yarmol alongside the narrative accounts of the study's participants. The larger versions of the portraits coupled with poignant statements from each individual artist's interview are exhibited in *Coffee Talk*, a series of *Elbums* or special type of handmade book I created (See Appendices A-C). These portraits with artists' statements and a collection of photographs I took of the artists' artworks will also be published on the Creative Village Studio's website ([www.creativevillagestudio.ca](http://www.creativevillagestudio.ca)). The artists' imagery is paired with brief statements written in cooperation with the artists themselves. Video stills and images of the artists' artwork also populate the text to help make it more relatable to the reader facilitating the reader's understanding of the artists' works and the findings presented.

In discussing the redaction of text from interviews with people with CIDs, inclusive arts researchers Fox and Hannah Macpherson (2015) state, "We have had to confront the tension between conventions of textual representation and retaining the unique voice and speech patterns of learning-disabled (CID) artists [sic]" as sometimes people with disabilities' "explanations challenge what is conventionally understood to constitute a narrative" (p. 28). In editing of the transcripts presented, the textual representation that embodies the distinctive voices and speech patterns of each artist interviewed have been selected. Extracts were edited for the clarity of message and sense of what the artist was expressing. By weaving snippets of the artists' conversations throughout the text, the intention is to honour the participants' knowledge and narrative insights.

References to support personnel figured prominently in the discourse of the artist-participants necessitating the interviews of three volunteers, three instructors<sup>117</sup>, the facilitator of

---

<sup>117</sup> Note that Shannon Groom is both an instructor at CVS and a parent of a child with a CID.

the program and three parents for their perspectives of the CVS programs. These interviews helped me to gain a more complete outlook of how CVS functions. These interviews occurred over several months and their duration ranged from 15 to 55 minutes.

**General findings for all CVS artists.**

After an analysis using Gabriela Spector-Mersel's narrative inquiry methods, the following overarching findings or as a/r/tography denotes 'new learnings' emerge for all participants: all participants consider themselves to be artists; all demonstrate extreme pride in showing their artwork; and all have limited knowledge of financial issues.

***Consider themselves to be artists.***

All the participants in this study see themselves as artists. Sometimes this is simply because they create artwork on a daily or weekly basis at Creative Village Studio. At other times it is because their work has been exhibited and sold to the public. Several of the artists continue their art practice at home and readily share accounts what they create.

Emily Parsonson (Figure 7) discusses other classes<sup>118</sup> she attends weekly (E. Parsonson, personal communication, November 17, 2019). She begins by talking about her cooking class but ends up taking about her view of herself as an artist, "I kind of like appreciate her [the instructor's] cooking class. It amazes me how I see myself as an artist and now I am. [She puts her right hand to her heart.] I am getting more and more creative everyday (Line 46)!"

Early in her interview Emily proudly holds up a card she created in her card making class (Figure 1 Image in Table and Figure 8).

Emily: ... And recently I did a church bizarre (Line 6).  
Christina: Okay (Line 7).



Figure 7: van Duffelen, E. and Yarmol, C. (2019), *Emily in Blue*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

---

<sup>118</sup> Currently Emily has an extremely active life: Cardmaking on Mondays at CVS, cooking class on Tuesdays on Advance Road, working at Winners on Wednesdays, volunteer work at the ice cream social Westburn Manor on Thursdays, Baby Club at LAMP (in a parent and toddler class) on Fridays and Sundays swimming with the Etobicoke Sharks with the Special Olympics. She also creates artwork at home.

Emily: Eleven out of sixteen cards...Christmas cards, my cards sold! I'm finished selling that. [Emily smiles widely.] ... This is the other canvas [Emily draws my attention to a canvas with two jellyfish painted on it.] (Line 8).

Christina: I am going to point the camera to your art (Line 9).

Emily: I did that with my company and my exposure will be amazing to get not only this going but a couple other stuff...That I am going to do as well [Pause.] (Line 10).

Christina: What is the name of your company Emily (Line 11)?

Emily: Emily Productions.

Christina: Emily's Productions (Line 13).

Emily: *Emily Parsonson's Productions* [She speaks more slowly emphasizing each word.] (Line 14).

Christina: Good (Line 15)!

Emily: Sorry, I got the name goofy there (Line 16).

The tag line on Emily's business cards and advertising merchandise is: "Emily Parsonson Productions: Artist and Imagineer". Laura Parsonson, Emily's mother who I also interviewed told me that Emily is not an engineer but has a wonderful imagination and so Laura fabricated the word *imagineer* to blend the ideas of *imagination* and *engineer* (Field note, June 28, 2019).

Her mother's understanding of the value Emily puts on her art practice helped Emily to feel confident in her work enabling Emily to confidently sell her artwork in a solo show. Laura created a memorabilia book for Emily entitled, *Emily Spring Collection*, May 7, 2016 to capture the opening night event in photographs for Emily. See the cover of the book in Figure 9.

As Emily shared in her interview, her mother helps her to organize the sale of the cards at craft shows and bazaars. The profits earned are donated to charities. According to Laura, Emily sees herself as a philanthropist, "She doesn't know how to say this word very well, but she knows she is one!" (Laura Parsonson, personal communication, November 17, 2019, Line 32). Laura shares that Emily decided she wanted to donate the profits generated from her art show to The Hospital for Sick Children where Emily spent a lot of time in



Figure 8:  
*Interview with Emily Parsonson.*  
[Video Still of Emily Parsonson with acrylic on paper cardstock from card making, CVS class, 5" x 7"].

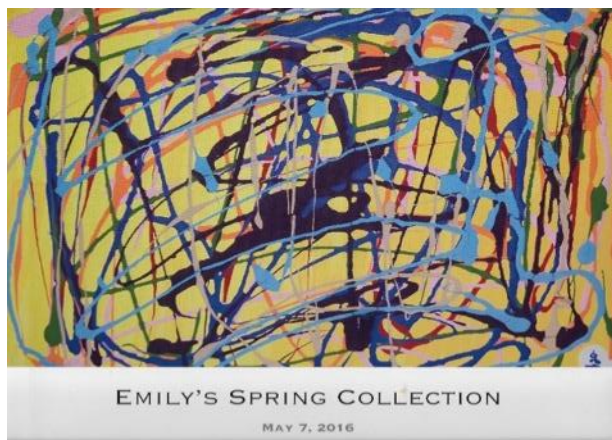


Figure 9: Parsonson, E. *Emily's Spring Collection May 7, 2016 book cover memorabilia book compiled for Emily's show*. [Ink on Paper, 8 ½" x 11"].

her childhood and youth (Line 28). Laura, an advocate of the studio program at CVS, had other ideas, "I wanted to give the money to Community Living which was my charity of choice and she would not be talked out of giving the money to where she wants it to go, so in an effort to value her opinion and respect her I had to acquiesce and I didn't like it [Laura starts to laugh and makes a gesture of crossing her hands across her chest.]. I totally understood that it was necessary (Line 32)." Emily considers herself as an artist and

acknowledges that CVS started her artistic journey.



Figure 10: van Duffelen, E. and Yarmol, C. (2019), *Juan Menezes*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

Juan Menezes (Figure 10) considers himself an artist and continues his creative process outside CVS studio (J. Menezes, personal communication, September 23, 2019). He says that he often uses his sketchbook as a place to draw out plans for his new ideas. Throughout history artists have employed sketchbooks so using one becomes the mark of an artist. Sketchbooks, considered, "the timeless friend of the artist" (Camhy, 2016), have been crucial to the careers of innumerable artists through history as they are the first point of departure for visual idea generation. Juan also photographs scenes using his cell phone camera to aid in decisions about colour palette and placement of shapes for composition of his subject matter.

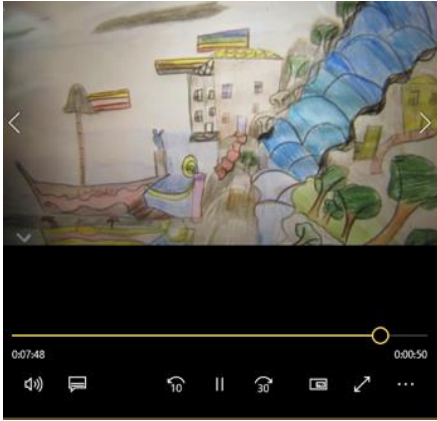


Figure 11: Meneses, J. *Menezes Video Still*. (September 23, 2019). [Video Still of a sketch Juan created at home for a painting captured on his cell phone].

Using photography, he documents his sketches so that he can work on his paintings when he arrives at the studio. For example, during his interview, Juan showed me a series of sketches about sea travel through history first drawn in his sketchbook and recorded on his cell phone (Figure 11). He says he uses his sketchbook as a way of thinking about his art. Intent on showing me his creative process, Juan brought his sketchbook the week following the interview to show me the sea voyage series he was planning to complete with acrylic paint.

***Communicate a sense of pride in their work.***

All artists interviewed demonstrate a willingness to readily share their art process or their subject matter demonstrating a sense of extreme pride in what they have

created. This desire to communicate their excitement about their work was also experienced outside of the confines of the interview in daily interaction in the studio.

Sabrina, (Figure 12) one of the newer artists at CVS, considers herself an artist. Not only was Sabrina glad to share the work she had created from both her drawing and her mixed media classes on the day of the interview, but several weeks after the initial interview was completed, (S. Simonyi, personal communication, October 12, 2010) she brought a collection of images that she had at home. She showed me some photographs of paintings that she had already sold (Figure 13). When asked to explain the painting she was working on that day *Walter Matthau as a Saint Bernard*. Sabrina explains:

Well, well...Walter Matthau is a Saint Bernard because when I went to work, it, that d- -that Saint Bernard is just like him [Sabrina moves her left hand expressively as she speaks. She points backward with her thumb on her left hand.]. I start... I started to work on my book



Figure 12: van Duffelen, E. and Yarmol, C. (2019), *Sabrina*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

about him [Besides her slight hand gestures toward her work. Sabrina is still rocking as she tells the story of the subject matter of her painting.] (Line 36). I made this because I love... [Sabrina stops thinking carefully about the words she chooses.] into him... [She speaks slowly.]. I'm interested in him (Line 46) [She corrects herself.]. And his acting, his ummm, like work and his ummm... comedy (Line 48).

Sabrina is always willing to show her work to interested parties. She is readily able to communicate her process and sports a broad smile after she has finished her explanation.



Figure 13: Simonyi, S. (2018) Sabrina with artwork from an art show and close-up of painting sold, *Frida Kahlo with Pet*. [Digital photograph].

In the interview with Sabrina's mother Anna (A. Simonyi, personal communication, October 12, 2019), Anna mentions that Sabrina has always enjoyed art but that in high school, "...her art was just something that people could let her do when she was finished doing everything else..." (Line 29). Sabrina writes and creates drawings and has drawn so many books at home that, "if you stacked the pile up off the floor it would come up about two feet [Anna held up her measuring about two and half feet from the floor.] (Line 30)!" Her time at CVS has definitively convinced Sabrina that she is an artist and she continues to build her repertoire of techniques she assiduously creates as a matter of course.

Johnfredy (Figure 14) (J. Salazar, September 19, 2019) is extremely proud of his photography that often sells to the public. The following excerpt from the interview with Johnfredy offers an example of an artist's self-satisfaction with his photographic artwork:

Christina: So, where did you take this picture of the wall (Line 42)?

Johnfredy: In Etobicoke (Line 43).

Christina: In Etobicoke (Line 44)?



Figure 14: van Duffelen, E. and Yarmol, C. (2019), *Johnfredy*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

Johnfredy: Right here [He jumps up and gestures to the right towards the door.] (Line 45)!

Christina: It was taken right over here just down the street? Wow, it has a wonderful sense of perspective. Nice, okay (Line 46).

Johnfredy: From here to over here---[Johnfredy proudly gestures to the photograph (Figure 15).] (Line 47).

Christina: Tell me that again please (Line 48).

Johnfredy: From here to here its 3D (Points in succession to both ends of the picture plane.) (Line 49).

Christina: Its 3D. Yeah it looks 3D; it looks like you could walk right in there (Line 50).

Johnfredy: Yeah (He answers smiling.) (Line 51).

Christina: So how do you get the ideas for these artworks (Line 53)?

Johnfredy: My idea (Line 53) [Johnfredy says enthusiastically pointing the fingers on his right hand at his chest and then at his head.]!

Johnfredy has been attending the photography class for

many years at CVS and has sold several enlarged photographic works. Whenever I come into the studio, he motions for me to come to where he is working so that he can show me his latest artwork.

#### ***Limited knowledge of financial issues.***

All the participants had little knowledge of financial issues regarding how they paid for the program, the cost of art materials or the economics of selling artwork. They either silenced or flattened the answer to the question



Figure 15: Interview with Johnfredy Salazar, Interview September 19, 2019, 3:06, *The Wall in Islington Village*. [Video Still containing digital print 18" x 24"].

with, “go ask Harold...my worker helps me...my mother/sister helps me...I don’t know”

responses. For example, Steve (Figure 16) asserts:

Umm I'm not into the money part you'll have to speak to Harold... (Line 81). I don't know the money part. I'm only here for the art. The money part is done through Harold so I can't talk about his finances (S. Nicholson, personal communication, September 19, 2019, Line 83).

This declaration indicates his discomfort with financial issues. The response is like other artist-participants' responses when presented with financial queries. Like many of his colleagues at CVS, Steve works with an individual who supports him in determining the funding of the activities in his weekly programming. He knows that when his work is sold, he receives a cheque that he deposits in the bank (S. Nicholson, Field note, September 24, 2018).

The participants who were interviewed have a variety of ways of paying for their studio time at CVS. At the time of the study, a total of five participants who were interviewed had access to *Passport Program* funding and had a vague notion about it but required support from a parent or a case worker to actuate and to upkeep the funding. Tasks such as fund dispersal to programs upon enrolment, careful recording of funds dispersed, receipt retainment, and receipt of cheques from the MCSS are all skills in order to maintain the *Passport Program* funding. All actions must be completed in a timely fashion or the designated funding will be retracted for that client. A few study participants know definitively that they are in line to receive *Passport* funding but are simply waiting tirelessly in financial purgatory; some may have given up waiting for it while others do not even know what *Passport Program* funding is or how it works.

The following interviews with Astra (A. Milberg, personal communication, September 19, 2019, Lines 91-95) (Figure 17) and Betsy (B. Pattinson, personal communication, September 19, 2019, Lines 56-58) demonstrate their understanding of the *Passport Program*:



Figure 16: van Duffelen, E. and Yarmol, C. (2019), *Steve*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].



Figure 17: van Duffelen, E. and Yarmol, C. (2019), *Astra*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

Christina: How do you pay for this program (Line 91)?

Astra: By cheque (Line 92).

Christina: So, are the funds through the *Passport Program* (Line 93)?

Astra: I don't think so. It would be nice to have a *Passport* [She giggles.] (Line 94).

Christina: There is some special money through *Passport Initiative* a kind of government funding. Some people have it and some people don't (Line 95).

Astra: I don't know (Line 96).

Betsy has an awareness of *Passport Program* funding because her roommate is a recipient, but she is still waiting to receive it:

Betsy: My worker helps me pay for it (Line 54).

Christina: So, they figure it out you don't have to bring any cheques or anything? (Line 55)

Betsy: Yeah. Well I did this year [She sighs.]. Sooner or later I'll have a *Passport* they've been talk' in about it (Line 56).

Christina: A passport for travelling (Line 57)?

Betsy: No! A *Passport* for paying [Betsy emphasizes the word paying and then furrows her eyebrows annoyed that I suggested that I mentioned a passport meant for travel in lieu of the funding initiative.] (Line 58)!

When I asked Johnfredy about how he pays for the studio program, he simply shrugs his shoulders making a 'no' gesture with his head and throws his hands in the air (J. Salazar, personal communication, September 19, 2019, Line 77).

Jack gets support from his family. He states, "I think that my step-mother pays... [Pause for 3 seconds starring at the table thinking.]. I think Susan pays (J. Homer, personal communication, September 19, 2019, Line 95).

Even though the intricacies of studio and class participation costs are not fully understood by the artists, there is a general understanding that materials to make art cost money. Most of this study's artists comprehend that a portion of the proceeds received from the sale of their art goes back to the studio to pay for studio supplies<sup>119</sup>. They also know that they will be

---

<sup>119</sup> Art organizations like The Toronto Arts Council (TAC) and the Ontario Art Council (OAC) have numerous grants to help support artists with understanding budgeting and money matters. For example, TAC has applications to apply for additional TAC funds to help cover accessibility costs for projects involving Deaf artists and artists with disabilities. Artists must "complete the Accessibility Expenses section of the application and including the requisite information in their budget. TAC Accessibility grants are available in applications to TAC Arts Discipline and Strategic project programs, including programs for individual artists" (*Frequently Asked Questions—Toronto Arts Council*, 2020). Retrieved from <https://torontoartscouncil.org/grant-programs/tips-and-resources/frequently-asked-questions#BUDGET%20AND%20MONEY%20MATTERS>

compensated if their work is sold. Steve Nicholson, (Personal communication, September 19, 2019, Line 10) shares:

I did photography (class) a long time ago and the photography, the photography that I took was a picture of a guy walking into the fog and everyone liked the picture so they turned around and bought it [Steve's voice rises at the end of the phrase.]! The image sold! I got some money. That was several years ago (Line 12)...And it was over near where, not too far from where I live... And it was over ...I think you've heard of the place, at Colborne Lodge Drive (Line 14) [Steve likes to be exact about the location and points in the direction of Colborne Lodge.]

Steve adds, "It also costs money to buy the things to get that... [He points to his canvas on the table.] and Harold usually gets these canvases and supplies at different locations where he goes" (Line 89).

Conrod (Figure 18) affirms:

Harold cuts me a cheque. And we get 50% of the cut for some reason. To send him away on vacation and to get his face fixed. [He says with a broad smile on his face, joking.] Joking! I don't know why they go to 50%. I don't know why they go 50% back to the place. Wait, I think I know why. I know, so they can buy more supplies (Interview with Conrod, 2019 October 3, 2019, Line, 166).

This prolific producer of artwork was able to purchase a bicycle (Figure 19) with profits from his art sales that enables him to be travel independently. He also purchases technological gadgets he brings to the studio like a microphone, speakers and a telephone that he shares with others at the studio. He is extremely proud of the fact that the public buys his paintings. Conrod also relies on other means of money collection: "I'm a DJ, I do house painting. I did a plain wall at my sister's house [He mimes



Figure 18: van Duffelen, E. and Yarmol, C. (2019), *Conrod*. [Felt tip marker and pencil crayon on cartridge paper, 8 1/2" x 11"].



Figure 19: Yarmol, C. *Conrod on Dundas Street Showing Me His New Wheels*, (October 3, 2019). [Digital Photograph].

holding a paintbrush and moving his wrist holding a ‘brush’ up and down.] (Line 190) ... And my neighbor's house. Right (192)... I also go around and collect beer bottles and bottles and scrap metal in my spare time...And go into the sides you know the beer store (Line 196)?

Quyen is not sure how he pays for the program, however, he has an awareness of financial compensation he collects for his artwork. He has sold many paintings since he arrived at CVS 10 years ago. He works steadily on his paintings hoping that he can sell them. He is keenly aware of the concept of money for his artwork, “I need more money (Q. Ngo, personal communication, October 23, 2019, Line 208) ...I have no money” (Line 212).

When asked how the art classes could be improved, Astra Milberg (Personal communication, September 19, 2019) says she has nothing to offer about how the painting classes are taught but really wants to sell her work:

Astra: I don't know.... but it is about the selling. I want him (She points at Harold, the CVS facilitator) to sell my work (Line 100)!

Christina: Okay (Line 101).

Astra: If I am able to paint like Leonardo da Vinci, maybe my paintings would be sold. But I can't do that [Astra shrugs her shoulders and laughs.] (Line 102)!

Christina: Well you may get there with your own style. You never know (Line 103).

Astra: Hmm [She raises her eyebrows, sighs, and looks at the floor] (Line 104).

Christina: You have to be patient. So, you would like to sell your work (Line 105)?

Astra: Oh yes (Line 106)!

Christina: So, you would like to sell paintings, that's how CVS could be improved (Line 107) ?

Astra: I don't know if they'd... probably if they could be sold [She peers closely at her dove and olive leaf painting.]. I don't know if I could sell the paintings, maybe I could put my name on top and maybe if I had a showcase at the volunteer di...dinner (Line 108).

Christina: That is an idea. Mount your artwork in a showcase to put it on display (Line 109).

Astra: So maybe they would take my picture with the paintings. So, they could just take my picture with the paintings then I'd have the picture and the painting (Line 110).

Christina: Maybe with the cards ---if you join cardmaking class (Line 111).

Astra: [Astra nods her head slowly in agreement and stops to think.] (Line 112).

Astra: It's just nice to... get money back... from all the work [She makes a sweeping hand gesture first towards her artwork on the table and then to points both hands towards herself.] (Line 113).



Figure 20: Milberg, A. (2018), *Be Kind & Truthful in Your Life*. [Two scrapbook pages, glue, magazine, ink, crayon, and felt tip marker on cartridge paper, 17" x 22"].

Astra is quite in tune with her social milieu; she sees many of the artists around her selling their work and wants to do the same. Later in the interview she communicates that her place is “covered in paintings” (Line 62). She wants to earn money for all the time she spends at the studio. This said, Astra’s favourite work is her scrapbooking pieces (Figure 20) which relate to her personal life; she brought these exuberant scrapbooks into the studio for me to see.

Participants are unsure of the economics behind their art classes or studio time but have a keen awareness that they get paid when their artwork is sold, a desirable end for the fruits of their labour. These funds give them independent purchasing power to buy what they want or require.

#### **Findings for specific CVS artists.**

The specific themes that emerge through the study’s findings for groups of artists at CVS are as follows: frequency and duration of participation affects confidence and individualized art production; time at studio equals increased level of confidence; development of style and preferred subject matter become more clearly defined.

#### ***Frequency and duration of participation.***

Participants were asked several straight-forward questions about the general nature of the programs they attended in their lives; their program selection and frequency of attendance at CVS specifically; how they pay for these programs and, the estimated distance they travel from their homes to the studio location. Their neighbourhoods were ascertained by transportation taken to arrive at the studio and amount of travel time required to arrive. Their answers were verified by the registrar-art facilitator.

There are three camps of artists at CVS: those artists who come in on a daily basis for an extended number of hours; those artists who come in for multiple classes at many points during the week and, those who come in for a single class as part of their habitual assortment of weekly programming. I concluded that the frequency and duration of attendance in the studio’s programs directly affects artists’ confidence and art making with reference to the choice of

subject matter and application of personal style. I have provided examples from their interviews, observations from transcribed field notes and samples of their work in the studio to support this claim. The findings below are shown in number of years participants have been coming to CVS: 6 to 10 Years, 3 to 5 years and 1 to 2 years to envisage possible trends. Note that there are outliers due to life circumstances, personal goals, skill level, personality and level of family involvement.

*CVS artists for 6 to 10 years.*

For 10 participants who have been at CVS for 6 to 10 years, four come to the studio daily Donna, Neil, Conrod, and Evelyn; five participants —Steve, Lisa, Patricia, Quyen, and Jack come 3 times a week and Emily comes once a week. The four artists who come in daily seem to view the studio as their workplace. They come in have their hot beverage and tend to get right to their artwork. Due to their frequent attendance, their artistic output is generally greater than their artist-colleagues. They demonstrate confidence and assuredness in their artistic ability, beginning work without hesitation. They select their subject matter with conviction. When discussing their next projects with the facilitator, they have a definitive rationale as to why they want to depict a certain subject matter in a certain way. Their styles have matured through the sheer number of artworks they have created and the number of years creating at CVS. Their studio costs are paid for by *At-Risk Youth Funding*, trust endowment funding or full program funding previous to 2010 also known as ‘grand-parented’ funding that is, a selection of activities are offered to recipients within Community Living Toronto and they may choose which offerings they want to enrol in with program costs covered. They all live in the community or in a 5 to 10-kilometre radius of CVS. They consider themselves artists who create artwork daily. Conrod states: “It (CVS) gives me a place to go, it keeps me out of trouble and keeps me off the streets (Line 218)!” Another time at the studio Conrod said, “This place keeps me out of jail! (C. Skyers, Fieldnote, September 23, 2019].

For the five artists who come two to three times a week (Steve, Lisa, Patricia, Quyen and Jack), CVS is a central part of their weekly activities, but they partake in other programming such as volunteering, *Windfall*<sup>120</sup>, social clubs, cooking programming, and sports. Only one

---

<sup>120</sup> *Windfall* is a non-profit agency in Toronto who provides supports for people who are marginalized, in transition or new Canadians. It also provides a place for volunteers to come and work weekly. For further details see the section on *Windfall* in this dissertation. Since several of the participants mentioned *Windfall*, I visited the location to see how it worked. *Windfall*'s name has been changed to *Brands for Canada (BFC)*, but it has the same function.

participant currently attends the former workshop, SWACA (Supported Work & Community Activities). He does not enjoy it due to the noise and the perpetual business and he constantly approaches me when I come to the studio to tell me, “Too loud at workshop! Too loud! Like it here better” (Q. Ngo, Fieldnote, October 16, 2019) [Quyen covers his ears, makes a grimace and shakes his head back and forth.]; the artist prefers the peace of the CVS studio atmosphere and says he would like to come to CVS more often. The participant’s family does not want him to lose a spot in the other programs he attends as they want him to have a varied program. All these participants have a form of grand-parented ODSP funding. In the past their families have been closely involved in their weekly programming and believed that their programming should be more varied and not just focused on CVS. All live within a 15-kilometre radius and arrive to the studio by public transit. These participants work in a range of disciplines including, photography, painting, drawing, and textiles. They are very serious about their art making getting right down to work as soon as they arrive at the studio.

For Jack (Figure 21), CVS is an integral part of his weekly programming. When asked if the programs add to his life? Why or why not? And what do you think you would do if you didn’t go to art programs? Jack said:

Yeah, they do (Line 113). Yeah, they add [Pause 5 seconds.]. They give me something to do. Well since I am not working or anything. I have to get a job [Pause 3 seconds.]. But it is hard to find jobs isn’t it (Line 115)” [Fieldnote, June 23, 2019 Jack has a college diploma in Hotel Management]? To the question regarding what he would do if he did not come to the art program, (Line 132) Jack says, “I don’t know what I would do [Nods his head from left to right.] [Pause 5 seconds.] (Line 133).

Jack enjoys painting landscapes and has a distinct style and keen colour sensibility that is eye-catching and sells his work on a regular basis.

Emily attends CVS one to two times per week all year and considers CVS as a small but important part of her weekly activities filled with art, music, cooking, volunteering, and working. She has *Passport Program* funding and personal funding through her family. Cost for the art program is a factor in participation because the artist’s family would like a range of activities in the community and programs cost money. She appreciates CVS has a distinctive style but is



Figure 21: van Duffelen, E. and Yarmol, C. (2019), *Jack*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

always willing to learn new techniques and tips. She paints and draws at home and frequently with a support worker or her mother; she sells her work privately. She demonstrates a confidence in her ability. Both participants live within a 10-kilometre radius. Jack takes public transit and Emily is driven to the class.

*CVS artists for 3 to 5 years.*

The five artists who have attended the CVS programs from 3 to 5 years Astra, Juan, Betsy, Matthew, Johnfredy have a range of reasons for why CVS is part of their lives. Two participants, Johnfredy and Astra, have attended CVS one to two times a week both see CVS as a very important part of their lives. The skill building and art making is their central focus and socializing is an added benefit of the studio environment. Johnfredy enjoys out trips to locations around the city when he enrolls in the photography class. He has a skill for capturing dynamic compositions and enjoys working with a variety of filters. He consistently sells many of his photographic works (Figure 22).



Figure 22: Salazar, J. (2018), *Gyration*. [Digital Photograph, ink on photographic, 24" x 32"].

Astra has her selected subject matter of wedding dresses and anything that has to do with romance and love. She is eager to sell her artwork but believes she must find a way to market her work or improve it for sale.

Both Astra and Johnfredy would like to continue to build their art skills and sell their art for profit. Their family members take an active part in their weekly programming. Both partake

in other activities throughout the community and both have *Passport Program* funding. Both participants live within a 10-kilometre radius and arrive on their own by public transport.

Two participants, Matthew and Betsy, enjoy the art making classes and attend several classes a week. They both require step-by-step instruction with their art making and acknowledge that they require focused support. Their motivation for attending is focused on the opportunity to socialize. Both select their own programs with the support of a case worker. One has grand-parented and personal funding and the other has personal funding.

One participant, Juan, whose siblings are involved in the decision making about his activities, attends the studio once a week and is very serious about his art making and is trying to find a way to spend more time at the studio. He is employed part time. Juan travels for several hours from Scarborough simply for the love of art making. There is no studio program akin to CVS offered in the east or central part of the city closer to this artist's own community. He is developing his unique subject matter of landscapes and still-life scenes from both realistic scenes and his own imagination. He has sold several of his artworks to the public. His funding is through the *Passport Program*.

*CVS artists for 1 to 2 years.*

One participant, Sabrina, is new to the CVS program and attends three classes week. She is very serious about learning about art and quickly becomes an expert in historical facts about artists she likes, such as Frida Kahlo. Since she is transitioning from a high school program, her family is trying to help her to figure out next steps in life planning; they are closely involved in weekly scheduling of her program. All the art she makes has well-developed compositions and bright colours. Playing with a variety of media she is slowly developing her individual style. She has preferred subject matter of animals and figures but is willing to try new concepts and new techniques to build her skills. The family lives within a 10-kilometre radius and drive her to the program. The artist receives the *Passport Program* funding to pay for the studio costs.

***Time at studio = increased level of confidence.***

The artists who have worked at CVS for many years and come in either daily or multiple instances during the week started off taking the carefully guided step-by-step classes and then gradually over the years gained the confidence in their style development and selection of subject matter. They demonstrate a focus and attention in the creation process of their work. They have a thoughtful approach to their practice knowing what they want to create and how to create it.



Figure 23: van Duffelen, E. and Yarmol, C. (2019), *Neil*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

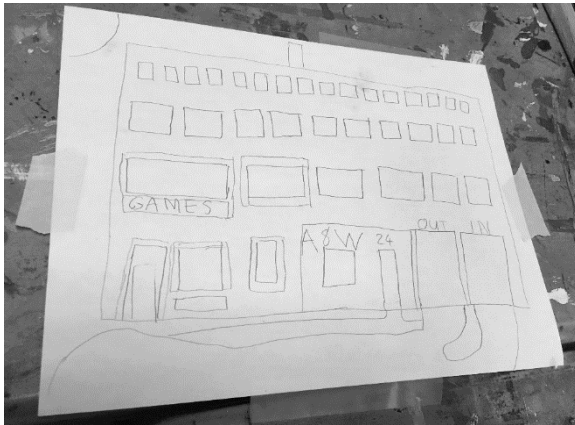


Figure 24: Clifford, N., (February 13, 2020), *Sketch of a proposed cityscape work*, [Pencil on cartridge paper, 8 ½" x 11"].

Neil (Figure 23) who has been at CVS for the last 10 years excitedly explains his work to me at length. Over the last 8 months he shares the subject matter of his work with me on a constant basis pointing to each detail in the painting explaining the function of the building and its location in the real world. Neil creates a series of sketches before he begins a new painting (Figure 24). Neil's work is a series of two-dimensional architectural maps appearing as living maps of cityscapes (N. Clifford, Fieldnote, September 23, 2019). He also has a fascination with airplanes and will add them into as many of his compositions as possible. A few years ago, his mother, knowing his love of planes, hired a small

private plane to fly them around northern Toronto to invigorate his passion. Neil's sense of humour is evident in his compositions as he inserts jokes within the work for example: Santa Claus' sled in desert pulled by camels (N. Clifford, Fieldnote, December 2, 2019).

Neil explains his process for developing the subject matter for his artwork, "Before the chair, I'm like okay, city buses... [Neil points out the front door gesturing his arm back and forth horizontally to indicate that he travelled on the city buses everywhere all of the time.]...( N.

Clifford, personal communication, September 23, 2019, Line 60). Before I have this baby here [Neil taps the right wheel of his wheelchair.]". Neil points to one of his artworks that says: Chinese Food, Pizza, Pizza, Fish and Chips AAA, CAA, No Frills, Hakim (Line 81) Figure 25 and Figure 26.



Figure 25: Video still of Interview with Neil John Douglas Clifford (4:52), September 23, 2019, *City Scene in process*. [Acrylic on Canvas, 12" x 14"]



Figure 26: Video still of Interview with Neil John Douglas Clifford (5:03), September 23, 2019, *Toronto*. [Acrylic on Canvas, 12" x 14" ]

Neil: [Points to Hakim store on his painting.] Hakim (Line 82).

Christina: Yeah, they sell eyeglasses. And you have United Airlines. (Line 83).

Neil: Yeah and Air Canada. [He points to a star outlined on the airplane in the background of his canvas.] Starlines...[Laughs.] (Line 84).

Christina: Okay. So, are those places you see (Line 85)?

Neil: My brain [He points to his right temple with his right forefinger.] (Line 86).

Christina: Yes, your brain. So, you've probably seen them, and your brain remembers. It stores them (Line 87).

Neil: Yeah, yeah (Line 88).

Christina: I noticed that you are always painting transportation... (Line 89).

Neil: Yeah... Yeah (Line 90).

Neil: Yeah. And, and, and farm [He points to the right side of the studio where another one of his artworks, a painting rests against the wall.] (Line 94).

Neil: Farm (Line 95).

Neil: Draw farm (Line 96).

Christina: Okay so these are memories, right ((Line 97)?

Neil: Then EX (Canadian National Exhibition), Florida, then EX, [Pause 10 seconds.] Then I forget [Runs his fingers through his hair.]. Rocks, rocks (Line 98).

Christina: Rocks? By the beach (Line 99.) ?

Neil: No in the EX [He gestures with his left hand to another direction. He is trying to communicate his idea.] (Line 100).

Christina: Oh, at the CNE (Line 101) !

Neil: Yeah [He smiles a wide smile.] (Line 102)!

Christina: Okay. Okay so you paint about those things, the places you have been (Line 103).

Neil: [Shakes his head in agreement.] Then I go park up far away past my place...all the way to the end [Reaches his arm out gesturing with his arm to indicate a far away place.] (Line 104).

Neil: I do golf courses too, [Neil leans forward emphasizing each word.] golf courses (Line 126).

Christina: You draw golf courses. Oh nice! Nice and green right (Line 127)?

Neil: ...And sand traps [He presses both hands in a downward motion to indicate sand traps.] (Line 128).

Christina: So, there is one on Islington and there is one near Centennial Hill (Line 129) near here.

Neil: Or Highlands [He points over his left shoulder with his index finger gesturing to another golf course location he knows.] (Line 13).

Every time I come to CVS Neil is working on a new project. He calls me over to share and to carefully describe every detail of the composition with me.

Artists who take part once a week and follow lesson parameters of a step-by-step studio class appear to feel satisfied with their artistic output. At the end of the two-hour session, most artists complete the basic elements of the composition, the work is left to dry and taken home the following week. Artists who have not finished their artwork may have some time to complete the work the following class but often a new project is begun. Despite the provision of samples demonstrating how a finished product could appear at the start of the class, the resulting artworks become quite unique. I witnessed a painting course where Matthew Sheeny (Figure 27) painted *Dandelion* and was quite content with his work. He was able to take the painting home at the end of the class. If drying time is necessary, the artwork is left at the studio and then stored in the basement office area. This structured, focused class enables new participants with CIDs to become comfortable with the technical and compositional aspects of art creation helping them to gain experience with the media and composition. For many of these artists the art making is reserved for the studio space alone and no additional works are by created themselves at home.



Figure 27, Matthew Sheeny, *Dandelion*. (September 1, 2019 Acrylic Painting Class creation), [Acrylic paint on canvas, 14" x 17"].

*Development of style and subject matter.*

Artists who attend CVS daily for more than twice a week for several years tend to select their own subject matter and develop their own unique style and colour palette with regularity. By learning from the courses, practicing and experimenting with artistic techniques and painting along side structured groups, they build their technical arsenal applying it to their own artwork in their own ways. By developing a deep sense of confidence in their abilities as artists they work to cultivate their personal distinctive style. At CVS artwork is often informally, openly but gently critiqued by the instructors and the artists' peers. After critiques, artists often revise or tweak the work through the addition of shapes, outlines, texture, colour, or painting of the sides of the canvas.

Artists like Conrod, Donna, Evelyn, Lisa, Neil, Patricia, and Quyen, and have all been at CVS for more than 6 years. They all spend a great deal of time in the studio and their styles and subject matter have matured. Conrod focuses on animals and Jamaican scenes; Donna illustrates people who visit the studio and who are in her neighborhood; Evelyn creates geometric and organically shaped ovoid figures, human and animal likenesses; Lisa selects subjects revolving around everyday articles and more recently mother and child imagery; Neil continually paints images about the neighborhoods he visits; and Quyen paints still life images, and figures that represent his relationship with his friends. After researching in the CVS studio for 7 months, without their names signed on the front of all canvases, I could easily pick out their paintings. This was evident when I visited the studio at Joshua Creek Heritage Art



Figure 28: *Joshua Creek Printmaking Studio* — from left to right the artwork of Conrod, Evelyn, Quyen, Neil, Evelyn, and Quyen hangs, December 9, 2019. [Digital photograph].



Figure 29: *Joshua Creek Studio* — from left to right the artwork of Donna, Quyen, Donna, and Conrod's hangs, December 9, 2019. [Digital photograph].



Figure 30: van Duffelen, E. and Yarmol, C. (2019), *Donna*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

Centre. As I walked up to the front door of the house, one of Donna's quick gesture portrait faces peaked out at me from behind the pane of glass. In the printmaking studio there are several of the CVS artists' artworks mounted (Figures 28 and Figure 29). I smiled broadly because I could recognize each of the artists' works by the way they apply the media, and their choice of subject matter or motifs. They have developed their own signature styles.

Donna Woroty nec (Figure 30) has been with CVS since its opening 10 years ago.



Figure 31: Yarmol, C. *Donna Woroty nec holding an image of her sold painting*. (July 3, 2019), [Digital Photograph].

Her work sells on a regular basis. One of her pieces recently sold and the buyer sent an image of it hanging in their home. Donna is eager to share details of the work's subject matter and style as she proudly holds up the photograph (Figure 31):

Donna: I've got them hanging together... (Line 39) And I had one taken away.... (Line 41) ... They bought it from me a while ago (Line 43)! And then I make another one (Line 44). Same portrait like that [Donna points with her open right hand at her painting to the nine quadrants of portraits.] (Line 51).

Christina: This is your style, right (Line 52)?

Donna: Yes [She says smiling broadly.] (Line 53).

Christina: Can you describe your style (Line 54)?

Donna: Okay well these are all people. Lots of persons (Line 55).

Christina: Yes (Line 56).

Donna: A woman this side and a man this side

[Donna has her right palm raised gesturing proudly back and forth referring to both sides

of the composition smiling as she describes her artwork.] (Line 57).

Christina: Oh, okay so there are men and women in each (Line 58).

Donna: Each (Line 59).

Christina: And what is in the middle (Line 60)?

Donna: And they are workers [She motions up and down the length of the painting with her right palm.]

(D. Worotyneć, personal communication November 6, 2019, Line 61).

Quyen (Figure 32) is a confident artist who usually creates work from his imagination. He draws several sketches of his ideas on white paper before deciding which ones to begin to paint. He also paints relatively slowly to paint each detail carefully.

Repeating patterns and electric, high contrast, vibrant colours are key features of Quyen's style. The subject matter consists of either Cézannesque<sup>121</sup> still life imagery or two-dimensional, front facing, figurative portrait renditions of couples walking beside one another (Figure 33). Quyen (Interview with Q. Ngo, October 23, 2019, Line 13) elucidates:

Quyen: This is about my girlfriend and I. That a boy and that a girl and a boy, me [He points to the figure on the left-hand side to indicate boy and then to the right-hand side to indicate girl.].

Christina: So that is her and the other one, is you? So, can you tell me more about the work (Line 22)?



Figure 32: van Duffelen, E. and Yarmol, C. (2019), *Quyen*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].



Figure 33: Ngo, Q. (2019) *Quyen, Girlfriend and Mountain*. [Acrylic paint on canvas, 18" x 24 "].

---

<sup>121</sup> Cézannesque refers to the art of Paul Cézanne who was a largely a self-taught, French artist who focused on the art process itself. He believed that the subject of the painting was first to be "read" by the artist through the understanding of its essence and secondly the essence was "realized" on a canvas through forms, colors, and their spatial relations. Rigid, academic rules of perspective and paint application were obliterated as he experimented with painting. Cézanne executed numerous still-life subjects (scenes with everyday objects) and portraits from nature completely reinventing the genre in the two-dimensional mode. He shifted attention from the objects themselves, to the focus on the forms and colors that communicated by their surfaces and contours, the essential qualities of the objects themselves. An extensive body of self-portraits exhibit the same set of traits as a still-life painting as he considered the sitter's individual characters as unimportant. The vividly impersonal compositions had formal and coloristic possibilities of the human body and its interior nature were featured. Retrieved from: Art Story foundation: Paul Cézanne, 2020.

Quyen: Use of colour [Points to the painting moving his figure in a circular motion to help describe the undulating blue line in the background on the green background. He references his colour application by continuously moving his finger in circles.]. Blue green [Pointing to the background.]. Can you see [He continues to make a circular motion.]. (Line 23)?  
Christina: It is kind of wavy (Line 24).

Quyen: Yeah. Wavy. Then there is the sun [He points to the blue circle in the background of the painting.].

Quyen creates numerous paintings based on the same subject matter. He shows me a second artwork depicting the companionship with this friend. Quyen reaches for a radiantly coloured Cézannesque, still-life work (Figure 34).



Figure 34: Ngo, Q. (2019), *Still-life with Flowers in process*. [Acrylic paint on canvas, 24"x 18"].

Quyen: That one matches. That flower [He exclaims excitedly as he points to some fresh Black-eyed Susans and other wildflowers I brought in that day and placed in a Mason jar with water on the nearby table.].! Flowers, food, with shade [He gestures toward the background describing his paint application with his hands. He points to the lines in the foreground. He uses a poking motion to indicate the dots in the background.] (Line 35).

Christina: And dots? And shading (Line 36)?

Quyen: Yeah and dots and shading (Line 37).

Christina: Good. So how did you think of that one (Line 38)?

Quyen: Think, head! [He points with his index finger to his head.] (Line 39)

Christina: From your head (Line 40)?

Quyen: Yeah head! Yeah. Here. [He points to another one of his canvases in the pile.] Here (Line 41).

Quyen's black outlines create simplified shapes of both human figures and still-life scenes. These subjects are further highlighted by repeating radiant patterns and varied texture created through thicker paint application in the middle and foreground contrasting with wide black contour lines. Quyen's blazing, coloured patterned backgrounds make his artwork distinct from others' artwork.

Conrod paints brightly coloured scenes of animals from around the world and of subjects of either his Jamaican heritage or themes from the media he watches. When I asked him where he gets his ideas he says: "I just get an idea, I just...sometimes bump! Do you know what that means (Line 74)? Conrod communicates that the ideas just pop up in his head from the world



Figure 35: Skyers, C. (2019) *Canadian Scene*. [Acrylic paint on canvas, 24" x 32"].



Figure 36: Skyers, C. (2019), *Out of Africa*. [Acrylic paint on canvas, 24" x 32"].

dream girl (Figures 37 and 38). He had picked up a large, heavy Masonite board a neighbor down the street offered him and dragged it into the studio. He had also collected a series of photographic images of himself and magazine images of Beyoncé Knowles-Carter and drew his

around him. He is not afraid to experiment. When asked to describe his work "...Animals, [He picks up a painting with tulips and turns to point to other artworks he completed that are up on the walls.] jungle, Canadian themes, South African thing fish...Japanese garden" (Line 127) (Figure 35 and Figure 36).

He usually sketches out his ideas on paper then requests or finds a series of photographic sources from which he works. He draws directly on the canvas in pencil. Conrod's compositions are packed from edge to edge of the sub-substrate. His work pulsates with the fierce, electric energy that his personality exudes. Sometimes Conrod adds mixed media to his work including collaged images or pencil crayon. He is always experimenting with new techniques.

During the interview, Conrod was working on a large scale, portrait project that he said was with his



Figure 37: Skyers, C. (October 3, 2019) *Video-Still of Conrod and Beyoncé Painting in Process*. [Acrylic on masonite, 48" x 72"].



Figure 38: Skyers, C. (2019) *Conrod and Beyoncé*. [Acrylic paint on masonite, 48" x 72"].

sketch directly on the board without gesso and then painted it with acrylic paint. Conrod was now applying the finishing touches with pencil crayon and he wanted to explain his “dark” technique to me (C. Skyers, personal communication, October 3, 2019):

Conrod: It is like dark, dark and then it is light, in the end it turns out being light. Dark and light mixture (Line 79).

Christina: Okay (Line 80).

Conrod: Dark and light mixture (Line 81).

Christina: So, you start with dark then you add light (Line 82)?

Conrod: Yep. Sometimes when the paint dries as you can see it. I go around with pencil crayon-- I go around with pencil shadings. I shade around the pencil to make it glow (See Figure 37). [He points to his materials in the corner. Spreads his hands apart and flutters them to indicate a “glow” or luminosity that the work exudes.] (Line 83).

Christina: [He turns the camera toward his work.] So, make it glow... (Line 84).

Conrod: Yeah (Line 85).

Christina: So, you added pencil crayon around this figure here ((Line 86).

Conrod: Yeah. You can see it right? The pencil shading around this one is done [He points to the line around his self-portrait.] (Line 87).

Christina: Yeah. I do (Line 88).

Conrod: Lots of shad’ in around it. It all stands out (Line 89)!

Christina: Yeah (Line 90).

Conrod: They pop! That’s the word I am looking for (Line 91)!

Conrod has an uninhibited desire to constantly create artwork. He is bombarded with ideas and can’t wait to get into the studio to realize them on canvas. Harold helps Conrod to channel this unbridled energy so that each work is completed.

During her interview, Lisa (Personal communication, October 28, 2019) (Figure 39) showed me one of her photographs of a mare and her foal on the photography class outing I attended. Lisa revealed that her mother had recently passed away. She discussed death and the grieving process with some of the other trip participants (Centennial Park Green house trip personal communication with L. Tuckwell, Fieldnote, October 18, 2019):



Figure 39: van Duffelen, E. and Yarmol, C. (2019), *Lisa*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

Lisa: This is my mother's favourite place (Figure 40). Where I have my mom's memorial [She points to the north attempting to describe where her mother's memorial was located.] (Line 147).

Lisa: It is a mother and child (Line 149).

Christina: Beautiful! So, it has a special kind of meaning for you doesn't it (Line 150)?

Lisa: [She points to the horse on the left.] This one.... [Three-second pause, Lisa stops to swallow hard and a tear begins to run down her cheek from her right eye. She hides behind the paper as tears stream down her face.] (Line 151) (Figure 40).

Christina: It is okay. It is okay to cry. I lost my mother recently. I know how you feel (Line 152).

Lisa: [She sniffles and looks down at the next image.] (Line 153).

Christina: Everybody has to grieve... (Line 154).

Lisa: [Lisa holds up a photograph she took of Nathan Phillips Square to refocus her attention on her artwork and away from the painful memory of losing her mother.] (Line 155).

Lisa divulged earlier that day that the studio helps her to focus on other things besides the death of her mother. She also disclosed that her mother really supported her art creation. (L. Tuckwell, Fieldnote lunch time, October 28, 2019). Like many artists, Lisa's themes emerge from her life experience. Her favourite disciplines are painting, and photography and her subject matter focuses on depictions of mother and child or landscapes from interesting angles.

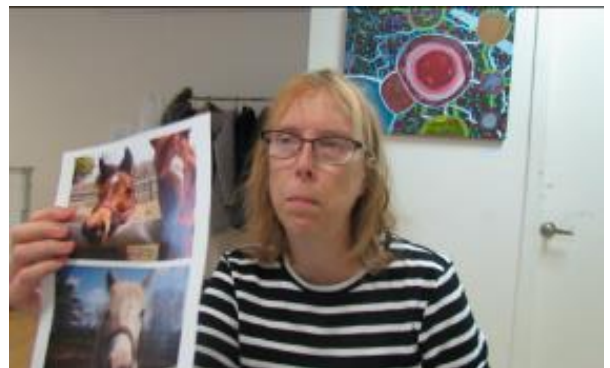


Figure 40: Tuckwell, L. (2019). *Video Still of Photograph of Mare and Foal*. [Photograph, digital print, ink on photographic paper 5" x 7"].

When the artists develop their own style, their individual identities clearly emerge. They seem to feel empowered by the independence of creating work that is unique and meaningful to

them. When this work is displayed in public exhibitions the public is given “the opportunity to view them as skilled individuals first, and people...with disabilities second” averting labelling allowing “the public to focus on their abilities, their individual art styles, and their skills rather than on their disabilities” (Edelson, 1990, p. 94).

### **Operationalization of studio experiences for people with CIDs.**

*Why do artists enjoy coming to the studio? “It is an enjoyable place to be”.*

There are several reasons why artists come to the studio besides the fact that art making is part of either a daily or a weekly schedule. The studio offers a predictable, organized routine; a friendly, welcoming atmosphere where the socializing is important; and program accommodations provided by the facilitator, instructors, and volunteers support art creation.

#### ***Predictable, organized, routine.***

For many professional artists art making is a structured activity. Laurie Lambrecht, one of famous Pop artist Roy Lichtenstein's studio assistants says that Lichtenstein, “structured his day in a way that allowed him to be prolific, with a morning session from 10:00 am to 1:00 pm, a second after lunch from 2:30 pm to 6 pm, and often, a third session in the evening. He worked in parallel, on multiple canvases, and kept groups of works in progress at both of his studios” (Conley, December 9, 2012). Many of the artists who have been at CVS for a long-time work in similar ways: they work in segments of time, and on multiple canvases.

The media for projects were easily accessible for the artists; they were set up by the volunteers or the instructor teaching the class prior to the start of the class. For example, an assortment of acrylic paint hues in clear egg cartons with palettes to mix colours, a range of brush sizes, blank canvases, table mats paper towels, multiple clean water jars placed on the tables and an apron left on the back of every second folding chair were all readily available.

If the course is offered once a week, like mixed media, the instructor had their materials stored in a large plastic bin. The instructor divvied up these media to the participants for the duration of the course. For courses like knitting, each artist had their own clear lidded box labelled with their name, their yarn, knitting needles and their project instructions accompanied by a guiding image.

Incomplete artwork from the previous class was labelled in boxes and placed on a table or the floor for easy access so that those who might arrive early could finish their work from the previous class. Individual artist's projects and multiple projects of artists were stored downstairs

in a storage bin labelled with their names. If artists wanted to begin a new work, they briefly proposed their ideas to Harold who found substrates (canvas/paper), media and a series of source images to support their compositions or expressed ideas. Often artists would create preparatory drawings if they were drawing from their imagination so that the facilitator could support their art creation (See Figure 24). If artists required other materials not present on the table, they could go to the supply cabinet at the back of the studio to acquire them, they could ask a volunteer to fetch it for them or Harold to assist them.

For Conrod, setting up coffee at CVS is part of the daily routine at the studio. Soon after making coffee, he immediately went to his artwork (C. Skyers, personal communication, October 3, 2019):

Christina: So, when you first come in what do you do at the studio (Line 39)?

Conrod: Set up the coffee and the tea for everyone and get my paint jugs and things [Harold has given Conrod an open workspace for his art making at the front of the studio near a mechanic's garage door. A lot of Conrod's work sells outside to the local community.]. I don't need to do that anymore because they are already set up (Line 40).

Christina: They are already set up over here [See Figure 41.] (Line 41).

Conrod: Tucked underneath the chair. You see (Line 42)?

Christina: Yes (Line 43)?

Conrod: And I am a "window painter" [He says with a laugh.] (Line 44).

Christina: A window painter (Line 45) [I repeat and laugh as I consider his joke.].

Conrod: Yeah. I attract people with my artwork basically [He says as he points out the mechanic's garage door-like window at the front of the studio.] and they come in and say, "What is this place all about (Line 46) [Conrod smiles.]?"

Artists who attended the studio more frequently had specific studio areas they liked to work at like Conrod's preferred workspace (Figure 41); Evelyn's pencil crayons, electric

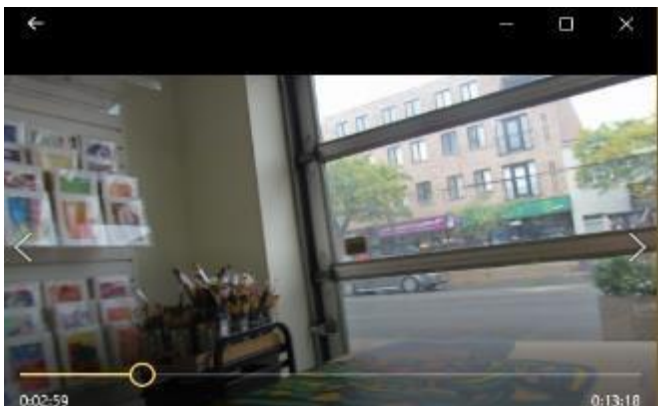


Figure 41: *Conrod's "Window Painter" Space.* [Video still from C. Skyer, personal communication, October 3, 2019].



Figure 42: *Patricia's Pink Bin.* [Digital photograph], February 13, 2020.

sharpener and paper at a round table at the back of the studio (E. van Duffelen, personal communication, September 23, 2019, Lines 53-64); Patricia's pink bin (Figure 42) set up especially for her that rested on the half wall ledge leading downstairs containing some 5" x 7" cardstock with masking tape around the perimeter, pencils, coloured pencils and a pencil sharpener.] (P. Habuda, personal communication, November 19, 2019, Line 40). This ready-made pink box filled with supplies enabled her to quickly get to work when she arrived. Patricia said that she liked to work at a table in the centre of the room where there was a lot of light.

Artist Emily Parsonson's mother, Laura, asserted that, "Routine is so important in so many ways [Laura closes her eyes and looks up at the ceiling.]. Emily likes to have coffee at art, she like to have water at choir.... [Laura presses the thumb and pointer finger on both hands creating precise O's to indicate the precision and need of routine for Emily.] with her 'friends' [Laura makes air quotes.] and all that stuff" (L. Parsonson, personal communication, November 17, 2019, Line 51).

Steve, a long time artist at CVS, highlighted the daily routine of the studio environment, "Well, after you have a drink in that you sit, relax with your drink for a couple of minutes and then you try to think, [He put his pointer finger of his left hand to his temple.] either about what you want to do or what you have done and come and search for your painting and then finish where you left off" (S. Nicholson, personal communication, September 19, 2019, Line 40).

The calm atmosphere of the studio with predictive routines eased the participants' minds enabling them to focus on their artwork. Over the course of the interview Quyen underlined that he did not like the workshop but preferred the studio environment, "I would, I would. Anything else. You wouldn't take my time. You okay. No workshop [He waves his hand no.]. Too loud [He points to his ear with a circular motion...]" (Q. Ngo, October 23, 2019, Line 164)! Like it here!"



Figure 43: Meneses, J. (2020), *Flowers in Vase in Process*. [Acrylic paint on canvas, 26" x 24"].

Describing what he likes about the studio Juan (J. Meneses, personal communication, September 23, 2019) said, “It keeps me calm when I do work” (Line 96). Juan often worked with headphones on playing Colombian music as he painted. He felt confident that he would gain support to execute what he saw in his mind’s eye (Figure 43). No one hindered Juan’s painting progress as he intently painted in the studio space on his large-scale work. Occasionally I encourage Juan to put his work up against the wall and to step back from the work to self-assess his progress to determine what parts of the composition required more attention (J. Meneses, Fieldnote, September 23, 2019). When he applied this approach, he would make several additions to the artwork.

***The importance of social aspects at the studio.***

All artists seemed to enjoy the social aspects of the program, the chance to talk about life issues, chat and the opportunity to offer critique or advice about one another’s work. Art educator and disability theorist Doris Guay believes that, “As individuals interact with each other, their definitions of situations, of things (including disability), and of each other, derive from, or arise from the social interaction that one has with one's fellows [sic]...meanings are handled in, and modified through, an interpretive process” (2006, p. 22) thus artists’ self-concepts are supported by their social circle at CVS. For some artists the social aspects of the studio were of extreme value and perhaps came before the artwork. The art making was almost an addendum to the lives of artists like Matthew (M. Sheeny, September 1, 2019) (Figure 44), and Betsy (B. Pattison, September 1, 2019). These artists participate in 1-2 classes weekly. Matthew explains what he does when he comes to CVS classes:

Matthew: I kind of buy my lunch here (Line 20) ... There are a number of restaurants and a Rabba Foods near CVS.

Matthew: I paint (Line 27).

Matthew: I listen to my music here (Line 29).

Matthew: You know what my favourite song is? ...*American Woman* [He sports a big smile.] (Line 31).



Figure 44: van Duffelen, E. and Yarmol, C. (2019), *Matthew*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"]



Figure 45: Yarmol, C. (October 3, 2019). *Matthew Sheeny enjoying a coffee at a weekly painting class before he starts to work.* [Digital photograph].

Figure 46: Yarmol, C. (February 13, 2020). *Matthew Sheeny working on a painting for Valentine's Day for his girlfriend.* [Digital photograph].

Christina: Can you show me your artwork (Line 40)?  
 Matthew: Okay [He turns to his painting and points at the stem of the flower.] (Line 41).  
 Christina: Yes. Can you talk a bit about it (Line 42)?  
 Matthew: I do a whole bunch of stuff (Line 43).  
 Christina: So, this one is about flowers, right (Line 44)?  
 Matthew: A friend of mine named Betsy helped me out with that [Opening his water bottle.] (Line 45).  
 Christina: A friend of yours? Betsy? (Line 46)  
 Matthew: [Nods] (Line 47).  
 Betsy: [Betsy shouts out from the back of the room.] Yeah that is my name (Line 48)!  
 Christina: Betsy helped you out (Line 49)?  
 Matthew: You got it [He smiles widely.] (Line 50)!  
 Christina: Which part did she help you out with (Line 51)?  
 Matthew: [He points at the background and the stem of the flower smiling.] This (Line 52) (See Figure 27 *Dandelion*).  
 Betsy: [Jumps up from her seat across the room.] The background plus the white things... (Line 53).  
 Matthew: No, I would like most everything [Smiles broadly.] (Line 94).  
 Christina: You like most [I placed emphasis on the word most.] everything (Line 95)?  
 Betsy: (Betsy is nearby and has been listening through the entire interview.) Especially friends (Betsy listens and then adds to the conversation.) (Line 96).  
 Matthew: Especially well, my friends [Matthew looks up at Betsy smiling.] (Line 97) (Figure 45 and Figure 46).

Betsy (Figure 47) was less confident about her art making ability than she was about her social skills. She claimed that she required the support of the instructor, “Well they just help me sometimes ‘cuz sometimes I don't know how to do things (Line 50). For the duration of the

painting class, she made a concerted effort to stay focused and to finish her artwork today, as in the past I witnessed Betsy commented on segments of the others' conversations. When I asked Betsy what she liked best about the art classes she said:

Betsy: Ummm, I like concentrating and I like people helping people out (Line 15).

Christina: Who do you help out (Line 14)?

Betsy: [Points her thumb back at Matthew] Matthew (Line 17).

Christina: Matthew (Line 18)?

Betsy: Yeah, last week [She gestures towards Matthew.] (Line 19).

Christina: Alright (Line 20).

Betsy: He was having problems, so I helped him out (Line 21).

Christina: That's great (Line 22)!

Betsy exhibited much self-satisfaction and pride in supporting her artist-colleagues. It was evident that she thoroughly enjoyed the socio-cultural interactions at her weekly visits to CVS.

### *Safe and welcoming atmosphere.*

Betsy and the other participants knew that there was emotional support offered by the facilitator, the instructor and the volunteers at CVS. Some of the participants have suffered violent, and/or traumatic experiences in their living environments, on the streets or at former workshop placements due to social devaluation or stigma. Participants seemed to feel a sense of safety at CVS. Patricia, a long-time participant at CVS, started her interview with pleasant comments about the studio. As the interview progressed, I learned that she had come from the workshop program and had some negative encounters there (P. Habuda, personal communication, November 20, 2019) (Figure 48):



Figure 47: van Duffelen, E. and Yarmol, C. (2019), *Betsy*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].



Figure 48: van Duffelen, E. and Yarmol, C. (2019), *Patricia*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

Patricia: I like Harold. I love my friends (Line 20).

Christina: Yes (Line 21).

Patricia: I'm happy here (Line 22).

Christina: Good. How come you're happy here (Line 23)?

Patricia: Why I'm happy because...[She looks towards the door because someone has just come into the studio.] I come in and I'm happy to talk to people and because, [She emphasizes each word raising her right-hand palm to the ceiling.] I come and I make art (Line 24).

Patricia: And I didn't like it there (At the workshop placement). So, I had some issues that I couldn't handle (Line 67).

Christina: Okay (Line 68).

Patricia: I can't... remember I told you about that guy and my girlfriend there [She tries to explain a difficult issue she had with a male client at the workshop.] ...he wouldn't leave me alone [She leans in closer to me and the camera. Her voice becomes quieter.]. He kept on... [Patricia rolls her hands in a circle.] (Line 69) ...

Patricia: Yeah. So, I had all of these problems there [Patricia makes a dismissive gesture with her right hand indicating over there.]. So, I had all these problems with him. I had enough so I wanted to leave. So, then I came here where I was happy [For a moment she rests both hands holding up her chin.]. I was safe [She throws her hands in the air.] (Line 87).

Christina: Yes (Line 88).

Patricia: Why I had to be safe is here [She sticks her thumbs on both hands pointing outward.]. Not there [She points with her index fingers towards herself.]. Because I knew he was going to come after me (Line 89) ...

Patricia: But it's nice to be here [Her hands are folded together and support her chin.] (Line 97).

Patricia: I met Harold. I had an interview with Rogers Cable [She waves her hand in the air like it was nothing.]. They asked me like, "How do you like Harold?" I like Harold (Line 98)!

Patricia showed that she felt safe and content at CVS; she enjoyed creating greeting cards whenever she came to the studio. At the end of her interview she showed me a card she had just completed (Figure 49). She was confident that the staff would glue it to a card backing, get an envelope and place it in the acrylic display pockets at the front of the studio for sale.

In the interviews with the artists, volunteers, and parents of the artists interviewees pointed out the magnanimous spirit of the facilitator, Harold Tomlinson. The facilitator and



Figure 49: Photograph of a Greeting card: *Tropical Flower* (2019), P. Habuda. [Felt tip marker and pencil crayon on cardstock, 7" x 5"].

instructors acted as gatekeepers engendering a positive atmosphere and mediating any possible conflicts among all occupying the studio environment. There was extreme trust in Harold, the instructors and in the volunteers at CVS.

When I first started to visit the studio in May 2019 one artist, Evelyn earnestly shared, “Christina, you can stay because you are not an asshole! If you were, Harold would not allow you to be here!” (E. van Duffelen, Fieldnote, June 23, 2019). To me Evelyn’s comment was an affirmative response to my presence and a clear indicator that I had passed the test to be allowed to remain at CVS. I felt as though I had achieved both Evelyn’s trust and her approval; I was welcomed into the studio. Universally participants saw Harold as an artist and life mentor as well as a protector (H. Tomlinson, Field note, November 20, 2019). I believe that these responses signalled that participants have the utmost confidence in Harold.

I attended several photography classes where participants had the opportunity to capture new, interesting scenes with digital technology, giving them the chance to interact with one another. Use of the Community Living van made it fast and easy to get to locations and the social atmosphere inside the van was pleasant and collegial. When asked what she liked best about the classes, Lisa, who was enrolled in the photography class, described her experience, “I get to go out places and to be with people” (L. Tuckwell, personal communication, October 28, 2019, Line 8). In Lisa’s tone and expression, one could sense of safety and comfort with the CVS class; if she did not feel safe, she would not go into the community to attempt a new skill.

Neil said he liked coming to the studio because, “Like people (sic) [Neil points to the people around the room.]. Like people and “Lois always helps me” (Interview with N. Clifford, September 23, 2019, Lines 38-40). Neil only allowed certain volunteers to help him with the details on his canvases and Lois was someone who he permitted to outline his drawn geometric shapes of his architectural canvases when he became frustrated (N. Clifford, Fieldnote, September 19, 2019). Her careful and serious attention to his work met his high expectations. The personalities of the volunteers, instructors and facilitators created a safe and positive atmosphere that was convivial to artists with CIDs.

**Instructional methods, accommodations and supported learning through the facilitator, instructors, and volunteers.**

Alongside the patient, positive and humorous personalities of the volunteers were the accommodations provided. Art education researcher Doug Blandy (1993) states, “Instructional methods create an environment in which people with and without [intellectual disabilities] act on

their common interests in art. Instructional methods are non-stigmatizing and do not bring undue attention to any learner” (p. 171). In their book *Art and Disabilities*, Ludins-Katz and Katz (1990) offer a comprehensive guide of what is necessary to operate an art studio for people with CIDs in an independent art centre setting, believing that art programs could be set up in other service-oriented organizations and schools (p. 125). They outline a typical day of an artist working in the creative art studio (p. 24-27), illustrate how art to organize and adapt art media (pp. 29-49) and tools (pp. 145-154); explore art experimentation (p. 51-54); discuss out trips (pp. 55-56, 63-64); describe how to set up the space and prepare the facility for use (pp. 109-120); itemize possible media for art use (pp. 155-158); and offer job descriptions for the director, teachers marketing specialist secretary and aides (pp. 162-168). This detailed information can be helpful when so few resources of art programs for people with CIDs are available but at the same instance are largely reliant on funding, experiences of staff, space available and the needs of the participants.

Acknowledging the limited number of studies of art studio spaces that support people with CIDs, I looked to art education comparing the studio to a form of an art classroom. More recent literature from leading art and disabilities studies researchers Doris Guay (2006) and Susan Loesl (2006) provides practical suggestions. Underlining the importance of an accessible studio, Guay (2006) lists *Five Environmental Domains* as an approach to problem solving and organizational strategy in the inclusive Art space as she believes that some environments can constrain learning (p. 10). By replacing the term *teacher* in Guay’s list with *art instructor* or *art studio manager* and the term *students* with *artists*, many of the ideas can offer ways to further operationalize the physical studio environment creating deeper art engagement opportunities.

These domains include:

1. Students [Artists] with disabilities where possibilities for self monitoring, becoming more independent and responsible for personal actions are considered;
2. Peers, paraprofessional, and other classroom assistants where possibilities for working cooperatively or collaboratively and co-teaching are considered;
3. Students’[Artists’] environment where room spaces and places including signs, visual installations, learning centers and each student’s [artist’s] placement and personal space are considered;
4. Curriculum [Project] designs where goal orientation, flexibility, and differentiation are considered to meet the needs and interests of the diverse [artists]students;
5. Teachers [Art instructors/Art studio facilitators] as learners in their own classroom where proactive problem finding, knowledge seeking, and understanding assistance are considered (p. 10).

I view Guay's first *Environmental Domain* in terms of artists becoming more independent with their art creation and developing confidence in crafting their personal style. Guay (2006) asserts that the art instructor/art facilitator as a colleague can support the artist to develop their artistic potential. The students [artists] are taught to share responsibility for classroom [studio] routines and supported by the teacher [art instructor], paraprofessional, and peers within the classroom [studio] (p. 10) as they continually enrol in classes or create artwork in the communal environment. This is not simply in terms of preordained socially constructed behaviour management, but an acknowledgement that monitoring one's social skills and civility towards others can be important for all artists in general working in a shared space. Cooperative skills are further developed through positive physical and emotional studio environment, supports and engaging art curriculum [projects] which challenge the students [artists] (p. 10) who are constantly developing new artwork.

Secondly, paraprofessionals who accompany students [artists] to their classes or are already present in the studio should have first-hand knowledge of the adaptations that have worked well in the past and about the artists' general attitudes toward art making adaptations (Loesl, 2006, p. 129). Definitions of both effective and ineffective art facilitation and the possible adverse effect on the students' [artists'] independent art making process are discussed in Chapter 4. The physical presence of the paraprofessional also has the potential of adding an extra support for the instructor and the students [artists] as they can survey and monitor art making positively contributing when required. The key is open communication between the student [artist], the paraprofessional member or team and the lead art instructor.

Thirdly Guay believes, "The teacher [art instructor] must strive to create unencumbered accessibility, clear expectations, organizational predictability" (p. 12). Practices of 'organizational predictability' such as: communication, supply distribution, movement in the art studio, and cleanup expectations should be clearly outline and remain consistent (p. 12). Guay emphasises that stable organization and access to labelled, orderly drawers, shelves, and cabinets becomes a catalyst for self-reliance and creative thought (p. 12) for artists so that art production is uninhibited. Art studio expectations become a routine to build a structure for art creation.

Loesl (2006) underlines that we must, "consider the wheelchair as an extension of a student's [an artist's] person" (p. 115) allowing paths for easy movement and access to artists'

workspaces, materials and the cleanup stations. If spaces are more crowded, the art materials and cleanup materials must be accessible on a table near where the student [artist].

Guay's idea of "Group Share" involving open-ended or thought-provoking questions of critical inquiry, aesthetics discussion, and peer critiques (2006, p. 12) through small group conversations enable students [artists] to converse amongst themselves and to learn from one another. Within a studio setting of adult artists, instructor(s) and paraeducators this process often emerges organically.

Fourthly, when interested individuals come to the studio as adults, flexibility, differentiation and goal orientation are definite considerations when art instructors develop their programs. Art educator and researcher Olivia Gude (2007) discusses her development of contemporary art engagement strategies in her article *The Principles of Possibility* suggesting "that learning begins [with a] deeply personal, primary process of play. Such play must be truly free, not directed toward mastering a technique, solving a specific problem, or conscientiously illustrating a randomly chosen juxtaposition" (p. 1). The possibility of play and chance should be naturally embedded within art projects themselves rather than a following of pre-scripted, formulaic notions of art making. Art instructors can provide basic directions and artists complete their projects with their own creative flare or artists work on their own self-defined and self-guided projects outside of the more formal class structure. The only set expectations are those determined by the artists themselves.

Fifthly, Guay underscores the importance of [art instructors/art studio facilitators] teachers as learners in their own classroom where proactive problem finding, knowledge seeking, and understanding assistance are considered (p. 10). Guay's assertion aligns with educator and critical theory philosopher Paulo Freire's concept of *problem-posing education* (2000). In *Pedagogy of the Oppressed* (2000), Freire critiques what he calls the "'banking concept of education' where education becomes an act of depositing in which the students are the depositories and the teacher is the depository [sic]" (p. 72). The teacher's task "is to 'fill' the students with the content of his [sic] narration—contents which are detached from reality, disconnected from the totality that engendered them and could give them significance" (p. 71). Freire proposes that through *dialogue* "problem-posing education, which breaks the vertical patterns characteristic of banking education" (p. 80) new relationships emerge. "The old terms of teacher-of-the students and the students-of-the-teacher cease to exist and [a] new term emerges,

‘teacher-student with students-teachers’” (p. 80). In this joint process the teacher also learns from the students and grows (p. 80) in a reciprocal “problem-posing” fashion where people teach each other. Freire explains that banking education maintains the *submersion* of consciousness (p. 81) and problem-posing education, “strives for the *emergence* of consciousness and *critical intervention* in reality” (p. 81). The theory of problem-posing education sees people, “as beings in a process of becoming—as unfinished, uncompleted [sic] beings in and with a likewise unfinished reality” (p. 84) and indeed these people themselves are aware of their incompleteness living in a transformational character of reality seeing education as an ongoing activity constantly remade in the praxis (p. 84). Both Freire’s and Guay’s concepts of art educators as students or participants in a learning process along side other artists are ideas that can be actively practiced in art studios.

In their book *Art and Disabilities*, Ludins-Katz and Katz (1990) offer a highly descriptive comprehensive guide of the operationalization of an art studio that supports people with CIDs. What the Katz’s do not do in their book is ask participants about what they need. The following findings emanated from accounts derived from the voices of the study’s participants who offered straight-forward descriptions of the basic accommodations that can be implemented in numerous small studio settings to meet the needs of artists with CIDs.

***See it, say it, do it approach.***

In structured art classes like expressive painting, all materials were provided for the artists including a range of hues on a palette, canvas or paper, water containers, varying sizes of brushes, an apron and paper towels. In these six to twelve-person classes, skills and confidence building were a focus. This class was akin to recently popularized *Paint Nights* that have opened in studios around urban centres. At the outset of the class, a few samples or models of artwork were provided. Aligning with their comfort levels, participants were urged to interpret photographic sources, alter shapes, colour palettes, and paint application as they saw fit. The instructor orally delivered a scaffolded model of how to formally structure the composition guiding artists through the technical aspects of painting. The oral directions were accompanied by a physical demonstration of the process and the manageable steps were frequently repeated. Volunteers and the instructor circulated around the studio space and artists sought out support when they required it. Figure 27, *Dandelion* by Matthew Sheeny is an example a work completed in a structured painting class.

Those who have taken classes before were encouraged to come to the lesson with their own subject matter and ideas to paint. For artists working on their individualized projects, there were many one-to-one conversations about the work or check-in points with the instructor over the time that artists were working. Essentially instructors showed a model and later orally explained the techniques. They physically demonstrated the skills required to achieve the model shown. Artists could then apply their own practical experiential knowledge.

### ***Supports for illustration.***

To alleviate the stress of drawing an initial image onto a canvas, instructors gave artists carbon paper to place below either photographic images provided or the artists' own hand-drawn sketches. This support acted as an accommodation for artists who might have had depth perception issues or who had difficulty translating images to the canvas surface. For those who experienced frustration tracing over a line and felt enabled to move forward, a volunteer or worker would help the artist to transfer or initially draw the preparatory work at the artist's request. Verbal encouragement was also used to embolden the artist to make marks on the canvas. Accommodations ranged dramatically based on the artist's physical ability. For example, for those who experienced issues with fine motor skills, large brushes and a larger canvas could be employed.

For larger scale artwork like murals, Harold would on occasion encourage the use of an overhead projector to enlarge an acetate drawing onto a larger scale surface just like Roy Lichtenstein (Conley, 2012) or Andy Warhol (Marr, 2000) did in the past. These artists used overhead projectors to project small images on walls where they could trace their imagery on a larger scale <sup>122</sup>. Vexing emotions that emerge with precisely transferring an image were cast

---

<sup>122</sup> Through his experience working as an artist, David Hockney believes Old Masters, Michelangelo Merisi da Caravaggio, Raphael Sanzio, Frans Hals, Johannes Vermeer, Diego Velázquez and Jean-Auguste-Dominique Ingres used mechanical aids like grids, camera Lucida and lenses to map out, trace out or enlarge their pictures resulting in create exacting perspective (Jordan, C. 2017, July 31) and photographic realism. According to forensic artist and illustrator Karen Taylor (2000), "Artists have used a simple grid system to enlarge or reduce their preliminary sketches. A drawing or photograph may be enlarged or reduced by placing tracing paper over the image and drawing a grid at measured intervals" (p. 81). To enlarge small images so that you can draw them on a larger piece of paper, draw a grid of larger squares at measured intervals then trace your image on the grid in a linear and exact fashion (p. 81). "A projector is probably the best method for enlargement of a small facial photograph to produce a larger drawing. The three primary types of projectors are opaque, slide and transparency (Taylor, 2000, p. 82). A particularly useful tool for tracing is a light box, a simple box with lights inside and glass or plexiglass on top (Taylor, 2000, p. 82). An additional type of carbon-backed paper called *transfer paper* may be used to copy an image onto another surface without a change in scale (Taylor, 2000, p. 83).

aside, removing a roadblock to artistic production. Artists could easily move to the next step of media application with paint, pencil crayon or collage pieces; they exhibited confidence in their ability to create. Artists who demonstrated a facility with drawing moved directly to the canvas surface like Sabrina who said, “I just do it (draw) by hand instead of copying” [She smiles as she explains.] (S. Simonyi, personal communication, October 12, 2019, Line 40).

Artistic tricks and strategies were employed in the studio that the participants themselves might never consider using. To preserve the perimeter of a paper from marring and to achieve a professional-looking work, the area beyond the central working surface was masked off with a green painter’s tape or masking tape. Masking was frequently employed by instructors of the card making class and the mixed media classes. Participants “ooooed” and “ahhed” at the professional-looking appearance of the work when the masking tape was removed.

The following text outlines Johnfredy’s experience with art making supports in CVS studio (J. Salazar, personal communication, September 19, 2019):

Johnfredy: He (Harold) helps me on the computer with photos (Line 69).

Christina: Oh, so he helps you on the computer to find some of the imagery and with your photographs in photography class (Line 70)?

Johnfredy: Yeah (Line 71)!

Christina: Okay (Line 72).

Johnfredy: If I need anything, need anything, need anything... all of this (Line 73) [He pointed to the canvas and to the acrylic paints he was using (See Figure 50)].

Christina: What else does he give you? You said pictures. Did he give you materials (Line 74)?

Johnfredy: This [He points to the canvas with the peace sign on it.] (Line 75)!

Christina: So, he provides materials (Line 76)?

Johnfredy acknowledges the volunteer Lois’ support of his work. He says that Lois helps him to tidy up with the corners and edges of his paintings (Lines 95-97). He says that not all volunteers are nice (Line 124) but that Lois is, “Very nice” (Line 122). Harold believes that Johnfredy has a “good eye” for composition as evidenced by the strength of his photographic compositions which Harold often sends to photographic contests or gallery exhibits, however, he requires some technical support with cropping of photographs on a computer program. Harold notes that sometimes Johnfredy requires some initial discussion



Figure 50: Salazar, J. (2019), *Peace. in progress*. [Acrylic paint on canvas Felt tip marker and pencil crayon on cartridge paper, 11" x 17"].

around ideas for the subject matter of his paintings and asks for guidance with new techniques or colours choices (Figure 50) (H. Tomlinson, Fieldnote, September 19, 2019).

Although many participants who have been to CVS for a number of years have their own style and could easily work from their imagination, the artists who came for weekly classes relied on samples of artwork and pictorial source-imagery to guide their process or for reference to feel confident drawing accurate proportions and colours in their interpretations of subject matter. Numerous artists referred to the facilitator's provision of source-images as a major support that they appreciated. Providing source-images in a binder, through books or magazines or printing them on a colour printer and offering carbon paper, stencils or tracers like a circular plate were accommodations made by the instructor that aided the artists' art creation process.

A number of public images have been recently made available for artists such as the Wellcome Library in London England recently made 100,000 art and medical images available online for open use. As the Open Education Database (2014) indicates, "This collection is where to look for offbeat, bizarre photos including medical art of all types including manuscripts, paintings, etchings, early photography and advertisements".

Positive encouragement was frequently given. Work was critiqued within a group setting to share the opinions of other artists in the room with the goal of bettering the final artwork. The instructors also offered suggestions about how the work could be improved. For example, Harold put forward, "Donna why don't you touch up the sides of your canvas? What other colours do you think could be used for these faces over here?" [Harold says pointing to two faces yet unpainted beginning a discussion about balancing colour and pattern with Donna.] (H. Tomlinson, Fieldnote, September 23, 2019).

Lisa stated:

He (Harold) shows me how to get everything centered [She puts both palms facing down on the table moving them back and forth to indicate centering of image.]. And stuff like that. He talks with me about my work and what is good about it and how it can be made better.” (L. Tuckwell, personal communication, October 28, 2019) (Figure 51).



When asked how the instructor supported Sabrina's journey as an artist Anna, Sabrina's mother responded:

Anna: [5 Second pause.] This is going to sound crazy but... I think the biggest thing is the compliments. When someone turns around and says to you all the time, “That's amazing! Wonderful! That's really good work!... And, “ I'm really happy for you.” ...it builds... confidence. The first couple of times it may be oh, somebody likes it (Line 49).

Christina: Yes (Line 50).

Anna: And after a little while it becomes a part of who you are. Like my artwork means more to someone than just Mom and Dad [Laughs] (Line 5).

Christina: Yes. [Laughs.] Because my parents will like whatever I do or at least say they like it (Line 52)!

Anna: Exactly [She smiles.]. There is somebody out there who thinks that what I'm doing is good [She emphasizes the word good. Moving her hands in a circular motion as she speaks but with elbows still on the table.]. And taking her to..., and we went to Joshua Creek (Line 53).

Christina: Yes (Line 54).

Anna: That was a matter of...its the same person that's giving you the compliments is now telling you that your work is good enough to be put on the walls and viewed by a lot of people so, I mean, that to me is huge [She falls back in her chair.]. Absolutely huge (Line 55)!

Figure 51: van Duffelen, E. and Yarmol, C. (2019), *Lisa Painting*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

The facilitator backed the individual needs of artists, for example, Evelyn worked almost exclusively with pencil crayons for hour after hour in the studio. She pressed so hard on the paper that the wax and pigment glistened. When asked what the instructor did to support her art making Evelyn explained:

Evelyn: Yes, he says he's going to get me another pencil sharpener, right?

[Harold walks by.... Evelyn smiles...]. Right Harold? A nice new one (Line 53)!

Harold: Yes, the Cadillac of sharpeners (Line 54)!

Christina: The Cadillac of sharpeners [Laugh.] (Line 55) (H. Tomlinson, Fieldnote September 23, 2019)! [Harold recently purchased the third electric sharpener as Evelyn wore out the motors on the first two electric sharpeners.]

Evelyn: Harold is sharpening my pencils. If I go say goodbye and then I can sharpen my pencils (Line 56).

Christina: So, you like to draw with pencil crayons the best (Line 57)?

Evelyn: Yeah, pencil crayons are better, but my best thing is just to draw and colouring (Line 58).

Christina: Yes (Line 59).

Evelyn: But sharpening pencils can drive anybody around the corner [She smiles a broad smile.] (Line 60).

Christina: It really can, and I noticed that you press really, really hard (Line 61).

Evelyn: [Nodding affirmatively.] Especially me, it can drive me around the corner (Line 62)!

Christina: I know, I see your figures. [I point to her artwork behind her on the wall (Figure 52). I don't think anyone in here colours as hard and for as long as you do Evelyn! You are the *Queen of Colouring* (Line 63)!

Evelyn: What? I hardly touch the paper and then it looks like I am really pressing! [She emphasizes the words really pressing. She motions back and forth along the table]. That is why the pencils break (Line 64).

Christina: Wow! That is such a great skill. Did you always do that (Line 65)?

Evelyn: Yeah. I learned it here. I hate the ones that break from under you. Those are the cheap ones [She looks right at me and nods.] (Line 66)!

Christina: Maybe you can teach me your technique (Line 67).



Figure 52: van Duffelen, E. (2018), *My Community* on the CVS wall. [Painting, mixed media, pencil crayon on paper, glue, acrylic on canvas, 24" x 36"].

The pencil sharpener was also used by Patricia Habuda and other artists in the cardmaking class (Figure 49). The upkeep of equipment and all purchases of new equipment to meet artists' needs was one way that the facilitator supports the artists at CVS who might not be able to afford materials like their own electric sharpeners.

***Exhibition: Names for the planned show.***

Over the course of the interviews, participants were asked to consider a name for an art show at CVS where their work would be featured. The following is a list of show names the artists interviewed suggested:

Collage of Paintings/ Space/ Collage/Private Diaries/ Personal (A. Milberg, Lines 150-155);  
A Great Experience, Spending Time Together (E. Parsonson, Line 161);  
Doing Paintings (B. Pattinson, Line 93);  
Grand Opening (D. Worotyneec , Line 125);  
Harold's Art Store, Harold's Art (J. Salazar, Line, 144);  
Classic Arts. ...Gallery (S. Simonyi, Line 118);  
The Experience of a Lifetime. (S. Nicholson, Line 111);  
Disabilities Are... (J. Homer, Line 178);  
More Than Art (L. Parsonson, Line 80)

Other artists like Neil and Matthew were unsure of a suitable name. Juan, Quyen, Lisa and Patricia asked me to ask them on another day. Many of the artists discussed the importance of the social aspects of the studio and having a hot beverage when they arrived. In discussing the possibility of having a show and what the title should be, Evelyn thought out loud and said:

An art show is like a gallery (Line 150) ...drawings, colourings, and paintings. You could dance if you wanted to (Line 152). Or you know sit there and do your work (Line 154). Yeah! Or coffee. Sit and have coffee (Line 156). In an art show have coffee” (Line 158).

As I listened to the voices of the participants throughout the interviews and Evelyn's commentary noted above, I thought that a wonderful name for the show could be *Coffee Talk* and that I could create coffee table books to display their artists' profiles (See Illustrations 15-16 and Appendices A-C).

Noticing that Matthew's cup had left a coffee stain on some newsprint beside him, I considered the kind of residue or mark that the liquid from the overfilled coffee cup left. I asked artists in the studio to place their coffee cups on my sketchbook to create a kind of print of their active presence in the studio (See Illustration 22: *Coffee Talk-Leaving a Trace*).



Illustration 22: Yarmol, C. (2019). *Coffee Talk-Leaving a Trace*. [Sketchbook Drawing, Coffee on paper, 12" x 9"].

The interview responses from the CVS participants reinforce the belief that they were art practitioners; their art was considered their trade as early art and disability theorist Rae Temkin Edelson (1990) believed, “the emphasis is on art as work, rather than on art as therapy or hobby, and the proper role for staff is artist rather than therapist or recreation coordinator” (p. 85). Through self-expression and production of artwork, artists see their work as part of their vocation. They see themselves as a group of artists rather than simply clients of Community Living Toronto, a disability service provider.



Figure 53: van Duffelen, E. and Yarmol, C. (2019), *Beverly*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

### **Interviews with volunteers.**

*A/r/tography* uses processes of action, research, plan, act, observe, reflect without prescribing a concrete plan or method. While engaging in narrative research with the artists, the volunteers engaged at CVS figured prominently in the artists’ narratives and daily art creation in the studio. As I began to reflect about the continuous mention of the volunteers, I felt that they might have important information to share about their experiences at the studio (Interview Questions posed appear in Appendix T) and that I should interview them. The presentation of the responses to the questions posed to volunteers Lois, Pina and Beverly are intertwined in the following section.

### ***Why volunteer?***

The volunteers shared their rationale for why they volunteer and how they heard about CVS. Lois heard about CVS from her sister. When she retired from her job, she decided that she wanted to give back to the community and six years ago she landed at CVS. She now volunteers once a week on Thursdays with the painting class (L. Langdon, personal communication, Nov. 7, 2019, 2019).

Pina lives in the community and knew some of participants from a local Islington Village coffee shop. After her life situation changed, she decided to ask Harold if she needed help in the studio because she wanted to support people in her community. Pina has volunteered at the studio for 4 ¾ years. Currently she volunteers on Mondays for painting class and Wednesdays

for the drawing class, and with SWACA participants' art classes (P. Barci, personal communication, November 7, 2019).

Beverly (Figure 53) lives in the community and first entered the studio to buy a Christmas tree ornament that she noticed for sale in the window. She has volunteered for the last 10 years because she, “thought she could do some good” in supporting the studio’s participants. She used to come 4 days a week participating in all daily classes but due to chronic health issues comes in on Wednesdays to support the SWACA art class (B. Gordon, personal communication, Nov. 7, 2019, 2019).

All three of the volunteers wanted to support their local community; volunteering is their way of positively giving back to the world. Lois appreciated the atmosphere at CVS. She explained:

I really like interacting with the... artists [Fieldnote: Matthew is growling like a tiger in the background]. [Lois looks at Matthew at the other side of the room as she speaks.]. They can be zany and there's a lot of times, that they, they horse around.... and they goof around [An artist enters the studio and shouts hello to Lois. Lois waves and says “Hi!”]... And there are times when they come up and immediately engage with you for no reason... Well they have a reason, but you don't know what it is, or don't quite have time to know (Interview with L. Langdon, November 7, 2019, Line 14).

Harold had mentioned that these three volunteers had been at CVS for many years; they were helpful, good-natured, and trustworthy, acting as invaluable assets to the studio environment. Harold underlined that reliable volunteers who attended and were committed to the classes were sometimes difficult to find (H. Tomlinson, Fieldnote, November 20, 2019).

### ***Training.***

Volunteers were asked about their background training in visual art or social services. Lois did not have any training in the visual arts (L. Langdon, personal communication, Nov. 7, 2019, 2019, Line 24) but had some job training from her former employment that enabled her to easily support people with either physical or cognitive challenges (Line 26). Pina had acquired all her training in visual arts and working with people with CIDs at the studio; she has no previous experience in these areas. Pina liked coming to the studio because she gained a new life perspective, “It makes me feel that life is better just through their eyes (P. Barci, personal communication, November 7, 2019, Line 4).” Beverly did not have visual arts training or training working with people with CIDs she shared that she has learned a great deal from the artists and instructors at CVS. She first came to the studio after her husband died. “Instead of

having a pity party, I walk away feeling as if [She thrusts her fist in the air.] I did something good today (B. Gordon, personal communication, November 7, 2019, Line 98).” She earned a *Toronto Community Award* for her volunteering at CVS at a public, municipal celebration dinner in 2018.

***Essential attributes of a volunteer.***

Volunteers all shared the personality traits that they believe were essential for volunteering at CVS. Lois said, “You have to be open. You have to be open to people from all walks of life...accepting of people, of their abilities and their challenges... You need to have patience (Line 34)” (L. Langdon, personal communication, November 7, 2019, Line 28). Pina believed that, “Patience... and compassion [Pause 5 seconds.] and a listening ear (Line 9)” were necessary attributes to hold if one is to act as volunteer at CVS. These personal characteristics were desirable “to make the artists feel as if they're part of something, not excluded, but included in things that we talk about or that we do” (P. Barci, personal communication, November 7, 2019, Line 11). Beverly believed that people who work in the studio cannot be judgemental, they should be energetic and positive, tolerant, caring and giving (B. Gordon, personal communication, November 7, 2019, Line 23-26). A positive, upbeat attitude is critical for volunteers working in the studio. When asked what could be improved in the studio Steve (S. Nicholson, personal communication, September 19, 2019) highlighted, flattened and then silenced some experiences with past volunteers and students who were not particularly amenable or responsive to his needs of those needs of other artists at CVS.

You know just to tell Harold that when some of the volunteers... come in there are some days when you try to come in and work and some of the volunteers might not be in such a good mood when you want to work with them so some of the volunteers just try to be a bit friendlier than they are. It is not the people it might be...Harold is fine, but it is just some of the volunteers who come in to help him [His hands are flat on the table. His head is turned to the left side.] (Line 93).

Harold elucidated, “There have been some volunteers who don’t get it; they are not particularly attentive to the needs of the artists but are busy meeting their personal needs on their phones” (H. Tomlinson, Fieldnote, November 20, 2019). Harold’s comment highlighted the focused attention and positive attitude compulsory for volunteers to be effective agents in the studio environment. Steve’s comments demonstrated that the behaviour and attitudes of the volunteers were of paramount importance in crafting a comfortable, welcoming atmosphere.

***How volunteers support artists in the studio.***

Lois (Figure 54) articulated:

Oh, so I help them finish up their artwork...um, get coffee or tea for them, talk to them, interact with them.... If they're being goofy or the next day they're horsing around or the next day they are upset because they have a problem and they want me to tell me about it, I listen. Sometimes a situation has happened in their life and then I go and tell them a direction they can take (Personal communication, Nov. 7, 2019, 2019, Lines 36-39).



Figure 54: van Duffelen, E. and Yarmol, C. (2019), *Lois*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

From field observations, I have witnessed artists specifically request Lois' assistance. For example, Neil Clifford would wait all week until Lois came into CVS on Thursdays for her ability to carefully outline the shapes on his paintings the way he liked it; he requested her expertise for adjustment of particular areas of his work (N. Clifford, Fieldnote, October 31, 2019). I believe this relationship is also due to how Lois approaches and responds to Neil who was consistently making specific requests about particular sections of his work. Lois' calm demeanor and focused approach to each situation made Neil feel confident and secure in asking for her support.

Steve (Personal communication, September 19, 2019) acknowledges that sometimes he worked with volunteers who help with his idea generation, composition and image searches:

If I can't think of an image and if they are very good at sketching they can try to sketch out what I am looking for as best they can....then...if Harold sees part of what it is they are sketching and [He points down at the table and then points up to his head with two fingers.] thinks of what it is, then he will try and help me find the, the umm correct version of it in a photograph. To help me out as best as he can (Line 71).

A single instructor was not enough to manage groups of ten or more artists with CIDs thus volunteers were a very important part of a studio environment.

Pina supported the artists with their material needs, repeated the directives given by the instructor and socially interacted with artists about everyday occurrences. She said, "Well, I, I

come into actually socialize with them or help them with their paintings if they ask (P. Barci, personal communication, November 7, 2019, Line 13). I viewed Pina supporting the SWACA crew who came in weekly for art programming. Pina habitually offered verbal encouragement to some participants who required consistent guidance to stay on task or assistance with their physical supports. Several of the artists from this group required one-to-one support with their art making processes (Fieldnote, November 7, 2019).

Beverly was present in the studio walking around, “seeing what each person needs” (Line 3) to assist the artists in any way possible such as helping them to trace or draw, cleaning their brushes or changing their water containers, tying apron strings, cleaning up, or if they are in a particular step-by-step painting class helping them to follow the instructions (Line 2).

Overall, the long-time volunteers understood their purpose in the studio was helping the artists reach their full artistic potential without undue influence or intervention (Lige, 2011, pp. 73-75). They cued into the requests for support from the artists, keeping with the artists’ creative intentions and understanding of the lessons. They also responded to the directives of the class instructor deferring to him/her/them when specific questions about technique, composition or style come into play.

It was imperative for volunteers and instructors to develop an ability to differentiate between participants’ functional inability to perform a task due to cognitive misunderstanding of an instruction or physical disability or lack of confidence. If the staff recognized the queries of the participants and their genesis, then they could better support or redirect the artists so that participants could complete pieces independently, truly calling the result *their* own artwork. Volunteers’/Instructors’ understanding could be achieved by getting to know the participants, learning about their personality traits, and working with them by patiently offering repetition of instructions and verbally encouraging them before rushing to touch or alter their artwork.

***How the instructor supports the artists.***

From Lois' perspective Harold offered the artists advice about composition and colour in their paintings (Personal communication, November 7, 2019, 2019, Lines 49-50) or offered "suggestions on what pictures they make, want to paint or if they are stuck for ideas" (Line 51) to support their new work. Pina said that Harold, "Guides the lesson giving step-by-step instructions" (P. Barci, Fieldnote, November 20, 2019) teaching the classes in a gradual, unhurried way (Figure 55). Beverly stated that Harold the instructor, "tries to expand what they are already doing [Her hands move outward from the globe position.]. He tries to see how far he can open them up to new ideas (Lines 37-38)." Beverly offered Donna as an example claiming that Donna used to draw stick figures with a pencil, but that Harold encouraged her to expand her drawings by add clothing, hair and expressions (Personal communication, November 7, 2019, Lines 39-43). "Since that she does other things and she does a marvellous job but, he opened up her horizons for her (Line 44)." Beverly also claimed that the facilitator /instructor often has a heightened awareness of the personal issues the artists are facing and how these issues affect their mood and emotionally supported them accordingly (Lines 48-50).



Figure 55: van Duffelen, E. and Yarmol, C. (2019), *Pina*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

***Studio successes and challenges.***

When asked to share the program's greatest strengths, Lois answered, "The strengths are getting people together. It is an environment where everybody is accepted. Everybody is happy to be here. They seem to enjoy what they're doing. Ummmm. They are proud of their work" (Personal communication, Nov. 7, 2019, 2019, Line 53).

One day at CVS one of the artists not in the study mentioned that the show *Cheers*, a 1982-1993 sitcom where the characters shared their experiences and lives with each other while drinking or working. We discussed how CVS is somewhat reminiscent of *Cheers*. The *Cheers* theme song chorus rang out:

Sometimes you want to go where everybody knows your name, And they're always glad you came; You want to be where you can see; The troubles are all the same; You want to be where everybody knows your name (Where Everybody Knows Your Name, written by Gary Portnoy and Judy Hart Angelo, and performed by Portnoy, 1982).

I thought that this pop culture comparison was quite an emblematic way of the describing the atmosphere created by the participants, volunteers, instructors and facilitator at CVS. CVS was a real-life version of *Cheers* only the beverages of choice were coffee and tea!

Beverly asserted that the biggest success at CVS was, “Seeing them all come in here and they're excited to come in to make art” (Personal communication, November 7, 2019, Line 53). Pina believed that the program's greatest strength was that, “The art helps make the clients feel empowered that they can do something wonderful” (Personal communication, November 7, 2019, Line 21). Pina had witnessed the broad range of artwork produced in a variety of classes and the positive responses artists have to their creations.

The program’s challenges were thoughtfully expressed by the volunteers. From Lois’ viewpoint the challenges of the program included developing positive relationships with the artists and other volunteers, “Sometimes you're getting people who are having tiffs and stuff like that, so you have to tell them look...so its a ‘stress free zone’, and everybody's accepted so you can't, you can't say [Lois raises her shoulders up and then down.] or do something nasty about somebody else in the program cuz that's not what the program is all about [Louis has left hand makes a slashing motion in the air]! Those are the challenges (Personal communication, November 7, 2019, 2019, Line 54-56)!”

From Pina’s point of view the greatest challenge was “communication sometimes... because they are trying to understand and sometimes, they kind of get frustrated” (P. Barci, personal communication, November 7, 2019, Line 23). Several participants required additional communication supports. I witnessed Pina using her sense of humour and simple language to slowly break down the steps of an art task beginning with the preliminary contour line drawing until the work’s fruition as the artist required more time to fully process and grasp the sequence of steps involved in the art making (P. Baruci, Fieldnote, September 23, 2019).

Beverly said that learning about the variety of personalities could be challenging for a volunteer. Some people did not want your support, they wanted to be totally independent. Beverly gave the example of one participant in the Monday class who became highly agitated if you even moved to help her (Personal communication, November 7, 2019, Line 62). She

explained how she had learned to manage the artist even when she saw that she was struggling, “You wait for her to say she needs help, and I say, ‘Would you like me to give you a hand for a sec [Beverly makes a slow, flowing motion with her hands to the left side.] (Line 66)?” Beverly noted that sometimes the clients of CVS have endured terrible injustices where they have been taken advantage of (Line 78) and that these incidents sometimes came to light in the safe environment of the studio. Beverly reported that she informs the facilitator immediately when she learns of a particular incident that upsets the participant, “because he's in a position of responsibility. He runs the place and he can do something about it” (Line 82)! When individuals with CIDs were comfortable with their surroundings, truths about their daily lives would periodically emerge; they required additional support to cope with aspects of their lives that were troubling.

#### ***Suggestions for improving the program.***

When asked about what she believed could be improved in the program, Lois is hesitant to answer. She did not feel as a volunteer that it was her place to comment on the studio’s program however, she did comment about the physical space, “Maybe a little bit wider because we have more people coming in with wheelchairs and mobility devices and what have you” (Personal communication, November 7, 2019, Line 58).

Both Pina and Beverly saw nothing to improve with the program and silenced the question believing it was “really not their job” to criticize the program (P. Barci and B. Gordon, personal communication, November 7, 2019). They felt that they were there to support the participants art making and the art instructors’ teaching of the programs while at the same time learning and socializing with others in the community.

#### ***Sharing their learning and end points of interviews.***

The volunteers were asked to share something they had learned from their experiences working at CVS. Lois shared: “Yeah actually people with intellectual disabilities, they are like everybody else [She says nodding her head.]. They have their feelings, their ups and their downs. They're no different than anybody else [She nods her head up and down.] (Personal communication, November 7, 2019, Line 61).” I believe that this observation about people was true especially when I considered and compared the workplace dynamics where I am employed.

Volunteering at CVS had an impact on Pina. Coming to the studio had made her feel wanted, “They appreciate me...so I like coming here...cuz they make me feel just like how I

make them feel as if... they feel... like they are always asking for me when I am not here so its the same, I feel like welcomed. Makes me feel good (Personal communication, November 7, 2019, Line 27)!”

Beverly elucidated,

I've learned more than I give [Beverly says as she points her right hand to her heart.] I, you know.... (Line 36) [Makes a wide mouthed expression and pauses for 3 seconds then answers.]. It is so..... simple. Before I would come in here... you have people say you know they have intellectual or physical disabilities... but I have learned more than I've ever done. It is amazing some of the talent that these artists have. They would make you and I look like chopped liver [Beverly moves forward as she says this phrase.] (Personal communication, November 7, 2019, Line 86)!

Firstly, Beverly communicated that the artwork of the artists working at CVS was wonderful and unique. It was not the art of the people with disabilities, it is “simply art”. Beverly found an example of an artist to prove what she was saying, “Like Neil's drawings of his areas... Yeah, he could go anywhere in the city and he would come back and he could draw the area of the city he was in right down to the coffee shop the grocery store the building he was in front of! Amazing (Personal communication, November 7, 2019, Lines 89-92)!” Secondly, Beverly asserted, “They need more places like this studio, and they need more caring people to look out for them so that they don't get into trouble or so that people don't take advantage of them (102).” Thirdly, Beverly astutely mentioned the age group of many of the participants whose families were passing away (Line 103) and “they have nobody out there anymore fighting on their behalf” (Line 104).

Although the perceived end point (Spector-Mersel, 2010) of the interviews was to learn about studio supports for people with CIDs, this end point grew to be peripheral to the central idea that people with CIDs should be treated with respect and dignity like everyone else through calm, attentive, and non-judgemental attitudes. A clear appreciation and admiration of the artists' abilities to create memorable artwork emerged from the interviews. From these interviews the idea that CVS was a safe and secure home-away-from-home for many of the artists. It became apparent that the studio was a special place because both the artists' skills and personalities were encouraged to flourish in a way that they were not encouraged in a normative public sphere. The comfortable community of friends and colleagues at CVS was obvious in the volunteers' discourses about the studio--- a kind of creative camaraderie existed where artist-participants were not only art making but socializing, laughing, conversing, learning and

collaborating. These interviews with community volunteers indicate that the artists at CVS are actively engaging in a mode of cultural citizenship within this community.

### **Interviews with parents.**

Just like volunteers, parents and family caregivers played a prominent role as support mechanisms for people with CIDs. Over the course of the interviews, participants made active mention of both their living and their deceased parents and supportive family members. Parents, the main care givers, offered a plethora of information about community engagement in programs. Two participants, Emily and Sabrina, spoke about their mothers' approval of their art making. I contacted both Laura Parsonson and Anna Simonyi requesting interviews to gain a broader insight about their views on their children's art making experiences. Laura Parsonson (Personal communication, November 17, 2019) the mother of Emily Parsonson and retired Toronto District School Board educator, has been involved with Community Living for 36 years. She has acted as an advocate for her daughter and for community programs including being a Community Living Toronto Board member. Laura has witnessed a range of levels of service delivery. Anna Simone (Personal communication, October 12, 2019) whose 23-year-old daughter Sabrina just left the secondary school system 2 years ago was searching for programming for her daughter. She accompanied Sabrina to the program acting as volunteer at the CVS classes mentoring to individual artists in Sabrina's classes. The third individual, Shannon Groom, held numerous roles; she had been an instructor of an i-pad class at CVS, a drama instructor at SWACA, a support worker at Community Living Toronto, and was a parent of a child with an intellectual disability. The presentation of the majority of the findings from Shannon's interview lie in instructor's section of this dissertation however, a brief excerpt of the interview is presented in the *Interviews with Parents* segment as it speaks to parents' wishes and desires for their children with CIDs as they applied to Visual Art and Performing Arts programs. The open-ended questions posed are listed in Appendix T however these interviews were more casual conversations. I communicated Laura's and Anna's responses to the questions individually in a storied fashion to deliver cohesive accounts of their narratives.

***Laura Parsonson's view of program.***

As mentioned in the *Consider Themselves to be Artists* section, Emily has a very busy weekly program in the community and defined herself as an artist. This was because Laura (Figure 56) wanted Emily to have an active life and rejected the idea of Emily sitting around at home. Early in the interview Laura silenced that it was difficult to program for and manage individuals with CIDs as there were copious support requirements. She gave the example of chauffeuring Emily to the scheduled activities; she brought it up later on in the interview. It was important to note that Emily's art creation class at CVS was just a very small part of her full array weekly activities.



Figure 56: van Duffelen, E. and Yarmol, C. (2019), *Laura*. [Felt tip marker and pencil crayon on cartridge paper, 8½" x 11"].

When asked about her experience at CVS Laura said that the programs were good but not long enough. Recently Laura needed Emily to be engaged for more than a two-hour time block so that Laura could care for her ill sibling. This longer engagement was how Emily's art company, mentioned in *Consider Themselves to be Artists* section, *Emily Parsonson Productions* got started, "She was making extra cards with somebody from the studio because I needed her busy...She has business cards that she flips out to total and complete strangers who have no interest and carries them in her purse (Personal communication, November 17, 2019, Line 6)". Art making was so integrated into her routine that she created art at home on a regular basis. Laura said that Emily had sold a lot of cards but that, "it's a pittance of money in terms of the actual amount of money it costs to keep something like rolling because you have to buy so many supplies. Anybody's who has ever taught art knows there's no money to be made so this has nothing to do with making money and everything to do with empowerment and encouraging her feel good about herself (Line 8)".

***Artist as self-concept.***

Laura acknowledged Emily's self concept as an artist is well-intact. Laura states, "I think we may have tipped the scales TOO FAR because she really thinks she's all that [Laura

emphasizes TOO FAR with an elevated volume. She chuckles.!] She's pretty creative (Line 9).” Laura said that Emily definitely considers herself an artist, and she shared an anecdote that happened while Emily was getting her hearing aids fixed. Emily told the audiologist technician:

“I'm an artist [Laura says in a higher pitched voice.] (Line 12)!”  
And he says, “Oh great (Line 13)!”  
Emily says, “Yes, my work's been compared to Jackson Pollock (Line 14)!”  
The guy says to her, [Laura laughs.] God help him, “Who's Jackson Pollock (Line 15)?”  
And then Emily, my daughter who is not particularly patient with him says, “You don't know who Jackson Pollock is [Laura's voice rises, and her eyebrows rise up.] (Line 16)?”  
And then she wasn't particularly sensitive or kind, so I gave her a hard time when she came out (Line 17).

Emily would share with anyone who would listen that she was an artist and that she had her own company, *Emily Parsonson Productions*.

#### *Available studio supports.*

When asked about how the instructors support Emily's work as an artist, Laura stated that the instructors were very patient with her and tried to teach her skills, like lighting, colour theory, shading, or how to create three-dimensionality (Line 21). She showed a painting Emily completed of her favourite show, *Dancing with the Stars* (Figure 57). “Her art is very interesting and lovely and bright and colourful but fairly rudimentary but this one... [Laura points to the background of a colourful painting waving her hand back and forth Figure V.]. I don't know what



Figure 57: Parsonson, E. (2019). *Dancing with the Stars*. [Acrylic paint on canvas,

you call this one...perspective (Line 22)? They must have been working on perspective because that isn't something that would have come naturally to her because she normally paints two-dimensionally” (Line 23). When the parent had little knowledge of formal art terminology, she/he/they were pleased that some basic art instruction was done at the studio.

#### *The funding process.*

When asked about the family's experience with the funding process Laura discussed that with respect to other families, Laura knew they were a privileged family because both she and her ex-husband were retired teachers. “I can get her everyday to something ‘cuz I got the gas, I got a car and I got the money and, ... I'm retired and I can make it happen” (Line 40)! Emily got

ODSP and *Passport Program* funding so they had the funds for Emily to attend most activities but Laura contended that, “the cost of these things is going up and up and it is less time (at the programs) [Laura raises her hands one on top of the other.]” (Line 38). Laura gives the example that it used to be \$100.00 for a 10-week 2-hour class and now it is now \$150.00 for an hour and half class (Line 39). Getting more and more agitated as she talked about it, Laura emphasized:

So, it's expensive and it is absolutely unfair there's no such thing as a workshop that they can go to all day for free anymore it's all “pay as you play”, “pay-as-you-play” (Line 35)! (During the interview a friend of Emily’s from one of the programs calls Laura on her cell phone to talk to Emily. The friend who cannot go to CVS on Mondays because she does not have the money...). Half of them don't have transit money to get there (Line 36)! Half of them can't afford the Presto Pass and they can't afford the fee so it's very.... I don't know what your question was, what was it (Line 37)?

Laura explained the *Passport Program* funding describing it as “onerous”. She asserted that many of the people with CIDs cannot handle the paperwork and that, it was illogical to “have paperwork standing in between someone who has an intellectual disability and something to do. It's not their strength, it's like saying you know I'll give you..., give you \$100 if you can make change. They can't make change! It is not good. I don't have enough time [Laura huffs exasperated.]. (Line 44)!” Laura did much community work to raise money for people who do not have the funds to attend CVS so that they do not, “sit at home languishing” (Line 43). Harold attested to the fact that Laura just forwarded grant money she applied for to support individuals who lack funding and want to attend CVS (H. Tomlinson, Fieldnote, December 3, 2019).

#### *Benefits and drawbacks of studio art programs.*

When asked about the benefits and the drawbacks of various community/studio art programs for people with CIDs, Laura saw socialization as the number one benefit of the programmes at the studio stating that the program is:

Great for socializing because who they think their friends are. They think their friends are the people who are at these things. And many of them can't have ‘natural’ friendships. They are not being called by people. They don't get phone calls so the people they see at these classes become their friends. Even the fact that they are transient, and the class numbers changed so socialization is a number one benefit (Personal communication, November 17, 2019, Line 42)!

Laura underscored the social importance of the classes, “For some of the classes like photography, they take them out to parks and things like that, so once again its very social exercise out in the community” (Line 51). Laura asserted that, “These short opportunities that

they have at the art class, it's more than art...that's what you should call your show. It's more than art (Line 80)! It is the opportunity to socialize while making art. Emily thoroughly enjoys the company of people like 'funny guy Matthew'. She just has to say his name and he starts to laugh. I don't know what that guy says that tickles her fancy, but he does (Line 89)! There is something about that guy she likes [Laura makes a waving motion in a circle with her right hand.]” (Line 90). Laura deemed socializing as the primary benefit to the CVS program.

Laura believed that the positive social atmosphere at the program was created by the strength of the program staff (Line 61). Laura shared her sense of Emily’s experience as an artist with regards to the studio staff and the atmosphere they created at CVS:

It has been wonderful for her. For her sense of self. She has a... [3 second pause] she has a good sense of self anyway but she particularly has been encouraged by Harold and Alex and lady this lady named Bev and I don't even know who the other girl volunteers are there...you may know now that you are there now... but she's been really empowered by people there to see really see herself and to think of herself as an artist and that's a good thing. When for most of your life, every classroom setting you were ever you were told what you couldn't do, what you were very good at doing, what a failure you are [Laura laughs.]. It is nice to go somewhere people celebrate you. She is somewhat celebrated. They all are! The other...they all are ...Nobody ever says, “Conrod is a better painter than you.” No, no [Laura nods her head from left to right in a no gesture and raises her index finger on her right hand into the air wagging it back and forth to indicate no.]. Nobody ever compares them! They are not pitted against each other they way they are in the school system [Laura raises her hands and folds them switching her fingers back and forth.]. Here's the 90 percent and here's you. So, it's so very ah.... egalitarian---Is that a word? [Her hand moves in a circle around and around.] (Lines 71-78).

Laura explains how the school system was a place of comparison that often decimated the skills and the self-esteem of people with disabilities. The residual scars of negative school experiences were verbalized and then silenced in the interviews with Anna, the parent of Sabrina, and the CVS artists Steve, Astra, Conrod, and Jack. Laura highlighted the importance of the atmosphere established by the staff’s attitudes at CVS that helped to empower Emily to consider herself an artist freely creating art.

Respite time for caregivers was the second perk the program offers that Laura cherished. “Respite for the parents. [Laura rolls the R.] Let me repeat RESPITE for the parents, number 2 [She rolls her R and holds up 2 fingers on her right hand in a V formation.]. Maybe repeat again. RESPITE for the parents” (Line 48). Laura expressed that she loves her daughter and said that her life has been enriched by her, but she silenced the unremitting issues in living and managing

someone with a CID. In emphasizing the social aspects of the studio and the benefits of the studio's programs, Laura delved into deeper issues at stake in the big picture in the lives of people with CIDs and their caregivers:

And it's not my voice (at the studio). Nobody needs to hear more of their parents... all of these people.... She's 36! Nobody should live with their parents when they are 36 [Laura grabs the camera and repeats the last phrase.]! I want to tap out! Tap the mat [Laura slaps her leather sofa.]! She doesn't want to be with me either. She doesn't have any ability to get out and get her own place [Laura put both hands together in a triangular prism formation then makes a circular gesture with her right hand to indicate 'out'.] and decorate and have friends...and drink hard and do whatever they do in their own places. But she wants it [Laura wags her index finger of her right hand in the air.]! And the closest she can get is these tiny step outs into these little programs [Laura gestures with her hand as if she is organizing seeds in various containers.]. She's telling me everyday that she wants to live alone and be independent and there's no where for her to go to live. And all the residential lists... she has been on a residential list since 18...she was 18! She has been on a list for half of her life to get into any kind of independent supported living. So, we can't have that... So instead we buy an hour and a half of art, two hours of photography class and there, and there, and there [Laura puts her hands 15 cm from one another and gestures downward three times.]. Because we were trying to come up with some kind of approximation [She emphasizes the word approximation.] of an independent life. Yeah [She scratches her head.]! It is, but it's too much for your deal but, ...but it is a lot of why people send them because we want them to have a meaningful life. You want them to have a productive life, you want them to have a happy life [As she says each answer, she stretches out a finger listing them on her right hand.]. They want, they want that. They want to be happy and a lot of them get that from art [Laura points to Emily's Dancing with the Stars painting.] (Lines 91-109)!

In this conversation, Laura focused on the actualities of social policies implemented and the emotional realities for people with CIDs and their families on the receiving end of those policies. Emily would have liked to live in a supported residential setting<sup>123</sup> independently attending programs but does not have the means to do so. A loving mother's frustration and fatigue was expressed with a situation where there was no simple solution. Laura has been an advocate of Community Living for 36 years. She has spoken to hundreds of parents in similar situations. Programs like the one offered at CVS do not solve the issues apparent in social policy support systems. For some individuals, being an artist who actively creates art was one way to have a

---

<sup>123</sup> "The waitlist for residential services sits at 11,000, and it is common that adults have to wait more than 20 years for residential supports (Beesley, 2018, June 8)". This statement is from Community Living Ontario CEO Chris Beesley upon election of the new PC Government in 2018. Beesley urges the premier to take action to provide necessary housing options for those with IDD's. It seems that crisis situations are dealt with first. Retrieved from Community Living Ontario. <https://communitylivingontario.ca/en/statement-from-community-living-ontario-ceo-chris-beesley-regarding-the-election-of-pc-government/>

meaningful, well-rounded, independent life—a way to attain cultural citizenship in their communities.

The third most important aspect of the studio was art skill development that enabled Emily to create art and consider herself as an artist, giving Emily “...something for her to talk to people about” (Line 52). A description of the studio art skills was provided in the section about how the instructors support Emily’s work as an artist.

Laura was open about the drawbacks of the program throughout the interview. She mentioned both the length and the cost of the program as shortcomings. “I have nothing but good things to say about the studio except that it is very expensive. I'd love to have any program of 4 hours” (Lines 78-79). Laura praised or “sings a song of wonder” for the efforts of Community Living, Christian Horizons and Reena who offered many, “No money” events for participants (Line 62). She said that, “They all have their arms tied and crossed because of the premier of Ontario” (Line 63). She begins to discuss the political climate where “Community Living Toronto hasn't had any new money from the government for 10 years” (Line 64). Laura is referring to Bill 148 and its revision Bill 47.

And there are more and more and more people in service with less and less to do in the day. All the workshops have closed. Yeah, that was a great idea and maybe they were getting paid too little... little pay packets of \$0.15 an hour putting widgets and smidgets in bags but you want to know something they didn't know what was in those pay packets and they didn't care they wanted a place to go to every day with their “friends” [She makes the gesture of air quotes when she says friends.]. And now the workshops are all closed [Laura makes a sweeping gesture with her hands.] and it's up to the parents to miraculously get them to and from all these little bits and pieces of whatever. You know it is a bits and pieces life (Lines 65-73).

Despite the cost and the length of the programs at CVS Laura was pleased with the service Emily received and believed that the CVS programs have supported Emily’s goal to be an artist.

*Anna Simonyi's view of program.*

Through the years Anna (Figure 58) and her partner have taken Sabrina to both privately and publicly offered arts youth programs at the Geneva Center, George Hull, an art program that Concord in the City had started (A. Simonyi, Fieldnotes September 23, 2019, Line 3). Anna acknowledges that it was Concord in the City that she liked the best but that, “It was more like a social program. It was for her to get involved with other people, to see other people and to meet other people...and just to not be at home. Anna nods her head earnestly.] I know she loves mom [Laugh] but she needs people” (Line 7). These programs were open to children, adolescents and their families but as someone ages, the number of programs diminishes drastically. In the interview, (Personal communication, November 7, 2019) Anna divulged that she has another child with autism. Her transferable skills as an insurance underwriter along with her deep love and for her children compelled her to meticulously and critically research all available options for her children. She acknowledged that the programs offered in Sabrina’s youth were mostly for parent respite. At other times she voiced then silenced her disappointment with the art programs in community and their “sameness” with respect to how they treated people with PDD<sup>124</sup>. “They want everyone doing the same thing at the same time and don’t



Figure 58: van Duffelen, E. and Yarmol, C. (2019), *Anna*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

---

<sup>124</sup> According to Autism Speaks (2019), “PDD-NOS stands for Pervasive Developmental Disorder-Not Otherwise Specified. Psychologists and psychiatrists sometimes use the term “pervasive developmental disorders” and “autism spectrum disorders” (ASD) interchangeably. PDD-NOS became the diagnosis applied to children or adults who are on the autism spectrum but do not fully meet the criteria for another ASD such as autistic disorder (sometimes called “classic” autism or Asperger Syndrome). Like all forms of autism, PDD-NOS can occur in conjunction with a wide spectrum of intellectual ability. Its defining features are significant challenges in social and language development. PDD-NOS is characterized by delays in the development of socialization and communication skills. Parents may notice associated behaviours as early as infancy. These may include delays in using and understanding language, difficulty relating to people, unusual play with toys and other objects, difficulty with changes in routine or surroundings and repetitive body movements or behaviour patterns.

appreciate difference. Sabrina does not fit into that mold” (A. Simonyi, Fieldnotes, October 30, 2019).

When talking about her views of the programs at CVS, I told her that Sabrina had shared that she had been in drawing, painting, sculpture, mixed media and i-pad classes (S. Simonyi, personal communication, Oct. 12, 2019, Line 2) and that Sabrina liked to “do new things... to use your imaginations [sic]” (Line 6). Anna articulated that, “It has been wonderful [She smiles.]” (Line 11)! Anna clearly communicated the overall welcoming atmosphere of CVS. She appreciated that her daughter is openly accepted at the program without question of her age, ability, artistic preferences, likes and dislikes. She confessed that she was scared the first time they came because Sabrina “was right out of high school, and most of the people we were so much older than her. I wasn't so sure how that was going to work” (Line 12). “They were so accepting of her [She emphasizes the word accepting.]. There was no, no age between them. It was a matter of, you are here for the same thing. You know someone would walk through the door just arriving for the program and everyone would be hurray so and so is here. It didn't matter who you were” (Lines 13-14). Anna claimed that the social aspects of the program are important for Sabrina who has learned “how to have friends on a daily basis which differed from the classroom setting where everyone’s attention was on the teacher” (Line 15). She articulated that it was the participants in the class who help each other along, explaining techniques and socializing with one another, (Line 17) developing inside jokes that go on for years. Sabrina has had to understand the jokes so she can take part in them; this is new learning about the world (Line 18).

*Artist as self-image.*

CVS has enhanced Sabrina’s self-image as an artist because when she was in high school, art was a past time that they ‘allowed her to do’, “when she was finished doing everything else” (Line 29). After six years they only knew Sabrina as a student taking math taking history, but art was not part of her daily program (Line 31) the Special Education staff at high school acknowledged that Sabrina liked to draw but did not realize that she actively wrote stories and illustrated them despite parental communication of that fact. Anna told them, “If you stacked the number of illustrated stories up from the floor it would come up about two and half feet [Anna held up her measuring about two feet from the floor.]” (Line 30). Art was something that really

drove (Line 33) and engaged Sabrina and that she was invested in it. It was one domain where Sabrina felt consistent control and success.

When I asked if the family had considered a college illustration program with an art focus Anna replied, “Somebody mentioned Seneca, but they are in the east end of the city and that's a long way away” (Line 39-42). Anna believed that the programs were too far for Sabrina to get to at this point. At the same instance she wanted Sabrina to be more independent:

Yeah. [She puts her elbows on the table.] You know what? As much as I can be here with her, because I've enjoyed it too, meeting people, meeting other artists with disabilities... And seeing how this whole thing functions and seeing how she's growing into it... But in all honesty, I think sometimes, I think that she could do better without me. I think it is time! You've got to let her spread her wings (Line 45)...Not always look back and see this mom thinking is this okay [Anna waves her hand over her left shoulder. She smiles.]? Does it matter if Mom thinks it's okay, is it what do you want [She raises one eyebrow and closes her right eye slightly.]? It is your life (Line 47)!

Through both Anna's discourse and her gestures, we can see that she really wanted her daughter to be more independent but then flattened the conversation. I saw the push and pull of parenthood as she said she wanted Sabrina to, “spread her wings, it is time” (Line 45), but silenced her worries about what would happen to Sabrina if she was not there as she herself ages or becomes ill with her own disability.

#### *Available studio supports.*

When responding to the question about how the instructor supported Sabrina's journey as an artist, Anna asserted that it was not only the art skills taught by the instructors of the mixed media course, sculpture, painting and drawing classes, it was the encouragement, the compliments and positive reinforcement Sabrina received on a consistent basis, “And after a little while it becomes a part of who you are..” (Lines 48-51). Anna says that Sabrina was invited to attend the *Art from the Heart* Joshua Creek, Oakville, ON show last year (Line 53) and that invitation further enhanced her self-image because that same work that previously received compliments in the studio was now mounted on the walls of a public gallery (Line 54). At the show, Sabrina received affirmation from outside sources that built her self-esteem propelling her art making forward.

#### *The funding process.*

Anna said that Sabrina received *Passport Program* and ODSP funding that helped pay for the 4 classes she enrolled in at CVS. Anna declared:

We have the ODSP and I know the ODSP, I actually phoned the *Passport Program* office and said listen, she's actually supposed to be using this money to pay rent and to buy food and whatever and it is a good thing that she is living at home because she wouldn't be able to do ANYTHING [Anna puts emphasis on the word anything.] so we are supporting her and we are like allowing her to use her money to do programs because otherwise how is she supposed to do this? Right? It took over, I think it took over four years before we got the *Passport*. The ODSP was much quicker [Three-second pause. Anna shakes her head back and forth.]. Ummm yeah...But the *Passport* was the same thing we'd phone up and, well, we know, and we know that she is on the list, but you have to wait...And you must have every single receipt (Line 63-69)!

Anna acknowledged that funding was a complex issue. She mentioned that *Passport* funding could go towards travel as long as someone else other than herself drives to the program or one took the bus or an Uber (Lines 71- 73). Without these funding options and her parents financial support of room and board Sabrina could not have attended these classes.

*Benefits and drawbacks of studio art programs.*

Anna listed the benefits and the drawbacks of programs for people with CIDs stating that the social aspects of the program were of paramount importance. Anna said that Sabrina has a “wonderful personality but because she has PDD and PDD people especially her, tend to blurt out sometimes. Or umm, just get on a subject and just stick with it what feels like forever umm and it might make people climb the walls” (Line 89)”. Anna gave examples of Sabrina’s most topics of focus, Walter Matthau, *The Odd Couple*, Medusa and Greek Mythology, and Frida Kahlo. Sabrina really liked Frida Kahlo and went to see her show at the AGO several times. (S. Simonyi, Fieldnote, September 23, 2019). [Sabrina was particularly drawn in by my Frida Kahlo marionette when I brought it to the studio at Halloween time. She continually came to look at the marionette and when I visited the studio throughout the fall and winter, she would ask me about the marionette. Fieldnote, October 30, 2019.] She said that at the studio, Sabrina taught what she knew about these topics to others and it was, “Amazing because usually it’s her learning from them and now the tables are turned [Anna makes a circular motion turning both hands in the air.]. And she is teaching them. It is nice to see that she was in those shoes for a change” (Lines 90-95). The studio has been, “Wonderful for her. It is more than just a social place. It is a matter of personal growth to learn social norms and art skills all at once” (Line 97).

Anna discussed the drawbacks of the program saying, “Sabrina is...she's lucky that I'm home, right. That I have been home with them all [In the ‘all’ Anna refers to her son with a disability.] through all of this. But if I wasn't, it's a very isolated assistance... ummm” (Lines 81-

83). Anna experiences her own chronic illness, so she is at home. If she was working, Sabrina might not be able to attend these programs at CVS on her own (Line 84). Anna shared that she was trying to teach Sabrina life skills like how to cook and how to do laundry so she could eventually learn to live on her own (Line 89).

A major drawback of attending the studio was that Sabrina did not know how to travel to the studio by herself. Anna said, “I would like to be able to get her to the point where she can travel, like leave home on her own, come in on her own. I mean. I know that it might be through Wheel-Trans or some sort of assisted travel thing, but I would like to get her to that point. I don’t think that she always needs me” (Lines 98-100).

Transportation to and from the venue due to physical disability, fear of travelling by oneself or parents’ fear of the child’s safety were roadblocks expressed by all three parents (Note that later in this findings chapter, Shannon an instructor at CVS also divulges that she has a son with a CID and was worried about how he would get to his programs.)

***Shannon Groom’s view of program.***

The interview with Shannon Groom (Personal communication, November 25, 2019), an instructor at CVS and SWACA support worker brought about a surprise. Throughout her interview, Shannon answered the art instructor questions with a knowing surety and passion, but near the end she disclosed that she wears “two hats: one of a staff member and one of a parent of a child with a disability” (Line 114). Her concern for the future of her child emerged because she works in the system which has a limited number of options for individuals with CIDs; she knew the challenges she would face finding placements for her son. She declared: “And I want something for my child that makes him get up in the morning and feel like a productive adult” (Line 118). Shannon explained the realities of our social policies from her experiences both as a parent and an employee at Community Living:

Right now, he is a kid, so he goes to school. But as he ages out of the school system...What is there for them to do? There is nothing for them to do! After age 21 you are... kind of in this parental limbo [She makes a scale with her left and right hand which moves up and down in the act of weighing options.] [She pauses for 4 seconds.]. What is there for them to do? They can’t work anymore unless, they can get paid minimum wage. And, you know they’re not [She shakes her head back and forth.]. It is not easy to get a person with a disability a minimum wage job. It is not easy! So, what do you do as a parent? You want them to feel good about themselves, to give them a sense of pride, a sense of accomplishment... especially if you have an artsy kid like my kid is, a theatre kid. There are lots of programs for kids but there are not lots of programs

for adults [She shakes her head back and forth in a no gesture.]. Life ends at 21 if you have a disability! And it does not!... Well there's no full-time spots anywhere. There's no base funding anymore. So, if my son ages out of the school system, I'm still going to be a working parent because I can't afford to drive K around everywhere where he needs to go. Driving him 2 hours here two hours there...that doesn't fill up his day! I don't know what I said... (Lines 120-133)

There are few provisions or opportunities for people with CIDs and the responsibility is left to the parents who themselves require support and respite. Organizations like CVS provide an environment to build skills and build communities where individuals can become artists. Because Shannon has had an inside view of how programs in this province operate, she wanted more opportunities for her own child to become an active part of society. She continues:

We define ourselves as things... like a social worker, a teacher, a doctor, a mother ...like whatever. Like when they go to Creative Village Studio, they can finally define themselves as artists, as SOMETHING and someone! They...they have a role, they have a title, and that comes all down to social valorisation. All the things that are important to people without a disability are important to people with disabilities. Why do we think it otherwise? It's the SAME [She emphasizes the word *same*.] [5 second pause.] (Lines 135-140).

Shannon spoke about the importance of work to engender personal fulfillment and happiness. This emanated from both her experience and her academic training as she has an awareness of disability German American disability theorist Wolf Wolfensberger's (1983,1972) research. Wolfensberger adapted his theories of the principle of normalization (Lemay, 1995; Wolfensberger, 1972) into the concept of Social Role Valorization (SVR) for the lives of people who are considered disadvantaged because of their perceived status in society. Wolfensberger's associate and director of Indiana Safeguards Initiative, an SRV-based project Joe Osburn (2006), explains that a basic idea of SVR is that the benefits inherent in specific cultures are more easily accessible to people who have valued social roles (p. 4). Osburn asserts that there is a high degree of consensus in the Euro-Western world about what the good things in life are (Wolfensberger, et al., 1996) and lists a few major examples being accorded: dignity, respect, acceptance; a sense of belonging; an education, and the development and exercise of one's capacities; a voice in the affairs of one's community and society; opportunities to participate; a decent material standard of living; a normative place to live; and opportunities for work and self-support. SRV is often employed in reviewing the services for children and adults with

impairments and elders who are perceived and interpreted as “deviant,” due to their negatively-valued differentness (Osburn, 2006) to enrich their social situation or to create or support socially-valued roles for people in their society. Wolfensberger (1985) encouraged, “the use of culturally valued means in order to enable, establish, and/or maintain valued social roles for people” (p. 61). He believed that if, “a person is accorded valued roles, life conditions, experiences, valued participants, autonomy, and choice that are available to at least the majority of other people of the same age and sex and... [when] these things have been accorded because the person is seen as valuable” (p. 31) and they can flourish.

As Shannon astutely pointed out, the act of considering oneself an artist or an actor can help an individual with a CID to gain social status as it can carry some cachet for the individual and for society at large. The society can see the artist as a valued member of society perceiving disability itself in a new, valuable and enlightened way. Places like CVS help to break down barriers about what it means to have a disability.

Aspects of disability and work theorist Dustin Galer’s research about identity formation of people with disabilities through their experiences and perceptions of work (2012) mirrors both Wolfensberger’s SVR concept and Shannon’s claims:

Many people with disabilities share the mainstream ethos that participation in the competitive workforce constitutes a primary feature of their identity. While unpaid work may fulfill the desire to be productive and provide a sense of purpose and contribution, the cultural imperative to achieve personal autonomy partly through material independence situates paid employment at the centre of personal identity formation.

Galer underscores “the importance often placed on work in the process of identity formation” through employment in the studio working as artists, the participants of CVS construct their self-identities. Galer’s four major themes about employment emerge in the narratives of artists who come to the studio on a regular basis including material drivers, performative sociocultural roles, image management, and emotional aspects. The theme of material drivers appears where work provides them with a sense of contribution or “giving back” to society, the economy, and a larger disability community; the theme of performative sociocultural roles where work [as an artist] was seen as confirming to themselves and others that they possessed a complex and multifaceted identity beyond the “master status” of disability; impression management where some participants felt it was necessary to actively manage their image around employers [instructors], coworkers, and to the public who enters the studio; and emotional factors where work was

closely connected to emotional health and individual identity goals [due to the subject matter selected and personal styles]. Many study artist-participants considered art making at CVS their job. Although knowledge of the economics of purchasing art materials, framing and sale of artwork may not be readily evident for the artists at CVS, their interviews indicate a realization that when their artwork is sold, they earn money and the independence to purchase goods they desire. They experience a sense of pride that someone has chosen to procure their artwork (Personal communication with Astra, Conrod, Donna, Emily, Johnfredy, Juan, Lisa, Neil, Patricia, Quyen, Steve, 2019). It is not only how they see themselves, but how they are seen by others in their families and in broader society.

One artist with a physical disability, Sunaura Taylor (2004) has voiced her views on work. She considers herself fortunate that she has been raised with a belief in her own inherent value knowing that she cannot work in a normative way. Taylor reveals that, “Many disabled people [sic] seem to carry a deep “non-working guilt,” even if they are successful in other areas. In the Canadian documentary film by her sister Astra Taylor, *Examined Life*, (Marin, Imperial, Mann, Basmajian, & Taylor, 2008) feminist philosopher Judith Butler and Sunaura Taylor discuss views of disablement and dependence. Butler asserts that it is a, “false idea that the able-bodied person is radically self-sufficient” and works independently in their communities. Why should people with disabilities feel guilt or pressure that they absolutely need to work? Butler likes Deleuze and Guattari’s (2004) question, “What can a body do?” as it isolates a set of capacities and instrumentalities or actions. Butler (2004) believes that, “we are assemblages of these things —it is not like there is an essence or a morphology of what a body should look like or what a body should move like”.

Although the perceived end point was learning about the CVS’s operational strategies and how they affect their children, the parents communicated alternate end points. A running theme through the parents’ narratives was that they want their children to feel good about themselves, to be happy, to give a “sense of pride and a sense of accomplishment” living lives as productive adults. What is unsaid but evident is that their children are participating in and have become part of a cultural community experiencing aspects of cultural citizenship. Those individuals who have artistic ability and interest in visual and performing arts require supportive venues to engage in art making of which there are few. Art making was one way that their children gained both social acceptance and personal fulfillment from creating a finished art

product on their own. Additionally, parents' voiced concerns surfaced regarding the eventual care of their children and the lack of social policies to support their children as they moved into adulthood.

### **Interviews with instructors.**

Since the study participants made frequent mention of the importance of their instructors, I believe that the instructors' voices should be included in the dissertation. A list of questions I asked the instructors are in the Appendix T Interview Questions: Questions for Instructors.

### ***Yona Reznick.***

Yona Reznick (Figure 59) was an art therapist who was hired privately to support a client at CVS. She was also scheduled to run a class at the studio in the winter. She was

trained as an art therapist, who was taught to accommodate the emotional, physical and psychological needs of a wide variety of clients (Line 4) and has chosen to specialize in working with youth with learning disabilities (Line 5). Although I was able to interact with Yona in the studio, Yona had responsibilities to her client and did not feel it appropriate to use face-to-face time in the studio. She also felt more comfortable answering interview questions in written format (Y. Reznick, personal communication, December 3, 2019).

Yona shared that she had an inner drive to create, spending much of her free time creating her own art and appreciating art; she had a background in art history (Line 7). She found that working with her clients was both rewarding and transformative for the participants (Line 6)!

When asked about the kind of art the participants create in the studio art classes and what her client creates Yona said, "There is such incredible work happening at the CVS! Participants are often creating work to be shown in exhibitions, sold to patrons, and for their own personal enjoyment (Line 8). Her client named "C", "is always very busy creating new pieces to be sold as commissioned works" (Line 9).



Figure 59: van Duffelen, E. and Yarmol, C. (2019), *Yona*. [Felt tip marker and pencil crayon on cartridge paper, 8½" x 11"].

When asked about how CVS has enhanced her client's self-concept as an artist, Yona shared that when her client first came to CVS they had, "a strong desire to create, but without any real direction or space to create freely". Now their self-concept had, "most definitely" been enhanced as her client now had "a space of their own, other creative friends to visit weekly, and an incredibly supportive artistic environment for them to flex their artistic muscles" (Line 10). CVS had inspired confidence in C. C brought work that was started at home into the studio to complete and vice versa. Yona believed that the goals for the artists at CVS were not only art making but socialization and community-building as artists through the "supportive and creative energy about the place" (Line 16). She had witnessed an openness and overall growth mindset in the artists over the course of the year. "They are active in their creativity and their enthusiasm for art making (Line 12). The instructors and volunteers supported the artistic process of artists by laying out the supplies for easy access, printing photographic references for the artists to use in their work, or providing accommodations like drawing on paper, transferring and mounting the drawn images to canvas" (Line 14). Yona saw the following challenges at CVS. The first challenge was:

Mobility in arriving and leaving the studio. Frequently, participants are left waiting for 30 minutes or more before their scheduled Wheel-Trans bus arrives for them. As a result, scheduling for programming can be a challenge for many of the CVS artists. Secondly, funding for materials is limited, which results in limited opportunities for the artists to create to their fullest ability (Lines 16-18).

The issue of transit times with public transportation was one that is ever-present for people with disabilities. Supply costs were the bane of artists' existence and indeed facilitators, educators needed to support the artists keeping costs in mind and budgeting accordingly when project planning.

To enhance programs at the studio Yona suggested that exposing the artists at CVS to a range of different styles and techniques in a number of disciplines could be beneficial. She gave the example of a visiting artist who does paper-making techniques or a fabric artist (Line 20). Yona communicated her belief that, "The studio is a very special place for everyone who visits regardless of physical or mental ability" (Line 22). Yona's end point of discussing the mechanisms that inspire artists with CIDs to create matches the researcher's end point.

***Cait Mitchell.***

The CVS artists spoke about the positive experiences they had with former photography instructor Cait Mitchell (Figure 60), who taught from 2008 to 2010 (Mitchell, n.d.). Since Cait moved to northern Ontario and no longer instructs at CVS, I decided to learn more about her through her online portfolio<sup>125</sup>. Through her website, I located her and requested an interview. Due to her time constraints, Cait agreed to answer my questions in written format<sup>126</sup>. CVS photography class instructor Cait Mitchell earned her Bachelor of Fine Art in still photography from Ryerson University in 2006 (C. Mitchell, personal communication, January 6, 2019, Line 4). Harold (H. Tomlinson, Fieldnote, January 20, 2020) said that Cait realized the positive power art could elicit with people with CIDs at CVS and took this knowledge forward to use in her social justice work with marginalized communities. In 2012, she earned her Bachelor of Social Work (BSW) from Laurentian University (Mitchell, n.d.).

Cait taught photography, a weekly day program through the Employment Training Services centre and a weekly evening drop-in at CVS. She said that she had no experience or training working with people with cognitive or intellectual disabilities but had learned about the possibilities of photography in art therapy taking an extra year in her degree program to complete psychology courses that were prerequisites for various art therapy programs as well as extensively reading about art and expressive arts therapies (C. Mitchell, personal communication, January 6, 2020, Lines 6-8). In the interview,



Figure 60: van Duffelen, E. and Yarmol, C. (2019), *Cait*. [Felt tip marker and pencil crayon on cartridge paper, 8½" x 11"].

<sup>125</sup> Her online portfolio Cait states, “I believe images are a way of knowing and a method for healing, discovering ‘truths’ and recording histories. Using traditional and new technologies, various methods and media I use image-making to document my present, past, and heritage. My personal work encompasses themes around nature, memory, ancestry, the manipulation of space and time, and the effects of development on our social and physical geography. I enjoy the many possibilities of exploring multiple disciplines.”

<sup>126</sup> I find that face-to-face narrative interviews allow more open-ended questions that build upon the interviewee’s answers leading in new directions while written format is less fluid and engaging as it relies simply on a question/answer mode.

Cait did not mention her emancipatory work as a photographer, mixed media and video artist<sup>127</sup>.

On her “About” page located on her online portfolio Cait (Mitchell, n.d.) said:

Being involved with community arts is important to me because collaboration and sharing stories is both enriching and essential. I recognize the therapeutic qualities of the arts and see great value and potential in using creativity to promote literacy, awareness, positive change, social inclusion, and resilience. Collective creation challenges assumptions, builds bridges, strengthens relationships, and can help identify priorities and assist with finding new possibilities and opportunities for growth. Facilitating, contributing to, and documenting community engaged art projects it is extremely fulfilling for me, encouraging and demanding critical reflection and interrogation: processes which are integral to my own creative process.



Figure 61: Mitchell, C. (2010). *The Photographers*. [Digital photograph].

This quotation demonstrates that Cait had a growth mindset and that she recognised the stellar photographic work artists with CIDs could make if taught a basic skill. In her interview, Cait described the structure of her studio photography class that included going on field trips to various places around the city to take photographs like Riverdale Farm, Centre Island, High Park, Centennial Park and Etobicoke Conservatory, downtown locations at various parks and the Canadian National Exhibition site (Line 10)

(Figure 61). Cait described in-studio work using studio lighting such as still life compositions, portraits of others, and self-portraits. The artists’ images were also used to collage mixed media images with a focus on composition. She mentioned that the artists also participated in the Contact Photography Festival in 2009 (Lines 11-13) (Figure 62).

Cait’s objectives for the artists were to learn how to use the camera to express how

---

<sup>127</sup> Cait has been actively involved in the Sudbury community as an artist, a researcher and an activist; Aboriginal healing garden in Sudbury; video with drumming (2011); Aboriginal Day celebration Ste. Anne Community Garden, June 21, 2011; Poverty, Homelessness and Migration (PHM) study project; Community-University Research Alliance (CURA) (2013); Advanced Practicum Project, Masters of Social Work (MSW) Open Arts Studio-An Arts Based Experiential Program 2014-2015 with the Elizabeth Fry Society Sudbury Branch for women in custody at the Sudbury District Jail, (2014-2015); -Holistic Arts-Based Program (HAP) 2014; Myths and Mirrors (2015) series of multi-disciplinary arts activities for women with lived experience in sex work; and Project ArmHer is a multi-year, multi-media, multidisciplinary project partnership between SWANS (Sex Workers Advisory Network Sudbury).

they saw the world; she wanted her artist-students to practice finding beauty in the ordinary, to challenge the way the artists saw the world and how they are seen by the world (Lines 15-16).

The accommodations Cait made were to gather and sort the digital images on a computer (Line 18) as participants did not have access to the equipment; they had not had the opportunity to practice organizing their digital work. She explained that there was always someone from Community Living Toronto co-facilitating except at the drop-in where

there would be a CLT staff in the studio but not actively participating in group unless emergency additional support was required (Line 19). Cait said her challenge was that, “The program involved a lot of behind the scenes work including managing and preparing digital files, equipment maintenance and that I had to use of some of my personal equipment” (Line 27). The job could not be completed within the time parameters of payment resulting in “volunteer time” (Line 28). More equipment at the ready needed to be made accessible to participants to prepare their digital files. One drawback was that artists taking photography had to have their own cameras or cell phones. Some funding from the *Passport Program* can now be allotted to the purchase of a cameras for those who receive it. In Cait’s eyes, the photography program was successful:

I think the photography workshops were a great way for the artists to get out of the studio and explore the world, to see and to be seen creating (Figure 46). Audiences were often surprised at how engaging the images the artists created were. In the studio lighting workshops, artists had the choice to be in front of or behind the camera (or both) and could choose how to be represented. I think the program promoted confidence and empowerment (Lines 21-25).

The participants reported that Cait taught them basic skills like how to look, “in the box-thingy [viewfinder] and line up a shot before we took a photograph” (J. Salazar and L. Tuckwell, Fieldnote: Photography Out Trip, personal communications, October 16, 2019). Many of the



Figure 62: Mitchell, C. (2010). *Contact Photography Exhibit: Creative Village Studio*. [Photograph of Participation in the Contact Photography Exhibit, Creative Village Studio from <https://caitmitchell.myportfolio.com/creative-village-studio>]



Figure 63: van Duffelen, E. and Yarmol, C. (2019), *Shannon*. [Felt tip marker and pencil crayon on cartridge paper, 8" x 11"].

photographs taken by artists enrolled in Cait's class were sold at various community art shows and at CVS.

### ***Shannon Groom.***

Shannon Groom has played multiple roles in the disability community (Figure 63). Her background was in theatre and social services. She attended a program at Humber College (S. Groom, personal conversation, November 25, 2019, Lines 8-10) and social services training for behaviour analysis at George Brown College (Line 16). Shannon worked for Etobicoke Parks and Recreation Adapted and Integrated Services in the early 1990s and with VITA Community Living Services<sup>128</sup> (Line 20). She has

been a support worker for 20 years at SWACA (Line 18). Shannon is also the mother of an 11-year-old boy with an intellectual disability (Line 130). More recently, Shannon worked as an instructor of i-pad classes at CVS and theatre groups at SWACA. Shannon shared that i-pad class that she taught at CVS were, "low key and not really art based" (Lines 34-35) as they involved guiding the participants to follow their own interests on the tablets. CVS acted as the

---

<sup>128</sup> According to their website (*VITA Mens Sana*. 2020), Vita Community Living Services (Vita CLS) founded in 1986 is funded primarily by the Ontario Ministry of Community and Social Services to provide a range of community-based, person-directed services for adults with developmental disabilities and dual diagnosis (a developmental disability and mental illness) that foster independence, enhance quality of life and community inclusion to optimize personal growth and independence and contribute to advancing the sectors within which they work as they grow and change throughout their lifespan. VITA helps families navigate Ontario's Developmental Services System offering respite services, clinical and educational services (CES) that provide therapeutic interventions and learning opportunities to help members acquire new skills and develop the abilities to live with a sense of well-being and support for the achievement of their life goals.

Mens Sana Families for Mental Health (Mens Sana) was created in 1991 by families in York Region who came together to support one another, and to provide the services and supports their family members needed. Funded almost exclusively by the generosity of donors (who first began in the Italian Canadian community), Mens Sana offers residential supports, clinical and referral services, and day services for adults with chronic mental illness. VITA operates about 70 residential programs including full support homes, supported independent living apartments and enhanced supported independent living apartments and run seven-day, community participation programs in King City, Richmond Hill, Markham, Vaughan, Thornhill and Toronto.

venue where the class was held and many of the participants are enrolled in other classes on the same day in the morning or over the course of the week.

The SWACA theatre group had a partnership with Lakeshore Arts and put on a performance last year (Line 24) where they created their own dances, their own skits and, their own performance pieces expressed through ensemble pieces (Line 26). Shannon described that the strategies used in this class were like those used in any drama class requiring little accommodation (Line 46).

Through basic instruction from both Shannon and the Lakeshore Arts facilitator, actors engaged with ease in “brainstorming, had peers supporting peers to come up with ideas, putting thoughts to music, putting movements to music” (Line 30). Each class they, “warmed-up, and went through theatre techniques...with much skill building in those classes, public speaking...speaking clearly, and relaxation” (Line 50) using “other skills that they could take away, not just art skills but life skills” (Line 52). Shannon emphasized that, “It [the resulting performance] was about daily life. It was not disability-based at all; it was people base [As she says the word *people* her palms turned outward and upward to face the ceiling in a quick pushing gesture.]. It was our participants showing their talents” (Lines 31-33)!

When asked what she thought the goals for the artists taking her drama classes were, she said that her end goal was for them, “to feel proud of something that they created. And to feel like they were part of a group performance” [Shannon puts her hands in the air forming an imaginary globe to indicate group.] (Line 40). Communicating the performance objectives Shannon articulated:

I wanted a group performance, that wasn't for a lack of a better term, that was “good for people with a disability” [Shannon motions air quotes in the air with her index and middle fingers on her right when she says, “a disability”.] (Line 41). I wanted people to be like, ‘Yeah that was good’! Take the disability out of it [She chops the air with both hands as she says ‘disability’.] (Lines 43-44).

Participants ultimately wanted to be successful and to be seen simply as performers and not as people with disabilities. Shannon knew that the performance and the drama classes were a success as parents and participants asked when the next session and performances would be because they enjoyed the experience and wanted more of it (Line 54); her pride in reaching her goals was evident as she described the performing arts program in detail with great enthusiasm.

According to Shannon, the challenges of the arts programs were, “Just having enough time to create, what we wanted to create. And you know budgets! Money is always a ...problem...a problem with anything in social services. It's a problem with anything in the arts and combine arts with social services and forget it. You have no money [Shannon shakes her head back and forth emphasizing no money.]. No money there (Lines 56-62)!”

When asked to add any further comments about the program, its delivery, and effect on participants, Shannon shared her views about the importance of the visual and performing arts for people with disabilities:

[Fingers pressed together she makes a point with the left and the right hand up pointing up to the ceiling in a contemplative prayer position.] I just think all arts programs are valuable. You can't put a dollar value on the value that an arts program brings to somebody. It can take somebody who, [2 second pause.]... they may not be able to speak, but they can express themselves through art [She emphasizes the word express.]. They can feel good about themselves through somebody's compliments about their work. When you walk into Creative Village, you can see the pride in the artists' work. And that is something that I feel is so [She emphasizes the word so.] important for people with disabilities. It is important for all people but especially for people with disabilities to have a sense of pride, to have a sense of accomplishment, to feel included, supported and free to take risks. Because with art, and anything to do with art there is a vulnerability [Shannon points both hands at her heart.] that you put yourself into [Both of her hands tap the table in front of her.]. And our participants are already vulnerable, so for them to take that added risk, in a safe environment like Creative Village, there's no, no...There's no better way to do it (Lines 68-76)!

In this interview, Shannon highlighted the core of the program's goals: to build self-esteem, a sense of accomplishment, skill and community through art. She tapped into the idea of an artist's vulnerability revealed while presenting artwork or performance piece(s) to the public where it was viewed and judged. When an artist's work is critiqued, the artist needs to have the strength to withstand the criticism, learn from it and move forward. When the artist's self-confidence may not be fully intact due to life circumstances, public appraisals of art or performance work can be hard-hitting, thus support systems like those structured at CVS must be in place to back up the artists, teach them to learn from the criticism, and to encourage them to continue to create.

Shannon's answers prompted another question about why a formalized art and studio program like CVS was not present in the SWACA building as artists need to practice with regularity. Shannon acknowledged that there were short sessions like *Elements of Theatre* that ran with the support of Lakeshore Arts (Line 90) only on Fridays but that, “the move to go out in

the community is such a push with Community Living [With her palms facing one another, her hands pulsate toward the wall indicating ‘out in the community’ .]...community-based activities, community-based activities, community-based activities” (Line 82) were the first priority. Shannon concedes that some of participants, “felt safer in an environment more supported with staff who they know and friends that they've established since high school” (Line 83) within the SWACA walls.

Shannon believed that the number one reason that such formal art programs have not been started is staffing (Line 86) which directly relates to funding. She believes that there should be more places like CVS in the community (Line 98). She questioned what happens outside of the Toronto west region. She asked, “What do they do in Mississauga? What do they do in Oakville or in smaller towns [Shannon puts her hand out to the right side indicating one direction and shakes her head making a fed-up expression with her bottom lip.]? What do they [people with CIDs] do out there? There needs to be more arts-based activities, studios, places where adults, cuz we're not talking kids, these are adults, who feel like they need to have a purpose [5-second pause.]” (Lines 99-102). Shannon’s questions provided opportunities for further research about social policies and services provided for the adult CID population.

The end points of both Yona and Cait’s interviews focused on the instructional approaches taught at CVS but due to Shannon’s multiple roles as a social services employee and parent of a child with a CID, the end point of her interview focussed on the rationale behind growing art programs. She underlined the importance of assuming the ‘role of an artist/actor’ she had witnessed in community-provided art programs culminating in the attainment of a life goal of happiness, fulfilment and sense of worth for people with CIDs—*a raison d’être*.

Instructors who have an arts-education are vital to technical and aesthetic education of the participants as well as role modeling and setting professional standards for art production. From my observations of a variety of classes including, cardmaking, drawing, knitting, mixed media, and painting, it is crucial that the instructor repeat instructions and only give one instruction or new activity at a time before moving forward. The allowance of enough time for each stage of the project’s progression or at the project’s completion is vital to recognize the physical or cognitive issues faced by some participants. An acknowledgement that people complete work at different rates and may exhibit high levels of anxiety about work completion necessitates the inclusion of ‘flex time’ to process and complete the artwork is essential in

alleviating feelings of frustration or a disheartening of their personal project's progress. I call this the "gift of time" (Yarmol, 2013, p. 164). Comments like, "It's good but it is not finished, and I don't know when I will finish it" (Artist at CVS the studio, Fieldnote October 3, 2019) will not likely arise if the gift of time is designated. Additionally, participants who arrived late due to circumstances out of their control like the Wheel-Trans also require this flex time. If simple instructions are given and time is allotted to allow artists to practice and to stretch their skills, success is guaranteed. Instructors should also be cognizant that the sense of studio art professionalism learned in their art schooling applies to the artists at CVS. As Ludins-Katz and Katz (1990) assert, the basic commonality of all art centres for people with CIDs, "is the focus on creativity, the belief that all persons can grow in many dimensions, can enjoy themselves, and can produce work of high artistic quality" (p. 19). There should be a studio atmosphere of freedom to create which is non-judgemental and non-competitive (p. 18). The director/facilitator and the instructors are the central architects of this positive studio atmosphere.

Due to the nature of some disabilities, the process of artistic development is often a lengthy one as many participants may require additional support to comprehend and process multifaceted verbal instructions, steps or more conceptual concepts. Facilitators, instructors and volunteers must deliver concrete, specific and scaffolded instructions whether they are working with a group in a class or with more experienced artists followed by a constant repetition of outlined steps. Instructors are reminded that most support occurs on a one-to-one basis as the instructor and volunteers circulate around the room helping the artists reach their art making goals. With these considerations in mind, the instructors and volunteers can provide an atmosphere that enables the artists at CVS to engage in art making exercising an act of cultural citizenship.

### **Harold: The key facilitator at Creative Village Studio.**



Figure 64: van Duffelen, E. and Yarmol, C. (2019), *Harold*. [Felt tip marker and pencil crayon on cartridge paper, 8 ½" x 11"].

Harold Tomlinson is the glue that holds the Creative Village Studio together. Guiding questions used to interview Harold are noted in Appendix T but I gained more information about how Harold operates the studio through querying and observation over an eight-month period collecting fieldnotes.

#### ***Facilitator's background.***

Harold (Figure 64) commenced his interview with the early beginning of CVS. His account is noted in the Chapter 5, *How Creative Village Studio Began*. Harold divulged that he is a self-taught artist who first painted East Coast architectural drawings and fashion designs; he spent a lot of time alone

developing his craft as a gay kid (H. Tomlinson, personal conversation, November 25, 2020, Line 284). He attended York University in Toronto, where he studied sociology minoring in art focusing on drawing, painting and sculpture classes. After university, Harold began to create large-scale folk-art paintings on wood and displayed them in a gallery space called *Elysium* that he and his partner shared (Lines 294-296). He began working people with disabilities in social services where he realized the immense power of art.

#### ***Goals for program.***

Harold's goals for people in the CVS program vary according to artists' personal ambitions. There are those participants, "who are in it to socialize and have a good time" (Line 67) and can do so; there are also individuals who want to learn some new skills and to complete work as serious artists. Harold tries to help participants attain their desired personal goals. He is able to spend more time with long standing CVS participants individually because they tend to attend the studio more frequently.

#### ***Accommodations.***

When asked about accommodations he makes, Harold explained the way he approaches artists new to CVS. The first concept he started using was, a "comfort before skills" (Line 327) approach. He elucidated:

They are not going to participate fully if they are not comfortable being here and they have to be comfortable to make mistakes and to learn new things. A lot of these artists were never actually given permission to learn. They were told they couldn't, and I find the battle is a lot of individuals, they never had choice. So, if you've never had choice you don't know what you like and what you don't like so there's a lot of experimentation. There is a lot of trying to figure out where you fit in. And you've got to let them do that. You know you can direct certain people, but you've got to let them figure it out for themselves and what they're comfortable with and what they like. Once I get their comfort, once I get their trust, that's when I can start (Lines 328-336).

Harold's comments indicated a deep understanding the educational histories and the resulting discomposure of people with CIDs necessitating a laying of groundwork for a positive environment to enable new art skill learning. If experimentation was a key component of the studio practice, there was no fear of making a mistake. The 16 study participants' explanations of their CVS experiences as well as the volunteers' and the parents' accounts evidenced Harold's *comfort before skills* approach at the studio: they come in early, have a hot beverage, relax and then get to their artwork (Fieldnotes, October 3, 2019). Harold added that when he received reports about new participants who were said to have severe behavioural issues or who case workers said needed "one-to-one supports," he tried not to judge them when they arrived because he found that, "if they are comfortable and someone enjoys what they are doing, behaviour issues are less likely to surface (Line 68)".

Harold declared that, "a lot of these artists were never actually given permission to learn. They were told they couldn't... they never had choice" brings this dissertation's title, *The Right to Be an Artist* into focus. Through their educational careers and their lives people with CIDs have the right to exercise their options and be given a chance to experiment with the arts, a form of cultural citizenship. Since education programs for people with CIDs are prescribed, as we heard in Sabrina's case, art opportunities do not readily present themselves as basic numeracy literacy skills and daily coping strategies are taught. With the creation of a positive environment individuals with CIDs can flourish both artistically and emotionally in this studio space.

For those artists who come to the studio daily or several times a week over an extended duration, Harold supports them to hone particular artistic elements in their approach to a discipline and "to develop a unique style over time" (Line 69). He does not consider their personal art styles as Art Brut, Outsider Art, Naïve Art or Mad Art due to their personal biographies as some art theorists and historians would. He stated: "They're not Outsider artists"

(Line 314). And why would they be Outside? Outside of what [Harold's eyes squint together and his brows furrow as he becomes irritated.]” (Line 310)? In fact, Harold said that he refused to place CVS artists work in shows whose moniker was Art Brut or Outsider Art (H. Tomlinson, Fieldnotes, October 3, 2019). I believe that Harold does not want the work of the CVS artists to be categorized or labelled in a limited way as art of people with disabilities. He wants viewers to appreciate the aesthetic value of the work —its wide range of techniques and variety of unique styles.

Artists and interdisciplinary disability theorist Sara Lige (2001) warns that often artists with IDD are subject to *undue influence or invention* in the studio to well-meaning facilitators who, “unwittingly direct an artist’s work to their own aesthetic preferences and satisfaction” with regards to their involvement and control of the finished work (p. 73) while believing that they are “aiding”. Lige asserts the interventions involve content, removing a work from an artist so that they don’t overwork it or intervening if they see that the artist is unsure how to proceed (p. 74)

Harold divulged that he noticed that some of the CVS artists have adopted a method of working that he taught as a basic process technique when they were beginning their first art pieces (Line 72). They “used a pen or the permanent marker (Line 73) in refining their subject matter”. He articulated that this method was a kind of accommodation because:

They would get lost in the doodling and then they couldn't see the imagery, so I would bring the pen to bring the image forward so that they could actually mark out what they wanted to keep in their doodle [Harold pens out an imaginary line in the air.]. And then they could actually erase or ignore the rest. But over time a lot of them go straight to the pen and if they don't like what they've done it is hard to cover up because it bleeds through [the paint’s opaque coating] (Lines 74-77).

Harold recounted an incident where an artist rushed with his painting and ended up placing an X on some of the drawing with a black Sharpie. Although Harold encourages artists to learn from experiences due to their CIDs, many artists forget about their past errors and constantly repeat them.

Harold is reflective about his instructional practices and tries to adjust the ones that are less successful. He questions his own practices with undue influence and intervention acknowledging that he endeavours to support the artists’ content choices by finding them multiple visual sources from which they can work; he also encourages artists to work from their imagination.

Harold demonstrated an awareness of undue influence and intervention with one particular participant who created beautifully abstracted characters with simple, clean lines and then painted over them until all initial shapes were unrecognizable becoming like a remanence of blended brown-hued paint on a palette after a painting session. (View Figure 65, preliminary imagery painted before the smearing of brown paint had been overlaid.) (CVS Artist, Fieldnote October 3, 2019). Harold admitted to, “rescuing an artwork” by taking it away before the piece was layered to preserve the initial aesthetic success. He noted that it was a choice he struggled with as overlaying paint was perhaps the artist’s intent. I have twice witnessed the artist of whom Harold spoke working process and resulting artwork



Figure 65: Artist at CVS (2019). *Painting Exercise in Progress*. [Acrylic paint on canvas, 12" x 8"].

(Fieldnote, October 28, 2019). I observed the artist expressing a maniacal laugh accompanying the act of covering over the preliminary image shouting, “Harold, Harold look what I am doing! Ha, Ha, Ha!” leading me to the conclusion that overlaying the initial image with all the colours on the palette (creating a brown hue) was an attention-seeking behaviour rather than seminal to the artist’s artistic intent. Harold acknowledges that, “Art facilitation for artists with CIDs is at times, a real dilemma. One must always walk a fine line of intervention” (Fieldnote, October 28, 2019). Over the years he has moved to working closely with the artists to listen to what their artistic goals and offered them verbal support rather than hand-over-hand assistance or removing artwork. Harold acknowledged that this was part of his learning process as an instructor/facilitator (H. Tomlinson, Fieldnote, October 3, 2019).

***Essential skills of instructors for people with cognitive and intellectual disabilities.***

When asked about the key or essential skills, background and personality characteristics necessary to do the job of a volunteer or an instructor Harold said that having an art background could be helpful at CVS but to be a volunteer it was not necessary to have art training. A successful volunteer must be compassionate; they should be a good listener, somebody who is a conversationalist and likes to engage with others. They need to have an interest in CVS, seeing the purpose it has within the local community. Harold noted that long-term volunteers lived in or lived very close to CVS (Lines 114-118).

Good instructors not only require art skills but, “It's the empathy; they have to get it” (Line 129)! The instructor must understand that, “these individuals are capable of producing great art. If you don't buy into it the thinking that these guys can't produce great art, then it doesn't matter what your skills base is (Line 130)!” Harold’s delivery became more intense:

It doesn't matter if you have the skills base if you don't have the empathy because you don't want to take the time to teach. I don't know if I am getting that across or not well—because you can teach and bring it across. It's that again and again and again. It's when to know when to back off as well [He rotates both of his hands in the air as if in a wheel.]. You can over teach as well, and I've learned over the years to let them [the artists] make their own mistakes sometimes that is the only way they are going to learn is if they screw up [He laughs.]! Well they [the artists] come to me and they say, “Why did this happen?” and I say, “Well remember when we were talking about blank?”... And then they get to experience it firsthand or they have beautiful accidents and make beautiful artwork (Lines 135-141)!

Harold explained further that he has met amazing art teachers, and artists who could never teach this population because they, “would find it monotonous cuz it could take years to teach certain skills and they feel as if they're bashing their heads up against the same wall all of the time” and they “don't really buy into the long-term benefits” (Lines 128-129). Harold said that sometimes he must reteach what he has taught for the last 10 years to the same people; it is “just the nature of the business” (Lines 130 -132).

Sybil Rampen, (Personal communication, December 9, 2019) owner, founder and operator of Joshua Creek Heritage Art Centre relied on volunteers to support her weekly 3-hour visual arts program. She drew her volunteers from her other art classes (Line 112) she believed that, “it is good if they are artists” (Line 112) so they understand how to direct the participants. When asked what she thought were the personality traits and characteristics a volunteer needed to work effectively with people with CIDs, Sybil says that volunteers have to be, “People lovers. People who have had experience with the challenged” (Line 106).

The notion of self-critique and group critiques arose as a habitual act in the art studio. Harold expounded:

And I found that the biggest lesson is for them is to critique each other's work and their own work. At first, they thought I was being mean, and I felt bad sometimes [Harold laughs.]. When I said, “You know you have done better!” and I explained, “No they're not picking on you, they're not making fun of you they're just sharing what they think about your work and how it can be made better. Now when we go out to a show of their work...just to see them at one of the art galleries walking around talking about the work... we're looking at each other's work [Harold's has a smile on his face indicating

that the participants understand how to critique artwork.] and they have got it now! (Line 143-148)

The honest opinions of the work provided in the safe environment of the studio can help to improve artist's artwork before it goes on display; it is an important part of being an artist and one of the reasons that artists worked in communities. Art critique skills needed to be modeled, taught and practiced on a regular basis in the art studio to have a positive outcome for the betterment of artists' artwork.

***Successes and challenges of the job.***

When asked about the greatest successes and challenges of the job, Harold noted that partnerships in the community have been essential to the recognition of the artists at CVS and have been an accomplishment. He included a number of projects including: working with Arts Etobicoke, wrapping a van in mylar that goes around the city (Line 157); painting a hundred foot mural down the street [At Islington Avenue and Dundas Street] (Line 158); working with a Muslim organization on Lakeshore, local Junior Public School, local United Church, Montgomery's Inn and Arts Etobicoke to develop a white ribbon campaign and workshops writing positive words about community and appreciation for each other in order to address poor treatment of Muslims in the neighbourhood (Lines 157-164). In the past Harold also entered CVS photographers' works into the Contact Photography Show (Figure 46).

Harold sees the location of the studio in the community, the studio space and its arrangement as a success. The space is large enough to accommodate the programs offered as he needs to be able to see what is happening across the studio floor (H. Tomlinson, Fieldnote, October 3, 2019). If a plan to run a "coffee/ice cream shop to teach money skills and service industry skills up front" came to fruition, it would require more space and the costs for plumbing and electrical were exorbitant (Line 252). Harold would require, "an assistant of some sort" (Line 260) but aside from minor changes to cabinetry this place works (Line 261).

Harold communicated some of the challenges he encountered running CVS. He underlined that hand-selected, appropriate staff for CVS can be taxing, "You need the right fit! It can't be just anybody slotted in here. It's about the engagement it's about the passion, the interest and an interest in them...the interest in the actual artists and the work that they're producing" (Lines 168-172)! Harold underlines the need for hiring people who are opening to new learning, know the arts and understand that the participants' desire to both socialize and to create artwork.

Managing time for all the responsibilities one has including a daily running of the program, instruction, supply purchases, and administrative duties is challenging (Line 180-181). For example, providing a rationale to account for a potential funding being spent for additional courses to Creative Village council and supervisors (Lines 174-176) is time consuming. “There are usually a lot of loose ends to tie up on a weekly basis.... the emails and... returning phone calls and lining up future programs and exhibitions” (Line 186). Disability historians Ivan Brown and John Radford assert that, “Today, community-based disability professionals are feeling many of the pressures that institutional staff felt years ago: increased workloads, reduced funding, and adherence by services and policymakers to accountability rules rather than the needs of people with disabilities (2015, p. 25). Harold is feeling the pressures that Brown and Radford express. He acknowledged that it would be good to have an assistant to allow him time to complete work that he now, “has to complete at night and on the weekends” (Line 264). He believes the CVS artists’ work could be further disseminated beyond the walls if he had more time to promote it (H. Tomlinson, Fieldnote, October 28, 2019).

Harold admits that it is difficult to switch hats from a social services lens to a business lens to run the studio (Lines 192-195) as one must jockey between the two positions. Harold said that, “I’ve always felt that we were successful because we kind of fit the program around the individual. Now I find that the individual has to fit around the program” (Lines 196-197). Teaching classes, Harold tries to ensure that there was enough flexibility in the programs to accommodate for strength and needs of each artist.

An additional challenge is that participants are supposed to enroll themselves into the programs through an online portal, *My Community Hub*, but may not have a computer or an understanding of how to work with computers, make a profile and sign up. Potential participants may not have access to computers or supportive case workers (Lines 227-228) willing to assist them. Participants then phone the studio for support.

### ***Program payment.***

When I asked Harold how people pay for this program, he said that there are a variety of ways including: special support funding and grand-parented ODSP individuals who are given full access to programs from the time they were enrolled in service for the duration of their lives. They have day programs and residential programs basically on a full-time basis payed for by the Ministry; *Passport Program* where individuals receive between \$5,000 and \$7,000 unless they

have a profound disability and the receive up to \$25,000; and those with personal money through their family and trusts (Lines 206-216).

Many participants hear about CVS and enter from “within service,” from day programs, residences and the apartment program. Others who may not be involved in Community Living Toronto or other Community Living regions come from other agencies like Vita, an Italian community organization, Reena, a Jewish community organization, Montage and Support Services. Still others come independently from family homes. A challenge is knowing where they come from in order to organize payment and service access and limitations based on the participants’ service models (Lines 217-226).

### ***Evolution and growth of the studio model.***

When I asked if and how Harold saw the studio model evolving in the future, he answered that in its early stages, he wanted to promote the branding of various CVS across regions (Line 268) “but all the regions just worked on their own stuff” (Lines 268-270) and various iterations arts and athletic programming emerged such as Big Dreams Art Company<sup>129</sup> in the North York region who focuses on participants creating paintings, jewelry, knitted items, painted plant pots, mosaic art work and greeting cards which they sell to the general public (Dyke, 2014); Community Junction in the west end region who focuses on a range of programming including music, Zumba, exercise, theatre, drumming, American Sign Language, and a few theme focused art 8-week art sessions; Community Living Scarborough region used to offer “a card making program and they went into recycled clothing, that was one of their businesses, but they really didn't get the art side of it going” (Line 276). My conclusion is that you need a key individual who understands both the art/performance angle and the social services angle to successfully run a studio in the community.

### ***Exhibition.***

To close the interview, Harold shared a story about a venue where the artists from CVS participate in an annual art show called, *Art from the Heart* at Joshua Creek in Oakville. At the

---

<sup>129</sup> Big Dreams Art Company 1122 Finch Ave. W., Unit 16 located in the former North York Community Junction 2934 Dundas Street West offers a variety of 8-week sessions.

show's opening, several hundred people attend and Harold's patient, measured approach to art instruction has proven to work. CVS artists' works were selected, and these artists usually attended the show opening. Harold recalled, "I knew that they had 'arrived' because basically they were walking around talking about their work to strangers. And just seeing them doing the route [Harold's hand circles in the air]. And people enjoying their work...and purchasing their work and taking it home and sending pictures of it hanging on the [Harold forms of frame in the air.] walls. That's when I knew that they had finally 'arrived', and people were helping me to dab my eyes all day (Lines 321-325)!"

Although the intended end point of this interview was how to operationalize studio practice for artists with disabilities, Harold's end point focused on the need to not only have background in the visual arts as well as an empathetic personality believing that people with CIDs have the potential to create successful artwork. The consistent message was that CVS is not simply a frivolous, "keep-em busy", social services day program but, a working art studio.

#### ***Conclusion of Harold's interview.***

Harold demonstrates that the staff and volunteers' personality traits like flexibility and patience with the artists at a studio like CVS are essential. A facilitator needs to have formal training in the arts to be able to both program plan and revise the plan to assist artists in developing their artistic styles. As CVS grows, the parameters of the job held by Harold need to alter. According to Katz and Ludins-Katz's (1990) conception of an art studio director the roles that Harold fills are too much for one person. The administrative duties should either be filled by a director who understands art making or a head art teacher. Katz and Ludins-Katz's outline job duties:

As soon as money is available, an art teacher should be hired by the director. A director cannot teach and run the Centre simultaneously, to teach art one must be completely engrossed in working with the students and not be bothered by constant interruptions. Art teachers must be practicing artists, preferably with a Master of Fine Arts degree or its equivalent. If possible, the teacher should have had experience teaching people with disabilities. In any event, a teacher should be able to work without prejudice toward persons with intellectual, physical or emotional problems...the teacher should have a wide variety of skills—painting, drawing, sculpture, printmaking, creative crafts. When the Art Center becomes large enough, each art teacher should be specialized in different art skills and interests (p. 99).

Harold is mired in a range of responsibilities at the studio. It is a dizzying experience watching him move responding to the, "Harold...Harold...Harold" calls in the studio. Some

days it seems difficult for one individual to manage all that his job seems to entail including, instruction, accounting, attendance, social worker to support the participants' experiencing difficulties, contacting appropriate social service agencies to support clients in need, keeping track of artwork, image printing for participants, selecting work for exhibition and sale in and outside the studio, keeping track of art supplies, purchasing new supplies to replenish stock, designing and using adaptations for artists with disabilities, helping artists to set art goals, photographing work, general clean-up and maintenance, public relations, course planning, and recording teachers' hours, to name a few.

The Katz's focus on qualified art instructors at Creative Growth Centre in Oakland, California matches Harold's thinking. The Katz's state that the director must examine "the philosophy and ability of the instructor to establish and maintain a creative environment within the centre believing that the creativity lies within each person and that their job is to release this power" (p. 99). Being genuinely excited by art outside of conventional style and not imposing their preconceived ideas in order to allow each student to find their own style is "doubly important since many persons with disabilities have long histories of being told what to do and how to do it. They have had limited opportunities for independent decision making and very often learn to be dependent on authority figures" (p. 99).

Problem solving and creativity are needed to accommodate for artists' disabilities and to quickly modify projects. An empathic personality, a genuine care for the people one encounters and a compassionate understanding of people with disabilities can assist in helping the artists to achieve success in achieving their personal artistic goals. Belief that these artists with a few provisions and encouragement can develop their own unique, recognizable styles is essential for the artists to develop a sense of confidence and create successful artwork. A background in social service provides insight into prevailing policies and procedures applicable to the client group. The realization that social relationships in the studio play a crucial part of in the lives of the participants and for some participants exceed the desire to produce art—art creation simply becomes a springboard for socialization. At the same instance, individuals who consider art making as their vocation require the support of an artist facilitator/instructor in the studio to build their confidence and knowledge as backing to grow as artists. Daily class and studio routines are imperative to create a level of comfort and assurance that it is a safe and predictable place to be vulnerable; thus, an art studio like CVS is about more than just art. From this interview I have

learned that Harold truly believes that art is an essential part of the human experience and engaging in it leads to cultural citizenship. Everyone has the potential to make art and artistic expression can be a means of self-growth.

### **Visiting Joshua Creek Heritage Art Centre.**

There are a limited number of venues who will exhibit works by artists with disabilities. Through the interviews I heard about the gallery at Joshua Creek in Oakville where CVS artists had the opportunity to mount their work annually. I decided to learn more about this art centre by reviewing online newspaper articles, taking a one-day workshop, attending a Monday art class for people with CIDs and by interviewing the gallery's owner Sybil Rampen (See Figure 66)<sup>130</sup>. From Sybil, I learned the rationale behind the opening of Joshua Creek's gallery space:

The gallery, the purpose of the gallery was to make a gallery for emerging artists because artists can not get into commercial gallery unless they have been in a gallery, so that was my major realization. They need to have an emerging artists gallery and we have marvelous openings! We have four more less permanent shows annually (Personal communication, December 9, 2020, Lines 54-56).

Astutely, Sybil acknowledges the art exhibition practices of contemporary galleries today who require artists to have previous art exhibition on their curriculum vitae. She

provides a venue to give artists with and without CIDs a start in their careers as artists. The *Art from the Heart Show* showcases the art from Sybil's free art classes on Mondays with members of Community Living Oakville and the art from CVS's artists every year.



Figure 66. Yarmol, C. (2019), *Sybil*. [Sharpie on cartridge paper, 8 ½" x 11"].

---

<sup>130</sup> Image of Sybil was not coloured by van Duffelen, E. due to government public safety measures imposed due to COVID 19 outbreak.

Conrod Skyer's *Arctic* (2019) an image of a 3' x 4' acrylic on canvas painting adorns the face of the catalogue (See Figure 67). The work was sold the first hour the show opened. Harold brought several artists to the opening to witness the public viewing of their work. Art exhibition is an important part of an artist's career; the annual Joshua Creek art show gives CVS artists an opportunity to engage in cultural citizenship building their personal art exhibition profiles.

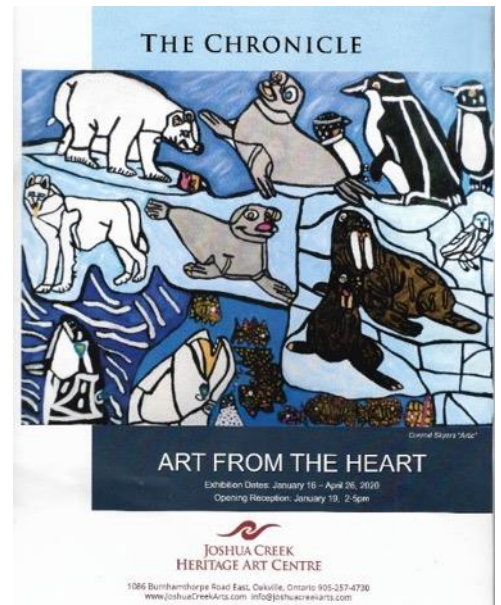


Figure 67. Skyers, C. *The Chronicle Pamphlet from Art from the Heart Show 2020* (2019). *Arctic*. [Original artwork acrylic paint on canvas, 3' x 4'].

## Chapter Six: So, What? New Understandings or Findings



Illustration 23: Yarmol, C. (2020), *Rhizomatic Engagement*. [Mixed media-acrylic paint on canvas, yarn, branches, glue, panel, Top panel: 16" x 18", Bottom panel: 40" x 22". Note that there is are two superimposed canvases but that the photographic representation exhibits the kinetic possibilities of the artwork.].

I started this dissertation with tree imagery in Illustration 1, *Replanting the Forest* and I chose to bookend it with Illustration 23, *Rhizomatic Engagement*. As I bring the dissertation to closure, I feel as if the research is not ending but just beginning as more questions than answers emerge. *Rhizomatic Engagement* is a visual representation of my overall thinking and growth about this interdisciplinary project.

The physical artwork itself, coupled with the research began with a representation of an arboreal metaphor of the ‘tree of knowledge’. The subject matter depicts growth based on a wide-trunk tree with far reaching linear branches that dynamically surge both upward and outward. The branches bare large-surfaced leaves that collect the sun’s energy for nourishment through photosynthesis. Rigid roots anchor the towering tree drawing in nutrients from the water and soil stabilizing the earth to prevent erosion. This tree is a metaphor for highly structured, firmly entrenched, societally system of thought that mediates views of theory, language, behaviour and culture —a hegemony of mainstream neo-liberate thought. The complex networks support hierarchical, binarized thought where something can grow securely while still being firmly located in its place by inflexible roots.

The arborescent metaphor is where I situated myself at the start of the project given my positionality. The tree itself as well as the overall palette of *Rhizomatic Engagement* in cadmium- red, orange, yellow, separated by intermittent by lines of malachite (green) or Tyrian purple, and backed by a blend of ultramarine-based violet with the addition of titanium white, recall a childhood memory. When I was in senior kindergarten, I illustrated a colossal tree with

a violet-coloured trunk and branches on very large, greyish coloured, thin piece of cartridge paper. I used crayons to add several brightly coloured red, orange and yellow leaves. My teacher came toward the table where I was working and said,

“Tina, trees aren’t purple!”

When I asked why, she replied, “Because that is not the colour, we find them in nature!”

She then ripped up my drawing and threw it away. I remember my eyes swelling up with hot tears as she curtly walked away. When I told my mother what had happened, she tsk-tsk-ed and said that some people just had no imagination or creativity and only saw things in one way. Mum said that trees could be any colour I thought that they could be. At home I kept drawing tree after tree in different colours until I was satisfied. I knew from spending a lot of time outside in nature that spring flowers or the fall leaves all bore these brilliant hues. I now realize that it was quite presumptuous of the educator to state that this was, “not the colour we find them in nature” but...the way that teacher saw the world. The teacher’s, “it had to be” response to my image of a violet tree represented limiting binarized thought —‘this or that’.

*Rhizomatic Engagement* was inspired by *Deleuzoguattarian theory* which subverts a fixed, foundational view of knowledge:

A rhizome has no beginning or end; it is always in the middle between things, interbeing, *intermezzo*. The tree is filiation, but the rhizome is alliance, uniquely alliance. The tree imposes the verb “to be,” but the fabric of the rhizome is the conjunction “and ...and...and...” This conjunction carries enough force to shake and uproot the verb “to be” (Deleuze, & Guattari, 2004, p. 27).

Opposed to linear modes of thinking, Gilles Deleuze and Félix Guattari use the rhizomatic metaphor to contest hierarchical structures and stratification of ‘the tree’. Rhizomes enable us to see the connection between topics as there is no predetermined path from one idea to another. Stirred by this idea, a critical disability studies stance questions and pushes the hegemonic views of what “to be” means as a binary structure of either-or, a dominant and oppressive dichotomy. By questioning *being*, rhizomatic thinking offers a new possibility of *becoming*.

I began thinking about Deleuze and Guattari’s theories through a coloured sketch see Illustration 24. I began to draw a central line of tree trunk with its branches twisting off the page. I was considering how this dissertation is interdisciplinary in nature as it includes visual

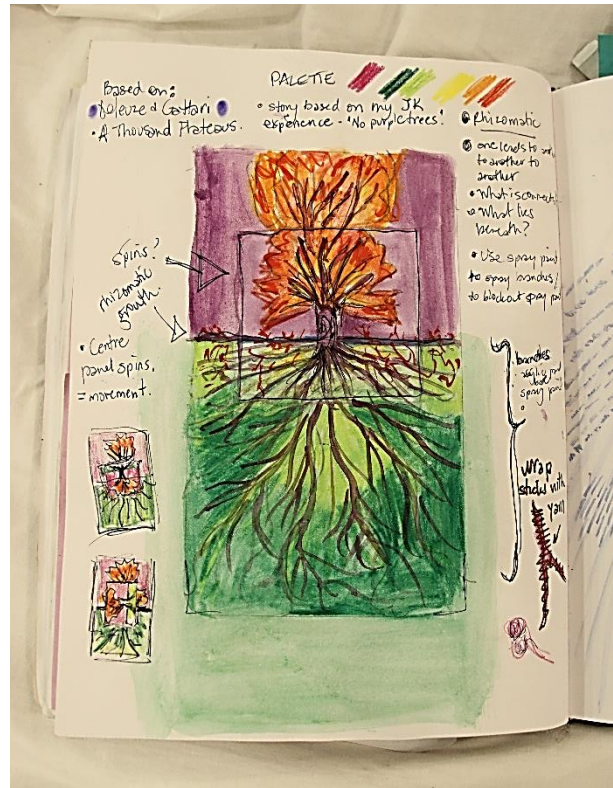


Illustration 24: Yarmol, C. (2018). *Thinking About Deleuze and Guattari*, [Sketchbook drawing with pen, coloured & aquarelle crayon, 11" x 8 1/2"].

art, art history, studio practice, critical disability studies, and social policy surrounding individuals with cognitive and intellectual disabilities. All disciplines seem to be profusely growing beyond the constraints of the canvas reaching out in all imaginable directions yet at the same time, they are fixed and quite distinct from one another. At the same instance, deeply rooted rhizomatic connections extend both o'er and beneath the horizon line meandering, winding and intertwining as one researches them more closely.

One can engage with the *Rhizomatic Engagement* by spinning the central canvas; fresh pathways are seen from every resting position and seen anew as the canvas is set in motion. Rhizomes become networks by continuously negotiating with their context and link some pre-existing gaps. These rhizomes challenge and actively resist rigid organizations and restrictions.

From the genesis of this project until now, I grown enormously. I now think more broadly opening-up to the potential of *becoming*. I think that when considering social policy for those with people with cognitive and intellectual disabilities who want to be artists, we must think in a rhizomatic manner striving to fashion "violet trees" as we will need all the creativity, we can muster to devise innovative solutions to funding unique social policy issues. Policy based on a mythical, normative stance should no longer be tolerated to 'service' people with cognitive and intellectual disabilities.

## Conclusion

The following questions were set out at the start of this study:

How can we operationalize and support successful studio art practices for people with cognitive and intellectual disabilities to exercise their right to become artists and achieve an aspect of cultural citizenship?

How can we support people with CIDs in new contexts to enhance their lives as artists?

How can we commend or credit the knowledge visual artists with CID communicate with their artwork?

Generally, all participants interviewed readily communicate pride in their work and expressed a desire to continually come to create art at CVS studio. Although they have limited knowledge of financial issues, that is, how they pay for the program, most artists understand that if they sell their artwork, they earn money to be able to make purchases of their choosing<sup>131</sup>.

At CVS, some participants consider the studio as the central program or their vocation and others enjoy coming to the studio but consider it simply as a small part of their weekly programming. All participants noted the relaxed and social atmosphere fashioned by the staff. This positive social ambiance is indeed a central reason some participants continually return. CVS offers a convivial atmosphere that nurtures their sense that they matter. It provides a gateway for socializing that builds a sense of community within the community— an aspect of citizenship. The facilitator’s “comfort before skills” (H. Tomlinson, personal communication, November 25, 2020, Line 327) approach is one way to operationalize successful social practices in the art studio before embarking on art education and art making. As Nancy Davis Halifax elucidates, “It is knowledge ‘from’ and ‘in’ art and with communities; it is a form of working in the social fabric” (Personal communication, April 18, 2020).

The participants who have been attending CVS for number of years or multiple times weekly demonstrate great confidence in discussing their work. They readily select their own subject matter and have a sureness about their artistic abilities beginning new artwork without any trepidation. They come to the studio constantly emboldened with fresh ideas. The duration and frequency of attendance have a direct impact on the development of a unique personal style

---

<sup>131</sup> At Creative Growth Art Studio in Oakland California, “Every artist receives a quarterly check from a common pot funded by sales of Creative Growth, T-shirts and other items, an effort to counter money anxieties and to create the sense that all art has value” (Rich, 2015).

and overall theme that is easily recognizable to an outsider of CVS with respect to subject matter, colour selection, colour placement, textural quality, line and pattern usage and placement of subject matter in compositional space. Participants acknowledged the importance of upbeat instructors and volunteers who supported their skill development and encouraged the execution of artwork.

Both the volunteers and the art instructors continually foster a sense of pride in participants' abilities to execute and see their art projects through to their fruition. Supported learning includes: setting out necessary media and materials for art creation; providing accommodations with special tools depending on the participant's disability; assisting with the writing of graphic texts in artwork; helping with set-up and clean-up (e.g. masking the perimeter of the paper with painter's tape and gently pulling or rolling it off after painting); scaffolding then repeating instructions; dedicating time for artwork completion; offering emotional encouragement through commentary about successes of artwork and practicing art critique models to encourage artists to improve their artwork. Of key importance is mounting and exhibiting of work in the community and maintaining an active, positive relationship with other organizations in the local, urban environs. Seeing their artwork mounted both inside the studio space and in venues outside the studio generates feelings of confidence and empowerment for the artists. These instructional support strategies help to ensure artists' active engagement in cultural citizenship.

A successful art studio for people with CIDs engenders an environment that offers an emotionally and physically safe space for artists to take risks stimulating opportunities to explore artistic ideas and solutions in new contexts. Making art is risk-taking because ultimately one is exposing part or parts of one's inner self to the outside world. Since people with CIDs are already vulnerable, they require a safe environment with demonstrative support to manage this risk. Artists come to the studio for its: feeling of safety, predictable, organized routine, active programming, social aspects and knowledge that their artistic learning will be reinforced by supportive facilitators, instructors, and volunteers who will consistently support their art creation.

The CVS venue fosters artists' abilities to learn artistic problem-solving skills through continuous hands-on opportunities for creative thinking without fear of making mistakes<sup>132</sup>, a

---

<sup>132</sup> Through the "banking concept of education" (Freire, 2000, p. 72) experienced in their pasts, many participants have been told that there is a right and a wrong way to do things. Many have not had the opportunities to create art

key process in art making and personal style development. CVS helps artists to develop ownership of the creative process by encouraging them to take responsibility for setting their own creative goals by providing artists with CIDs with ready physical, social and emotional supports. Experienced instructors highlight the artists' successful work and improve class participants' artistic progress through both informal group critiques and individual critique in order to strengthen work and to build artists' self-esteem resulting in confidence to create their own style and way of working.

Volunteers need not possess art skills but have empathetic personalities and be willing to encourage artists with their art making projects. They act as a positive force in the day-to-day operations of the studio in helping to communicate art instructors' directives and responding to participants' inquiries. Socializing with the participants is a key component of the volunteer's role at CVS. Not only the recognition of participants' immediate tactile needs of tasks like brush cleansing or water replenishment require immediate attention but respecting both the participants' goals and abilities as *artists* [emphasis added] are of utmost importance.

The selection of suitable instructors to achieve social and artistic success in the studio environment is essential. The instructor should have deep knowledge of the visual arts preferably a formal education that imbues technical skills, art criticism and art history. An aptitude to create innovative lessons and have the art know-how coupled with the ability to be a creative problem-solver to modify instructions or tools based on the needs of the participants is quintessential to CVS artists' success. Providing models and examples of projects at the outset for some individuals who may not have the ability to abstractly conceptualize or rationalize their end products is a beneficial teaching tool. Having extreme patience and the belief that their participants can and will achieve success is vital; understanding that this end is achieved through continuous reteaching of concepts, repetition and rewording of instructions, and extra time to accomplish projects. Instructors must realize that these participants see themselves as artists — art is their vocation and way of attaining in cultural citizenship.

The parents wish that there was increased funding and more time for respite hours involving the arts but acknowledge that CVS is a positive place where their adult children feel good about themselves through both their art production and the rewarding social environment.

---

outside the prescribed world of a "colouring book" where one needs to colour between the lines so attending the studio and being given the opportunity to create art freely may be a novel concept.

They recognise and applaud the supports their adult children receive at the studio. Parents acknowledge that their adult children consider themselves as artists gaining social acceptance in their communities; They “have something interesting to talk about” to people they meet in the communities outside of CVS. Taking on ‘the role of artist’ fosters engagement in the community, their personal lives, cultures, and home environments—resulting in a sense of purpose. CVS has given artists with disabilities a community of peers with whom they can create artwork. These peers continually inspire, teach and support one another on their creative journeys and in the process, they can grow as artists and as people. CVS allows them to become part of a larger community—a community of contemporary artists. An operationalization of the studio practices evident at CVS, could be a starting point for the opening of additional studio spaces in artists’ local communities. These would enable them to achieve their personal arts engagement goals.

After critical reflection, many questions arise about the purposes, methods and delivery about the *Passport Program* policy. Rioux and Valentine’s (2006) assertion that “substantive citizenship rights-especially at the provincial and municipal level—have not been attained in programs and services” (p. 48) through social policy is correct. Although at first glance, there seems to be a wide range of provincial income and personal supports for people with disabilities. After probing more deeply into the specific eligibility, and access requirements, there are a few programs offered by the government of Ontario designed to support individuals with intellectual disabilities in their everyday lives, and even fewer to support those wanting to engage in arts practices. Even the limitations of ODSP prevent financially successful artists from earning substantial monies from the fruits of their labour. Stapleton, Procyj and Kochen (2011) emphasize that the disincentive to work must be removed if public policy wishes to encourage people on ODSP to seek employment (p. 5). Punitive, coercive measures in ODSP must be further withdrawn to help avert social isolation, despair, a feast or famine existence, or long-term poverty for artists. ODSP needs to be reformed by developing more effective, comprehensive income measures and mechanisms to provide both personalized and individualized supports that could encourage social and economic inclusion for people with disabilities. The lack of disability supports leave many in a perpetual state of poverty.

There is patchwork of funding and service mechanisms difficult for any person to navigate. Families are forced to play a detective game researching and networking just to find

out where there might be some funding across two to three ministries and regional offices. According to Spindel (2013), they must then jump through hoops and bending themselves and their loved ones out of shape in order to fit into slots of funding or support (p. 13). Most individuals with CIDs receive their funding from multiple sources, which all have different applications and accountability approaches (Lord, 2006). Daily demands of meeting the complex needs of individuals with CIDs coupled with layers of bureaucracy are staggering and cause me to question the equity of programs like *Passport* for all as it currently exists. Thus, the ‘idea’ of achieving a “good life” (Johnson and Walmsley, 2010)<sup>133</sup> or “the degree to which a person enjoys the important possibilities of his or her life (Raphael, 1999, p. 201)<sup>134</sup>, might not come to be realized through public policy initiatives. Funding should be streamlined coherently and flexibility to meet the needs of the applicant.

Disability historians Ivan Brown and John Radford (2015) put forward that a challenge of policymakers is moving from an institutional-based system to a community-based system of services and supports for people with CIDs. “The overall approach to services still retains strong elements of ‘institutional’ thinking, and Ontario faces a challenge in devising new ways that match the real lives of people with developmental disabilities as they strive to live successful and happy lives in communities throughout the province (p. 25).

The realization of individualized funding is, “a creative response to consumer needs” (Roehrer Institute, 1993, p. 69) which could allow more artists to build their practices. It seems simple in theory, but more difficult to execute in practice. Bettering individualized funding

---

<sup>133</sup> Countless researchers have attempted to formulate a definition of the good life or quality of life (Howell, 2013). Dennis Raphael prolific author and professor on the social determinants of health defines quality of life as “the degree to which a person enjoys the important possibilities of his or her life (1999, p. 201). According to Psychology professors Keith and Watson (2002) researchers have not agreed on a single definition of the quality of life...quality of life is a human aspiration that encompasses success and satisfaction with the experience of life, and includes happiness and contentment in all its dimensions—physical, emotional, physical, financial and professional (Keith 2007, Watson & Keith, 2002, p. 149). One thing is clear, that the importance of voice of the person with the intellectual disability is central to the notion of self-advocacy [and QoL assessments], the process by which individuals or groups speak out their own behalf about issues that affect them and their own life quality (Williams & Schoultz, 1982 cited in Watson & Keith, 2002, p. 147) is imperative if any relevant supports are to be given or citizenship is to be realized.

<sup>134</sup> According to Dingwall, C., Kemp, K., Fowke, B. and the Individualized Funding Coalition for Ontario’s, *Creating a Good Life in Community: A Guide on Person-Directed Planning*, “A good life is different for everyone. It often means having relationships with friends, family, and loved ones; getting out and having fun; and having plenty of opportunities to try new things. It might mean volunteering, getting a job, or creating a meaningful day that reflects your personal gifts and talents. Planning will increase the amount of choice and control that you experience in all areas of your life” (2006, p. 7).

would include resolving administrative inefficiencies that create bureaucratic delays with reimbursement to individuals. A shift from supply-side to demand-side secure funding and enhancing appropriate supports within these programs could better meet participants' personal goals including arts engagement. "Leaving intact infrastructure of direct services accountable to consumers but placing report mechanisms reliant on consumer [person receiving the funding] satisfaction to help determine the effectiveness or ineffectiveness of these programs" (p. 69) could result in a greater potential for participatory success in the community.

The *Passport Program* seems to be of great importance to the daily existence of people with CIDs, who have been fortunate enough to enjoy it however, as it currently exists, it appears to be more of a privilege available to few, rather than a right. The system encourages dependency of individuals with CIDs on their families considering the family income to determine funding for programs and living accommodations over the course of a lifetime. If a person does have living, capable parents to care for them, these parents effectively become an extension of the social service network. The simplification of convoluted admission practices filled with procedural steps, to receive *Passport Initiative* funding, removing restrictive barriers, and reducing lengthy wait times that inhibit many people with CIDs from achieving full cultural citizenship, is both a novel and a powerful concept which should come to fruition. "When a person gains control over his or her life choices and this power has shifted, the quality of life improves" (Westgate and Blessing, 2005, p. 3)<sup>135</sup>. I believe that more open access to the *Passport Initiative*, lifting punitive ODSP constraints, person-centred planning, and individualized funding options, as a right, would help support full inclusion and citizenship of Ontarians with CIDs, and promote an individual's right to choose a livelihood including the choice of becoming an artist. Disability policy should not simply be a dimension of health, education, social services, and income security but an active conversation about dignity through cultural citizenship. The creation of processes and practices that enable individuals with CIDs to actively select what they want to do and be able to do it.

---

<sup>135</sup> Westgate and Blessing tell of their experiences seeing person-centred planning approach put into action at Pathfinder Village ([www.pathfinder.org](http://www.pathfinder.org)) in Edmeston, NY, the home to more than eighty individuals who have Down Syndrome ranging in age from 11 through age 61.

### **Questions for further study.**

There are many questions that arise that require further study. Which individuals with CIDs want to participate in art programs but due to life's circumstances cannot? How can we arrange for individuals who want to attend programs like CVS to gain access to them? How can operationalization strategies at CVS be adapted to programs like SWACA who support larger numbers of adults with CIDs? What steps can be taken to organize other studios like CVS both across regional and urban centres in Ontario? What studio programs supporting arts with CIDs exist across Canada? How are these programs funded? What do these studios see as the key components necessary to support artists with CIDs? How can we promote the opening of art exhibition spaces that welcome the art and the voices of people with CIDs? These questions can be addressed in further studies about art studios supporting people with CIDs.

### **Now what?**

Due to the success of this venue, more community-based studios like CVS could be established. Using CVS as a template for Community Living around Ontario as an accessible, urban open access space that can offer an opportunity for people with CIDs to become art-makers would be a way to get individuals out into their communities. Building other visual and performing arts studios across the 2.8-million-person city of Toronto and in rural areas could help to fill a gap caused by Bills 148 and 47.

Professional growth for some of the long-time artists at CVS is the next step. The facilitator's docket is filled with the daily operations of the organization so additional art and administrative supports are necessary to grow the organization. The engagement of instructor-art professionals at CVS could support artists to learn and develop new skills to further pursue their individualized goals. Engagement of working artists from the community could expand the studio art facilitator's scope of types of artwork trending in the marketplace facilitating the marketing of art through their professional networks, and the arrangement of art exhibits in and around the greater Toronto area. If funding is found, CVS has the potential to grow into a regional studio-art centre that can help build professional lives and careers in art for individuals with CID who express an interest in the production of both fine art and handicrafts for sale. A larger accessible space would be necessary.

A continued commitment to making artists visible through the Islington Village location of CVS and through the art exhibition throughout the greater Toronto area, builds social capital leading to interdependence, tolerance, and empathy within the community. Reaching out to

gallery spaces, including commercial galleries to promote CVS artists' work and increasing the number of show venues and the artists' exposure could emerge to help dispel the idea of artists with CIDs as Outsider, Art Brut, Naïve or Mad artists.

A review of the programs offered at the studio could result in the inclusion of crafts such as weaving, embroidery, pottery, or garments as a part of daily vocational program to produce saleable items for the public and increase the artists' profiles in the community. With greater support at the studio, these goods could be sold through an online store. Today it has become easier for artists and crafts people to market their wares globally to satisfy the growing demand for unique, individual and personalized handicrafts. The establishment of a storefront or online store to sell artwork and products could result in increased economic independence for artists and help them to gain recognition for their work. Building the 'commercial' side of CVS could help to alter people's perceptions about what disability is and is not enabling people with CIDs to actively participate in art making.

Liaising with existing organizations globally like Indefinite Arts Centre Calgary Alberta, Creative Growth Centre in Oakland, California, Gateway Arts run by the Vinfen Corporation, Cambridge, Massachusetts who offer studios for individuals with disabilities could sprout the birth of new ways of running studios supporting people with disabilities across Canada. Networking to learn about other studios funding formulae and operational methods could result in altering current fiscal studio operations and create growth.

With a larger space and assignment of more staff, CVS has the potential to become a creative hub offering services to teachers, caregivers, families, therapists and others who work in the fields of art and disabilities through classes, placements, and lectures. It could play a significant role in increasing the public's interest in the artistic capabilities of people with CIDs.

Although there is already a regular roster of students from social service sector educational programs from local colleges who complete placements at CVS, the development of collaborative projects with high school art departments and cooperative education course, more placements of students from art education/education/social science programs within colleges and universities could introduce a new generation of the public to the idea that artists with disabilities have similar desires and needs as artists without disabilities. These cooperative placements could train new arts-informed personnel to work at the growing number of studios.

Offering more artists in the studio the choice to work either in a structured, supportive class or to work more independently in a less structured environment could be introduced if more staff with visual arts education were hired. Artists could progress at their own rates. Hiring staff with backgrounds in fine art and craft could benefit the program in order to teach artists semi-professional and professional skills. This could involve basic curriculum vitae, graphic creation of business cards, oral practice of explaining artwork (key ideas, central themes, techniques, rationale behind work all already evident in the interviews for this dissertation), digital portfolio organization entailing support with writing skills and oral skills. This addition could lead to further development of on-line, co-operatively developed profiles of artists and the mounting of their artwork available in an online store. This action could place artists' artwork in local, national, and international art scene with options to sell their enabling recognition for their art.

The application of a multi-methods approach with a focus on art in this dissertation epitomised Sandra Weber's (2008) beliefs in the powerful possibilities of imagery in research. The imagery in *The Right to Be an Artist: Operationalizing Studio Art Practices for People with Cognitive and Intellectual Disabilities* as a data point credited the knowledge of CID artists by bringing it into an academic setting of critical disability studies making it, "accessible, evocative, embodied, empathic, and provocative" ... with its main goals of accessibility and breadth of audience (Cole and Knowles, 2008, p. 60). The use of narrative inquiry also examined artists' direct art making practice building on local knowledge from multiple voices. Listening to and analysing study participants' voices has led to conclusions about what supports are essential for people with CIDs to continue to attain their lifegoals of living as artists. The knowledge gained could help support the growth of art programs in new contexts.

The sharing of the CVS artists' journeys with me has taught me so much. I have learned that valuing and affirming their artistic expertise empowers them; this venture has become my praxis. The conclusions drawn can help inform potential community studio organizers about how to set up an open, welcoming environment, hire appropriately qualified personnel who believe in the creative power of artists with CIDs, offer some models of pertinent supplies, share accommodations to support artists with CIDs and act as a positive example of how an accessible community-based art studio can be run. The creation of projects like *Coffee Talk*, the books and the future accompanying art exhibit credit and praise the artistic practices and skills of the CVS artists in their community. By the very existence of the studio in the west Toronto community

and by offering frequent exhibition opportunities, the artists and their work can be formally recognized. Through their role as artists in the community aspects of cultural, and social citizenship are attained and can be expanded. It is my hope that the Creative Village Studio artists will continue to take pride in their artistic accomplishments and look forward to the successes that future holds for them.

## References

- About New – VITA Mens Sana*. (2020). Retrieved from <https://www.vitacls.org/about-new/>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, D.C.: American Psychiatric Association.
- American Psychiatric Association, & American Psychiatric Association: DSM-5 Task Force. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). Washington, D.C.: American Psychiatric Association.
- American Association on Intellectual Developmental Disabilities (AAIDD). (2010) *Intellectual disability: Definition, classification, and systems of supports*. Washington, DC: AAID.
- American Association of Intellectual and Developmental Disabilities. (2008). *Supports Intensity Scale™ Information*. Washington, D.C.: AAIDD.
- Anatomy of a Fly. (n.d.). Retrieved from <https://swattingflies.weebly.com/anatomy-of-a-fly.html>
- Art Story Foundation (2020). Paul Cézanne biography, life and quotes. Retrieved from <https://www.theartstory.org/artist/cezanne-paul/>
- Art History Net. (2017). Byzantine Art. Retrieved from <https://www.arthistory.net/byzantine-art/>
- Autism Speaks Canada. (2018). PDD-NOS. Retrieved from <https://www.autismspeaks.ca/about-autism/what-is-autism/pdd-nos/>
- Bach, H. (2008). Visual narrative inquiry. In L. M. Given (Ed.). *The sage encyclopedia of qualitative research methods*. (Ed.). Thousand Oaks, CA: Sage Publications. (pp. 939-41). Retrieved from <https://sage-reference.com.proxy2.lib.uwo.ca:2048/view/research/n490.xml?rskey=kC31Yw&result=1&q=Bach, Hedy>
- Balzer, D. (2014). *Curationism: How curating took over the art world and everything else*. Toronto, ON: Coach House Books
- Baumann, D. (n.d.). The reception of Adolf Wölfli's work, 1921-1996 [PDF file]. Retrieved from [https://www.sommerakademie.zpk.org/fileadmin/user\\_upload/2016/PDFs/Reader\\_Hilar\\_Stadler/adolf\\_woelfli\\_reception\\_english.pdf](https://www.sommerakademie.zpk.org/fileadmin/user_upload/2016/PDFs/Reader_Hilar_Stadler/adolf_woelfli_reception_english.pdf)
- Bell, J. (2005). *Doing your research project: A guide for first-time researchers in education*. (4th edition). Maidenhead, UK: McGraw-Hill Publishers.

- Bennett, S., Gallagher, T. & Community Living Ontario (2012). Community living Ontario's community initiative inclusive support on: *The delivery of education services for those who an intellectual disability in the province of Ontario* (Community Inclusion Report, p. 23]. Retrieved from <https://cacl.ca/wp-content/uploads/sites/3/2013/07/clo-delivery-of-education-services-1.pdf>
- Beveridge, A. (2001). A disquieting feeling of strangeness? The art of the mentally ill. *Journal of the Royal Society of Medicine*, 94(11), 595–599. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1282252/>
- Bill 47, *Making Ontario Open for Business Act, 2018*, 1<sup>st</sup> Session, 42<sup>nd</sup> Parliament, Ontario, 2018.
- Blandy, Doug. (1993). Community-based lifelong learning in art for adults with mental retardation: A rationale, conceptual foundation, and supportive environments. *Studies in Art Education*, 34(3), 167–175. Retrieved from [https://www-jstor-org.ezproxy.library.yorku.ca/stable/1320622?seq=1#metadata\\_info\\_tab\\_contents](https://www-jstor-org.ezproxy.library.yorku.ca/stable/1320622?seq=1#metadata_info_tab_contents)
- Brommer, G. F. (1997). *Discovering Art History*. Worcester, MA: Davis Publications, Inc:
- Bronston, W.G. (1974, September). *Concepts and theory of normalization*. Paper presented at the meeting of Down's Syndrome Congress, Milwaukee, Wisconsin. Retrieved from <https://mn.gov/mnddc/parallels2/pdf/70s/74/74-CTN-WGB.pdf>
- Brown, I. and Radford, J. (2015). The growth and decline of institutions for people with developmental disabilities in Ontario: 1876–2009. *Journal on Developmental Disabilities*, 21(2), 7–27. Retrieved from: [https://0-eds.b.ebscohost.com/aupac.lib.athabascau.ca/eds/detail/detail?vid=13&sid=b9364683-c4ca-4a1a-b480-63dac19a1fdf%40sessionmgr120&bdata=JnNpdGU9ZWRzLWxpdmU%3d#AN=112038238&db=a9h](https://0-eds.b.ebscohost.com/aupac/lib/athabascau.ca/eds/detail/detail?vid=13&sid=b9364683-c4ca-4a1a-b480-63dac19a1fdf%40sessionmgr120&bdata=JnNpdGU9ZWRzLWxpdmU%3d#AN=112038238&db=a9h)
- Burke, L. (2008). Introduction: Thinking about cognitive impairment. *Journal of Literary & Cultural Disability Studies*, 2(1), i–iv. Retrieved from <https://doi.org/10.3828/jlcds.2.1.1>
- Butler, J. (1993). *Bodies that matter: On the discursive limits of sex*. London, UK: Psychology Press. Retrieved from <https://www-taylorfrancis-com.ezproxy.library.yorku.ca/books/9780203828274>
- Cachia, A. (2015, June 18). *Flesh of the World*. [Essay]. Retrieved from <https://fleshoftheworld.ca/essay/>
- Cachia, A. (2014). From outsider to participant: Developmentally disabled dialogue in socially engaged art. *Museums & Social Issues*, 9(2), 109–123. Retrieved from <https://doi.org/10.1179/1559689314Z.00000000022>

- Cachia, A.: Cantor Fitzgerald Gallery of Haverford College. (2012). *What Can A Body Do?* [Exhibition catalogue]. Haverford, PA. Retrieved from [http://www.amandacachia.com/wp-content/uploads/2016/07/What\\_Can\\_a\\_Body\\_Do.pdf](http://www.amandacachia.com/wp-content/uploads/2016/07/What_Can_a_Body_Do.pdf)
- Camhy, S. (2016). Drawing: Timeless friend of the artist: the sketchbook. Retrieved from <https://www.artistsnetwork.com/art-techniques/sketchbooks-then-now-part-2-free-art-supplies/>
- Canadian Association for Community Living. (2017). Canadian association for community living: About us. Retrieved from <https://cacl.ca/who-we-are/about-us/>.
- Canadian Association for Community Living. (2017). *Disability Supports*. Retrieved from <https://www.cacl.ca/area/disability-supports>
- Canadian Association for Community Living. (2017). Canadian association for community living: Our mandate. Retrieved from <https://cacl.ca/who-we-are/our-mandate/>
- Canadian Association for Community Living. (2013). *Assuring income security and equality for Canadians with intellectual disabilities and their families* (Report to The House of Commons Standing Committee on Finance. Retrieved from <https://cacl.ca/wp-content/uploads/2018/05/CACL-Brief-Finance-Committee-Income-Equality-in-Canada-April-2013-2.pdf>
- Canada Council for the Arts. (2018). *Americas cultural summit report: Ottawa, Canada*. (Post-Event Report). Retrieved from <https://ifacca.org/en/what-we-do/networking/regional-initiatives/americas-cultural-summit/>
- Cardinal, R. (2019, June 7). An interview with, the father of outsider art (Part 1) (R. McDonald, Interviewer). *Diversity in the Arts Today*. Retrieved from <https://www.diversity-in-the-arts.jp/en/stories/12639>
- Cardinal, R. (1972). *Outsider Art*. Worthington, UK: Littlehampton Book Services Ltd.
- CARFAC Ontario. (2019). The voice for professional artists. Retrieved from <https://www.carfaontario.ca/>
- Carlson, L. (2009). *The Faces of Intellectual Disability: Philosophical Reflections*. Bloomington, IN: Indiana University Press.
- Centers for Disease Control and Prevention. (2019, September 26). Facts about developmental disabilities. Retrieved from <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>
- Centers for Disease Control and Prevention. (2020, January 2). Developmental disabilities. Retrieved from <https://www.cdc.gov/ncbddd/index.html>
- Center for Plain Language. (2019). *Five Steps to Plain Language*. Retrieved

from <https://centerforplainlanguage.org/learning-training/five-steps-plain-language/>

- Chandler, E. (2014). *Disability and the desire for community*. (Doctoral dissertation, University of Toronto, Toronto, Canada). Retrieved from [https://tspace.library.utoronto.ca/bitstream/1807/68432/1/Chandler\\_Eliza\\_201411\\_PhD\\_thesis.pdf](https://tspace.library.utoronto.ca/bitstream/1807/68432/1/Chandler_Eliza_201411_PhD_thesis.pdf).
- Clandinin, D.J., Pushor, D., Orr, A. (2007). Navigating sites for narrative inquiry. *Journal of Teacher Education*, 58(1), 21-35. Retrieved from <https://doi.org/10.1177/0022487106296218>
- Clandinin, D. J. (2006). *Handbook of narrative inquiry: Mapping a methodology*. D.J. Clandinin Ed.). Thousand Oaks, CA: Sage Publications.
- Clandinin, D.J., & Connelly, F.M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco, CA: Jossey-Bass.
- Clandinin, D. J., & Connelly, F. M. (1998a). Asking questions about telling stories. In C. Kridel (Ed.), *Writing educational biography: Explorations in qualitative research* (pp. 245–253). New York, NY: Garland.
- Clandinin, D. J., & Connelly, F. M. (1998b). Stories to live by: Narrative understandings of school reform. *Curriculum Inquiry*, 28(2), 149–164. Retrieved from <https://www.tandfonline.com/doi/abs/10.1111/0362-6784.00082>
- Clandinin, D.J., & Connelly, F.M. (1994). Personal experience methods. In N.K. Denzin and Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 413-427). Thousand Oaks, CA: Sage Publications.
- Clare, J. (1958, November 22). A better world for retarded children. *Maclean's: The Complete Archive*. Retrieved from <https://archive.macleans.ca/article/1958/11/22/a-better-world-for-retarded-children>
- Cole, A. L., & Knowles, J. G. (2008). Arts-informed research. In J. Knowles & A. Cole, *Handbook of the arts in qualitative research: perspectives, methodologies, examples, and issues* (pp. 55–71). Thousand Oaks, CA: Sage Publications, Inc. Retrieved from <https://doi.org/10.4135/9781452226545.n5>
- Community Living Toronto. (2018). *Milestones a Snapshot* [Brochure]. Retrieved from <https://www.cltoronto.ca/wp-content/uploads/2018/08/CLT-Corporate-Brochure.pdf>
- Community Living Toronto. (2017). Proposed Draft Eligibility Regulation for Developmental Services. Retrieved from <https://cltoronto.ca/proposed-draft-eligibility-regulation-for-developmental-services/>
- Community Living Toronto. (2008). *Community Living Toronto: Since 1948*. [Brochure]. Retrieved from

- <https://www.cltoronto.ca/wp-content/uploads/2018/08/CLT-Corporate-Brochure.pdf>
- Community Living Toronto. (n.d.). Supports & Services Fact Sheet: General Information. Retrieved from <https://cltoronto.ca/supports-and-services/>
- Conley, K. (2012, December 9). The king of pop. Retrieved from <https://www.townandcountrymag.com/leisure/arts-and-culture/roy-lichtenstein-interview>
- Contact Hamilton. (2018, October 29). History – Passport. Retrieved from <https://passportfundinghnr.ca/en/history/>
- Coons, K. & Watson, S. (2013). Conducting research with individuals who have intellectual disabilities: Ethical and practical implications for qualitative research. *Journal on Developmental Disabilities*. 19(2). 14-24. Retrieved from [https://oadd.org/wp-content/uploads/2013/01/Pages\\_from\\_41016\\_JoDD\\_19-2\\_14-24\\_Coons\\_\\_Watson.pdf](https://oadd.org/wp-content/uploads/2013/01/Pages_from_41016_JoDD_19-2_14-24_Coons__Watson.pdf)
- Crawford, C. (2013a). *Looking into poverty: Income sources of poor people with disabilities in Canada*. (Report). Ontario Institute for Research and Development on Inclusion and Society and Council of Canadians with Disabilities. Retrieved from <https://www.homelesshub.ca/sites/default/files/Income%20Sources%20Report%20IRIS%20CCD.pdf>
- Crawford, C. (2013b). *The Employment of People with Intellectual Disabilities in Canada: A Statistical Profile*. (Report). Institute for Research on Inclusion and Society. Retrieved from [https://irisinstitute.files.wordpress.com/2012/01/intellectual-disability-and-employment\\_iris\\_cr.pdf](https://irisinstitute.files.wordpress.com/2012/01/intellectual-disability-and-employment_iris_cr.pdf)
- Crawford, C. (2008). *No Place Like Home*. (Report on the Housing Needs of People with Intellectual Disabilities). Community Living British Columbia. Retrieved from <https://www.communitylivingbc.ca/wp-content/uploads/NoPlaceLikeHome.pdf>
- Creswell, J. W. (2013). Chapter 4: Five qualitative approaches to inquiry. In J. W. Creswell (Ed.), *Qualitative inquiry and research design: choosing among five approaches* (3rd ed, pp. 69–110). Thousand Oaks, CA: Sage Publications.
- Crossman, A. (2013). What Is a Snowball Sample in Sociology? Retrieved from <https://sociology.about.com/od/Types-of-Samples/a/Snowball-Sample.htm>
- Dačić, A. (2015, December 16). *Art Brut—Creativity from the Outskirts of Culture*. Retrieved from Widewalls Artist database: <https://www.widewalls.ch/art-brut-jean-dubuffet>
- davis halifax, n.v. (2016, February 7). Thoughts on 'crip arts' [blog post]. Recounting Huronia website.

- Definition of Bricolage. (2019). In *Merriam-Webster Dictionary*. (2019). Retrieved from <https://www.merriam-webster.com/dictionary/bricolage>
- Deleuze, G. & Guattari, F. (2004). *A thousand plateaus: Capitalism and schizophrenia* (Vol. 2). (B. Massumi, Trans.). New York, NY: Continuum.
- Deleuze, G., & Guattari, F. (1987). *A Thousand plateaus: Capitalism and schizophrenia*. Minneapolis, MN: University of Minnesota Press.
- Denzin, N. K. (1994). The art and politics of interpretation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (p. 500–515). Sage Publications, Inc.
- Denzin, N. K. & Giardina, M.D. (2009). Introduction. In N. K. Denzin, & M.D. Giardina. (Eds.), *Qualitative inquiry and social justice: Towards a politics of hope*: Walnut Creek, C.A.: Left Coast Press.
- Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research (3<sup>rd</sup> ed.). In N. K. Denzin & Y. S. Lincoln (Eds.). *The Sage handbook of qualitative research* (p. 1–32). Thousand Oaks, CA: Sage Publications Ltd.
- Developmental Services Branch, & Ministry of Community and Social Services. (2009). *About the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*. [Brochure]. Retrieved from [https://www.mcass.gov.on.ca/documents/en/mcass/publications/developmental/DSplainlanguage\\_en.pdf](https://www.mcass.gov.on.ca/documents/en/mcass/publications/developmental/DSplainlanguage_en.pdf)
- Development Service Office. (2014). *Passport Program Guidelines for Adults with a Developmental Disability and their Caregivers*. [Brochure]. Retrieved from [https://www.mcass.gov.on.ca/documents/en/mcass/publications/developmental/passport/passport\\_guidelines\\_en.pdf](https://www.mcass.gov.on.ca/documents/en/mcass/publications/developmental/passport/passport_guidelines_en.pdf)
- Developmental Services Office. (2014). *Tips Sheet: Passport Funding: What Can I Use It For?* Retrieved from [https://www.mcass.gov.on.ca/documents/en/mcass/publications/developmental/passport/Passport\\_Tip\\_Sheet-en.pdf](https://www.mcass.gov.on.ca/documents/en/mcass/publications/developmental/passport/Passport_Tip_Sheet-en.pdf)
- Developmental Services Ontario. (2020). *Funded and services*. Retrieved from <https://www.dsontario.ca/funded-services>
- Developmental Services Ontario. (2020, May 19). *Passport Program*. Retrieved from <https://www.dsontario.ca/passport-program>
- Developmental Services Ontario. (2016). *Community Participation Supports and Passport*. Retrieved from <https://www.dsontario.ca/community-participation-supports>

- Developmental Services Ontario. (2014). *Passport Program Guidelines for Adults with a Developmental Disability and their Caregivers*. Retrieved from [https://www.dsontario.ca/files/www/passport\\_guidelines\\_en.pdf](https://www.dsontario.ca/files/www/passport_guidelines_en.pdf)
- Developmental Services Ontario Central East Region. (2020). *DSO: Eligibility criteria and application process*. Retrieved from <https://www.yssn.ca/DSO-Eligibility-and-Application>
- Devlin, R. F. & Pothier, D. (2006). *Critical disability theory: essays in philosophy, politics, policy, and law*. Vancouver, BC: UBC Press.
- Dewey, J. (1950). *Experience and education*. New York, NY: Macmillan.
- Dewey, J. (1938). *Experience and Education*, New York, NY: Collier Books.
- Díaz, K. (n.d.). Paulo Freire. In *Internet Encyclopedia of Philosophy*. Retrieved from <https://www.iep.utm.edu/freire/>
- Dingwall, C., Kemp, K., Fowke, B. (2016). *Creating a Good Life in Community: A Guide on Person-Directed Planning*. The Individualized Funding Coalition for Ontario. <https://www.mcass.gov.on.ca/documents/en/mcass/publications/developmental/GuideonPersonDirectedPlanningFinal.pdf>
- Doris McCarthy Gallery, Justina M. Barnicke Gallery and University of Toronto Art Centre. (2015, June 25– 2015 October 10). *Flesh of the World*. Toronto, Canada. Retrieved from <https://fleshoftheworld.ca/gallery/#dm>
- Doyle, E. (2017, April 4). Amanda Cachia asks, “What can a body do?” [Canadian Art Gallery Educators]. Retrieved from <https://cageart.ca/amanda-cachia-asks-what-can-a-body-do/>
- Dubuffet, J. (September 1948). “Notice sur la compagnie de l’Art Brut”. In *Prospectus et tous écrits suivants*, vol. 1, pp. 489-91. Paris: Gallimard, 1967.
- Dyke, W. (2014 December -2015 January). Big dreams art company garners amazing support. *Community Living Toronto: Connections*, Retrieved from <https://cltoronto.ca/wp-content/uploads/2014/12/December-Newsletter-2014-2015.pdf>
- Edelson, R. T. (1990). Chapter 6: ART AND CRAFTS-Not “Arts and Crafts.” *Activities, Adaptation & Aging*, 15(1–2), 81–98. Retrieved from [https://doi.org/10.1300/J016v15n01\\_07](https://doi.org/10.1300/J016v15n01_07)
- Eisler, C. (1987). “Every artist paints himself”: Art history as biography and autobiography. *Social Research*, 54(1), 73–99. Retrieved from <https://www-jstor-org.ezproxy.library.yorku.ca/stable/pdf/40970448.pdf?refreqid=excelsior%3Ad3532e081125c6f95b02f815cfa25181>

- Eisner, E. (1997) What artistically crafted research can help us to understand about schools. *Educational Theory*, 45(1), pp. 1-13. Retrieved from <https://onlinelibrary-wiley-com.ezproxy.library.yorku.ca/doi/full/10.1111/j.1741-5446.1995.00001.x>
- Eiss, H. (2013). *The fairy feller's masterstroke*. Newcastle upon Tyne, UK: Cambridge Scholars Publishing.
- Elbel Libro Bookbinding. (2019). Elbel-Libro. Retrieved from <https://www.elbel-libro.com>
- Emerald Works. (n.d.). *SMART Goals—Time Management Training from MindTools.com*. Retrieved from <https://www.mindtools.com/pages/article/smart-goals.htm>
- Family Service Toronto. (2020). *PassportONE*. Retrieved from <https://familyservicetoronto.org/our-services/programs-and-services/passportone/>
- Family Service Toronto. (2019). *PassportONE: How to Submit Your Expense Claim*. Retrieved from <https://passportfundinghr.ca/wp-content/uploads/2017/02/2019-PassportOne-Tip-sheet-FINAL-1.pdf>
- Family Service Toronto. (2017). *Passport Program Information Package New Clients*. Retrieved from <https://familyservicetoronto.org/wp-content/uploads/2016/03/Passport-InformationPackageNewClients2017.pdf>
- Feder Kittay, Eva. (1999). *Love's labor: Essays on women, equality, and dependency*, Retrieved from [https://books.google.ca/books/about/Love\\_s\\_Labor.html?id=84CAezBBZBkC&redir\\_esc=y](https://books.google.ca/books/about/Love_s_Labor.html?id=84CAezBBZBkC&redir_esc=y)
- Ferenc, L. (2009, September 23). Gallery Encourages Artists to Touch the Sky. *The Star* [Toronto], Retrieved from [https://www.thestar-com.ezproxy.library.yorku.ca/news/gta/2009/09/23/gallery\\_encourages\\_artists\\_to\\_touch\\_the\\_sky.html](https://www.thestar-com.ezproxy.library.yorku.ca/news/gta/2009/09/23/gallery_encourages_artists_to_touch_the_sky.html)
- Ferguson, R. (2017, May 10.) Ontario parents want help for their developmentally delayed adult-age children. *The Star*. [Toronto], Retrieved from <https://www.thestar.com/news/queenspark/2017/05/10/ontario-parents-want-help-for-their-developmentally-delayed-adult-age-children.html>
- Finely, Crystal: Vanderbilt Kennedy Centre for Excellence in Developmental Disabilities. (2013). *Access to the Visual Arts History and Programming for People with Disabilities*. (Report). Retrieved from <https://vkc.mc.vanderbilt.edu/assets/files/resources/ArtsManual-P1-adj.pdf>
- Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings*. New York, NY: Pantheon Press

- Fox, A., & Macpherson, H. (2015). *Inclusive arts practice and research: A critical manifesto* (1 edition). London, UK: Routledge.
- Fox, D., & Willis, D. (1989). Disability policy: Restoring socioeconomic independence. *The Milbank Quarterly*, 67, 1-12. Retrieved from <https://www.jstor.org.ezproxy.library.yorku.ca/stable/3350234>
- Freire, P., Ramos, M. B., & Macedo, D. (2014, 2000). *Pedagogy of the oppressed*. New York, NY: Continuum.
- Freire, P. (1970). *Pedagogy of the oppressed*. In D. Flinders & S. Thornton (Eds.), *The curriculum studies reader* (2nd ed., pp. 125-133). New York, NY: Routledge Falmer. Retrieved from <https://lib.myilibrary.com.proxy1.lib.uwo.ca:2048/Open.aspx?id=15862&loc=&srch=undefined&src=0>
- Freire Institute. (2020). *Paulo Freire Biography*. Retrieved from <https://www.freire.org/paulo-freire/paulo-freire-biography>
- Funding Services. (n.d.). Retrieved from <https://communitylivingontario.ca/funding-services/>
- Galer, D. (2014). *Hire the handicapped!'' disability rights, economic integration and working lives in Toronto, Ontario, 1962-2005* (Doctoral dissertation, University of Toronto, Toronto, Canada). Retrieved from [https://tspace.library.utoronto.ca/bitstream/1807/65661/11/Galer\\_Dustin\\_201406\\_PhD\\_thesis.pdf](https://tspace.library.utoronto.ca/bitstream/1807/65661/11/Galer_Dustin_201406_PhD_thesis.pdf).
- Galer, D. (2012). Disabled capitalists: Exploring the intersections of disability and identity formation in the world of work. *Disability Studies Quarterly*, 32(3). Retrieved from <https://doi.org/10.18061/dsq.v32i3.3277>
- Garisto Pfaff, L. (Spring 2016). This mother knows best. *Sarah Lawrence College Magazine*. Retrieved from <https://www.sarahlawrence.edu/magazine/finding-courage/features/this-mother-knows-best.html>
- Gervais, M., Weber, S. J., & Caron, C. (2018). Guide to participatory feminist research: Abridged version. <https://uqo.ca/docs/21778>
- Gillmore, M. (2018, January 3). End of Ontario's sheltered workshops program drawing closer. *Rabble.ca News for the Rest of Us*. Retrieved from <https://rabble.ca/news/2018/01/end-ontarios-sheltered-workshops-program-drawing-closer>
- Glaser, M. (2008). *Drawing is thinking* (1st ed.). Woodstock, NY: Overlook Press.

- Glazier, J. A., (2005). Talking and teaching through a positional lens: Recognizing what and who we privilege in our practice. *Teaching Education*. 16(3), 231-244. Retrieved from <https://owl.uwo.ca/webct/urw/lc5116011.tp0/cobaltMainFrame.dowebct>
- Godfrey, T. (2014, November 17). *Windfall Basics gives men and women a chance to make professional strides*. *Toronto.Com*. Retrieved from <https://www.toronto.com/news-story/5042201-windfall-basics-gives-men-and-women-a-chance-to-make-professional-strides/>
- Government of Canada: Canada Revenue Agency. (2017). *Disability tax credit*. Retrieved from <https://www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/dtc/menu-eng.html>
- Government of Canada: Canada Revenue Agency. (2014, January 23). *Top things families should know about taxes*. Retrieved from <https://www.cra-arc.gc.ca/nwsrm/txtps/2014/tfsk07-eng.html>
- Government of Canada: Statistics Canada. (2012, April 13). *Participation and Activity Limitation Survey*. Retrieved from <https://www.statcan.gc.ca/eng/survey/household/participation/participation>
- Government of Ontario: Ministry of Children, Community Social Services. (2020). *Special Services at Home: Ministry of Children and Youth Services*. Retrieved from <http://www.children.gov.on.ca/htdocs/English/specialneeds/specialservices.aspx>
- Government of Ontario: Ministry of Labour, Training and Skills Development. (2019, October 21). *Archived—A plan for fair workplaces and better jobs (Bill 148)*. Retrieved from <https://www.ontario.ca/page/plan-fair-workplaces-and-better-jobs-bill-148>
- Government of Ontario: Ministry of Children and Youth Services. (2016). *Spotlight*. Retrieved September 8, 2017 from <http://www.children.gov.on.ca/htdocs/English/index.aspx>
- Government of Ontario: Ministry of Health and Long-Term Care. (2020). *Assistive Devices Program—Health Care Professionals—MOHLTC*. Retrieved from <https://www.health.gov.on.ca/en/pro/programs/adp/>
- Grattan N. (2011). *In the make: Studio visits with West Coast artists*. Retrieved from <https://inthemake.com/about/>
- Gray, L. (2017, August 27). *The importance of keeping a sketchbook by Lillian Gray fine artist*. Retrieved from <https://lilliangray.co.za/importance-sketchbook/>
- Guay, D. (2006). Special needs students in the art room: A journey. In D. Guay & B. Levett Gerber (Eds.). *Reaching and teaching students with special needs through art* (pp. 3-13). Reston, VA: NAEA.

- Guay, D. (2003). Paraeducators in art classrooms, issues of culture, leadership, and special needs. *Studies in Art Education*. 45(1), 20-39. Retrieved from <https://www.jstor.org/stable/1321106>
- Guba, E. G. & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N.K. Denzin & Y. S. Lincoln (Eds.). *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage
- Guest, D. (2006). Social security. *The Canadian encyclopedia*. Retrieved from <https://www.thecanadianencyclopedia.ca/en/article/social-security/>
- Guest, D. (1997). *The emergence of social security in Canada* (3rd ed.). Vancouver, BC: UBC Press.
- Halton Respite Services - (2017). The Passport Initiative. Retrieved from <https://www.respiteservices.com/Halton/index.aspx?ArticleID=386&lang=en-CA>
- Hamilton, M., Smith, L. & Worthington, K. (2008). Fitting the methodology with the research: An exploration of narrative, self-study and auto-ethnography. *Studying Teacher Education*, 4(1), 17-28. <https://doi.org/10.1080/17425960801976321>
- Harvard Graduate School of Education: Project Zero (2003) *Eight Habits of Mind*. Retrieved from <https://pz.harvard.edu/resources/eight-habits-of-mind>
- Held, D. (1990). *Introduction to critical theory: Horkheimer to Habermas*. Cambridge, UK: Polity Press.
- Hetland, L., Winner, E., Veenema, S., Sheridan, K. M., & Perkins, D. N. (2007). *Studio Thinking: The Real Benefits of Visual Arts Education* (8.2.2007 edition). New York, NY: Teachers College Press.
- Hogan, J., Hetland, L., Jaquith, D. B., Winner, E., & Nelson, D. P. (2018). *Studio thinking from the start: The K-8 art educator's Handbook* (1 edition). New York, NY: Teachers College Press.
- Holmes, C. A. (2002). Academics and practitioners; nurses as intellectuals, *Nursing Inquiry*, 9(2), 73-83. Retrieved from <https://onlinelibrary-wiley-com.ezproxy.library.yorku.ca/doi/full/10.1046/j.1440-1800.2002.00137.x>
- Houlberg, D. (2018, July 30). *Charity Intelligence Canada: Brands for Canada*. Retrieved from <https://www.charityintelligence.ca/charity-details/106-brands-for-canada>
- Howell, R.T. (2013, August 1). *Psychology today: How do people define the "good life"?* Retrieved from <https://www.psychologytoday.com/blog/cant-buy-happiness/201308/how-do-people-define-the-good-life>

- Income Security Advocacy Centre. (2018). Information Alert: Arts grants and ODSP and OW social assistance rules changed to better support artists in Ontario. Retrieved from <https://incomesecurity.org/publications/social-assistance-general/Information-Alert-Arts-Grants-and-ODSP-OW-January-2018.pdf>.
- Individualized Funding Coalition for Ontario. (2006, August). Direct/ Individualized Funding is Coming to Ontario. *IFCO Citizenship News*. pp.1-2. Retrieved from [2https://individualizedfunding.files.wordpress.com/2014/08/august-2006-volume-2-issue-2.pdf](https://individualizedfunding.files.wordpress.com/2014/08/august-2006-volume-2-issue-2.pdf)
- Individualized Funding Coalition for Ontario. (2006). *Rationale for Independent Planning and Facilitation in Ontario Why MCSS Should Move Quickly to Implementation*. (Report.). Retrieved from <https://individualizedfunding.files.wordpress.com/2014/07/rationale-for-independent-planning-and-facilitation-with-current-contact-info.pdf>
- Inductive Approach (Inductive Reasoning). (2017). Retrieved from <https://research-methodology.net/research-methodology/research-approach/inductive-approach-2/>
- Irwin, R. L., & Springgay, S. (2017). A/r/tography as practice-based research. In M. R. Carter and V. Triggs (Ed.). *Arts Education and Curriculum Studies: The Contributions of Rita L. Irwin* (pp. 7-21). Abingdon, UK: Taylor and Francis Group.
- Irwin, R. L., & O'Donoghue, D. (2012). Encountering pedagogy through relational art practices. *International Journal of Art & Design Education*, 31(3), 221–236. Retrieved from <https://doi.org/10.1111/j.1476-8070.2012.01760.x>
- Irwin, R. L. (2008). A/r/tography. In L. Given (Ed.), *The SAGE Encyclopedia of Qualitative Research Methods*. Thousand Oaks, CA: Sage Publications Inc. Retrieved from <https://doi.org/10.4135/9781412963909.n16>
- Irwin, R. & Springgay, S. (2008) A/r/tography as practice based research In M. Cahnmann-Taylor & R. Siegesmund. (Eds.), *Arts-based research in education: foundations for practice*. (pp. 103-124). New York, NY: Routledge.
- Irwin, R. L., Beer, R., Springgay, S., Grauer, K., Xiong, G., & Bickel, B. (2006). The Rhizomatic Relations of A/r/tography. *Studies in Art Education*, 48(1), 21. Retrieved from [https://opensiuc.lib.siu.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1004&context=ad\\_pubs](https://opensiuc.lib.siu.edu/cgi/viewcontent.cgi?referer=https://www.google.com/&httpsredir=1&article=1004&context=ad_pubs)
- Irwin, R., & de Cosson, A. (2004). *A/r/tography, rendering self through arts-based living inquiry*. Vancouver, BC: Pacific Educational Press.
- Ishida, E. (2019, June 7). *Diversity in the arts today: An interview with Roger Cardinal*. Retrieved from <https://www.diversity-in-the-arts.jp/en/stories/12639>

- Jaczek, H. (2017, February 14). *13,000 Adults with Developmental Disabilities Receiving Support*. Retrieved from <https://news.ontario.ca/mcys/en/2017/02/13000-adults-with-developmental-disabilities-receiving-support.html>
- Jean Dubuffet French Painter, Printmaker and Sculptor. (2019). In *The Art Story*. Retrieved from <https://www.theartstory.org/artist/dubuffet-jean/>
- Josephson, A. (2018, August 20). What Does “Means Tested” Mean? (2015, December 29). Retrieved from <https://smartasset.com/insights/what-does-means-tested-mean>
- Kafer, A. (2013). *Feminist, queer, crip*. Bloomington, IN: Indiana University Press.
- Kafer, A. (2013). *Feminist, queer, crip*. Retrieved from <https://www.library.yorku.ca/e/resolver/id/2476499>
- Kafer, A. (1998). *Resistant bodies: Disability as sites of resistance*. Paper presented at the International Leadership Forum for Women with Disabilities, Washington D.C. in 1999. Retrieved from <http://www.disabilityhistory.org/women>
- Keith, H. E., & Keith, K. D. (2013). *Intellectual disability: ethics, dehumanization, and a new moral community*. Chichester, UK: Wiley-Blackwell.
- Keith, K. D., & Schalock, R. L. (2000). Cross-cultural perspectives on quality of life: Trends and themes. In K.D. Keith & R. L. Schalock (Eds.). *Cross-cultural perspectives on quality of life*. (pp. 363-380). Washington, D.C: American Association on Mental Retardation.
- Keshen, J., & Blake, R. B. (2006). *Social fabric or patchwork quilt: the development of social policy in Canada*. Peterborough, ON: Broadview Press.
- Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research. *Disability & Society*, 15(1), 25–47. <https://www-tandfonline-com.ezproxy.library.yorku.ca/doi/abs/10.1080/09687590025757>
- Kits Media Tech. (2015, April 17). *Outside of what? Inside Outsider Art*. Retrieved from <https://www.outsiderart.me/outside-of-what/>
- Koskie Minsky LLP Justice Matters. (2018, November 30). Bill 47 Changes to Ontario Labour and Employment Legislation Have Now Passed. [Blog post]. Retrieved from <https://kmlaw.ca/bill-47-changes-ontario-labour-employment-legislation-now-passed-2/>
- Kuppers, P. (2012). Nothing about us without us: Mounting a disability arts exhibit in Berkeley, California. *Disability Studies Quarterly*, 32(1). Retrieved from <https://doi.org/10.18061/dsq.v32i1.1733>
- Kyle, G. (2019). *Finding the Way Home – A New Book About the Community Living Movement: The ideas, values and policies that have guided the work of Community Living Ontario*.

- LaRocque, J. (2005). Accounting for culture: Examining the building blocks of cultural citizenship. In C. Andrew, M. Gattinger, S.M. Jeannotte, and W. Straw (Eds.), *Accounting for culture: Thinking through cultural citizenship* (pp ix-xi). Ottawa, ON: University of Ottawa Press / Les Presses de l'Université d'Ottawa.
- Leadership and Learning Department: Toronto District School Board. (2018). *Special Education Plan 2018*. (Report, p. 234). Retrieved from [https://www.tdsb.on.ca/Portals/0/docs/Special\\_Education/2018TDSBSpecialEducationPlan.pdf](https://www.tdsb.on.ca/Portals/0/docs/Special_Education/2018TDSBSpecialEducationPlan.pdf)
- Legislative Authority, Section 11 of the ODSP Act, & Sections 23, 24, 29, 30, 31(2)5, 33.2, 35, 36 and 40 of the ODSP Regulation. (2008, July). Ontario Disability Support Program – Income Support Directives 6.1 Basic Needs Calculation. Government of Ontario. Retrieved from [https://www.mcass.gov.on.ca/documents/en/mcass/social/directives/odsp/income\\_support/6\\_1.pdf](https://www.mcass.gov.on.ca/documents/en/mcass/social/directives/odsp/income_support/6_1.pdf)
- Lige, S. (2011). *Adults with intellectual disabilities and the visual arts: It's not art therapy!* (Master of Arts Thesis, University of British Columbia, Vancouver, BC). Retrieved from <https://open.library.ubc.ca/cIRcle/collections/ubctheses/24/items/1.0072346>
- Lin, E. for Health Care-Access Research and Developmental Disabilities.(2011). *Prevalence of adult Ontarians with developmental disabilities higher than expected*. [Pamphlet]. Retrieved from <https://www.porticonetwork.ca/documents/38160/99698/Snapshot+2/d6ba814d-9ec0-406b-9f59-d7402543000e>
- Lindgren, K. (2014). Bodies in trouble: identity, embodiment and disability. In G. Bonnie and B. Hutchison (Eds.), *Gendering disability* (pp. 145-165). Piscataway, NJ: Rutgers University Press.
- Lindgren, K. A., Cachia, A., & George, K. C. (2014). Growing rhizomatically: Disability studies, the art gallery and the consortium. *Disability Studies Quarterly*, 34(2). Retrieved from <https://doi.org/10.18061/dsq.v34i2.4250>
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York, NY: New York University Press.
- Lord, J. (2006). *Moving Toward Citizenship: A Study of Individualized Funding in Ontario Study*. Toronto, ON: Individualized Funding Coalition for Ontario.
- Lord, J., & Hutchison, P. (2003). Individualised support and funding: Building blocks for capacity building and inclusion. *Disability & Society*, 18(1), 71–86. Retrieved from <https://doi.org/10.1080/713662196>
- Lord, J., Zupko, B. & Hutchison, P. (2000). *More Choice and Control for People with Disabilities*. Toronto, ON: Ontario Federation for Cerebral Palsy.

- Loriggio, P. (2017, April 24). Ontario suit alleges people with developmental disabilities denied services. *Globe and Mail*. [Toronto]. Retrieved from <https://www.theglobeandmail.com/news/national/ontario-suit-alleges-people-with-developmental-disabilities-denied-services/article34796765/>
- Ludins-Katz, F., & Katz, E. (1990). *Art & disabilities : establishing the creative art center for people with disabilities* . Cambridge, MA: Brookline Books.
- Lymburner, J. (2004). *Interwoven threads: theory, practice and research coming together*. In R. Irwin & A. Cosson (Eds.), *A/r/tograph: Rendering self through arts-based living inquiry* (pp. 75-88). Vancouver, BC: Pacific Educational Press.
- Marc Leroux as Litigation Guardian of Briana Leroux: Responding Motion Record of The Defendant, Her Majesty the Queen in Right of The Province of Ontario, No.: CV-17-573091-00CP (2017, December 15). Retrieved from Ontario Superior Court of Justice <https://kmlaw.ca/wp-content/uploads/2018/03/Responding-Motion-Record.pdf>
- Marin, L., Imperial, B., Mann, R., Basmajian, S. (Producer) & Taylor, A. (Director). (2008). *Examined Life* [Documentary Film]. Canada: Zeitgeist Films. Retrieved from <https://www.library.yorku.ca/e/resolver/id/2784691>
- Marr, A. (2000, February 6). Portrait of the artist as a cheat. *The Guardian*. [London]. Retrieved from <https://www.theguardian.com/theobserver/2000/feb/06/focus.news>
- Martinez, N. (2017). 10 Artist Interview Questions You Must Be Able to Answer. *Artrepreneur Art Business Journal*. Retrieved from <https://abj.artrepreneur.com/artist-interview-questions/>
- Maroto, M. & Pettinicchio, D. (2020). Barriers to Economic Security: Disability, Employment, and Asset Disparities in Canada. *Canadian Review of Sociology/Revue Canadienne de Sociologie* 57(1):53–79. Retrieved from <https://onlinelibrary.wiley.com/doi/full/10.1111/cars.12268>
- Marx, K. (1994). *Marx: Early political writings*. J. O'Malley. (Trans. & Ed). Cambridge, UK: Cambridge University Press. p. 7.
- Marx, K. and Engels, F. (1983). *Marx-Engels-Werke II im Berlin*: Dietz Verlag. London, UK: New Park publications.
- McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. New York, NY: New York University Press.
- Mercer, J. R. (1973). *Labeling the mentally retarded: Clinical and social system perspectives on mental retardation*. Berkeley, CA: University of California Press.
- Mishler, E. G. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard

University Press.

Monsebraaten, L. (2017, April 23). \$110M lawsuit targets Ontario waitlists for developmentally delayed adults. *The Star*. [Toronto]. Retrieved from <https://www.thestar.com/news/gta/2017/04/23/110m-lawsuit-targets-ontario-wait-lists-for-developmentally-delayed-adults.html>

Morse, J. & Niehaus, L. (2009). *Mixed method design: Principles and procedures*. Walnut Creek, CA: Left Coast Press.

Naïve art. In Encyclopaedia Britannica. (2019). Retrieved from <https://www.britannica.com/art/naive-art>

Nation Talk. (2012, April 13). Government of Canada announces funding to support Canadians with disabilities. *Nation Talk*. Retrieved from <https://nationtalk.ca/story/the-government-of-canada-announces-funding-to-support-canadians-with-disabilities>

National Geographic Society. (2019, July 16). Controlled Burning. *National Geographic Resource Library Encyclopedia Entry*. Retrieved from <https://www.nationalgeographic.org/encyclopedia/controlled-burning/Native>

Neuman, W.L., (2000). *Social research methods: Qualitative and quantitative approaches* (4<sup>th</sup> ed.). Boston, MA: Allyn & Bacon.

Obrist, H. U. (2014). *Ways of Curating*. New York, NY: Faber & Faber.

Ontario Arts Council and Toronto Arts Council. (2018). *ODSP & Arts Grants* [Pamphlet]. Council. Retrieved from [https://www.odspaction.ca/sites/default/files/resource/en\\_odsp\\_art\\_grants\\_2018\\_update\\_final\\_screen55704.pdf](https://www.odspaction.ca/sites/default/files/resource/en_odsp_art_grants_2018_update_final_screen55704.pdf)

O.D.S.P Action Coalition. (2011). *Dignity, Adequacy, Inclusion: Rethinking the Ontario Disability Support Program Submission to the Commission for the Review of Social Assistance in Ontario* (pp. 1–45). Retrieved October 2, 2017 from [https://incomesecurity.org/publications/social-assistance-reform/Social\\_Assistance\\_Review\\_-\\_ODSP\\_Action\\_Coalition\\_-\\_Dignity\\_Adequacy\\_Inclusion\\_-\\_First\\_Submission\\_to\\_the\\_Commission\\_-\\_2011\\_-\\_Word.pdf](https://incomesecurity.org/publications/social-assistance-reform/Social_Assistance_Review_-_ODSP_Action_Coalition_-_Dignity_Adequacy_Inclusion_-_First_Submission_to_the_Commission_-_2011_-_Word.pdf)

Ontario Disability Support Program Act, 1997, S.O. 1997, c. 25, Sched. B. (2014, July 24). Retrieved from <https://www.ontario.ca/laws/view>

Office of Communications Eunice Kennedy Shriver National Institute of Child Health & Human Development. (2016). Intellectual and Developmental Disabilities (IDDs): Condition Information. Retrieved from <https://www.nichd.nih.gov/health/topics/idds/conditioninfo/default>

- Offin, S. (2018, March 21). World Down Syndrome day hopes to improve community awareness and inclusion. *Global News* [Toronto]. Retrieved from <https://globalnews.ca/news/4097936/world-down-syndrome-day-hopes-to-improve-community-awareness-and-inclusion/>
- Ong, W. J. (1982). *Orality and literacy: the technologizing of the word*. London, UK: Methuen.
- Ontario Disability Support Program Act, & Sections 23, 24, 29, 30, 31(2)5, 33.2, 35, 36 and 40 of the ODSP Regulation. (2008, July). Retrieved from <https://www.ontario.ca/laws/regulation/980222>
- Ontario Ministry of Children, Community and Social Services. (2020). *Ontario Works*. Retrieved from <https://www.mcsc.gov.on.ca/en/mcsc/programs/social/ow/index.aspx>
- Ontario Ministry of Children, Community and Social Services. (2019). *Ontario Disability Support Program*. Retrieved from <https://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/index.aspx>.
- Ontario Ministry of Children, Community and Social Services. (2018, September 4). Ontario Disability Support Program-Income Support 6.1 Basic Needs Calculation. Retrieved from [https://www.mcsc.gov.on.ca/en/mcsc/programs/social/directives/odsp/is/6\\_1\\_ODSP\\_ISDirectives.aspx](https://www.mcsc.gov.on.ca/en/mcsc/programs/social/directives/odsp/is/6_1_ODSP_ISDirectives.aspx)
- Ontario Ministry of Children, Community and Social Services, & Ontario. (2018, March 22). *As an Ontario Disability Support Program recipient: Coming back to the program*. Retrieved from Ministry of Children, Community and Social Services, & Ontario website: [https://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/client/coming\\_back.aspx](https://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/client/coming_back.aspx)
- Ontario Ministry of Children, Community and Social Services. (2018, March 8). *Creating Good Life in Community: A Guide on Person-Directed Planning*. Retrieved from <https://www.mcsc.gov.on.ca/en/mcsc/publications/developmentalServices/personDirectedPlanning/about.aspx>
- Ontario Ministry of Children, Community and Social Services. (2018, March 8). *Help with daily living*. Retrieved from <https://www.mcsc.gov.on.ca/en/mcsc/programs/developmental/serviceSupport/passport.aspx>
- Ontario Ministry of Children, Community and Social Services. (2018, March 8). *The shift to community living: The 1990s, History of Developmental Services*. Retrieved from [https://www.mcsc.gov.on.ca/en/dshistory/community/1990s\\_beyond.aspx](https://www.mcsc.gov.on.ca/en/dshistory/community/1990s_beyond.aspx)
- Ontario Ministry of Children, Community and Social Services. (2018, March 8). *The shift to community living: The 1980s, History of Developmental Services*. Retrieved from [https://www.mcsc.gov.on.ca/en/dshistory/community/1990s\\_beyond.aspx](https://www.mcsc.gov.on.ca/en/dshistory/community/1990s_beyond.aspx)

- Ontario Ministry of Children, Community and Social Services. (2018, March 8). *The shift to community living: The 1970s, History of Developmental Services*. Retrieved from <https://www.mcsc.gov.on.ca/en/dshistory/community/1970s.aspx>
- Ontario Ministry of Children, Community and Social Services. (2018, March 8). *Person-directed planning*. Retrieved from [https://www.mcsc.gov.on.ca/en/mcsc/programs/developmental/serviceSupport/person\\_directed\\_planning.aspx](https://www.mcsc.gov.on.ca/en/mcsc/programs/developmental/serviceSupport/person_directed_planning.aspx)
- Ontario Ministry of Children, Community and Social Services. (2017). *Ontario Disability Support Program - Income Support, 4.1 - Definition and Treatment of Assets*. Retrieved from [https://www.mcsc.gov.on.ca/en/mcsc/programs/social/directives/odsp/is/4\\_1\\_ODSP\\_ISDirectives.aspx](https://www.mcsc.gov.on.ca/en/mcsc/programs/social/directives/odsp/is/4_1_ODSP_ISDirectives.aspx).
- Ontario Ministry of Children, Community and Social Services. (2016). *Help with daily living*. Retrieved from <https://www.mcsc.gov.on.ca/en/mcsc/programs/developmental/serviceSupport/passport.aspx>
- Ontario Ministry of Children, Community and Social Services. (2016). *The Passport Program Questions and Answers*. Retrieved from [https://mcsc.gov.on.ca/en/mcsc/programs/developmental/serviceSupport/passport\\_QandA.aspx](https://mcsc.gov.on.ca/en/mcsc/programs/developmental/serviceSupport/passport_QandA.aspx)
- Ontario Ministry of Children Community and Social Services. (2015). *Eligibility for ODSP Income Support*. Retrieved from [https://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/income\\_support/IS\\_Eligibility.aspx](https://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/income_support/IS_Eligibility.aspx)
- Ontario Ministry of Children Community and Social Services. (2013). *Treatment of income: When you work and earn money*. Retrieved from [https://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/income\\_support/odsp\\_workearn.aspx](https://www.mcsc.gov.on.ca/en/mcsc/programs/social/odsp/income_support/odsp_workearn.aspx)
- Ontario Ministry of Children Community and Social Services. (2012). *About the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* |. Retrieved from Ministry of Community and Social Services <https://www.mcsc.gov.on.ca/en/mcsc/publications/developmentalServices/servicesSupportsSocialInclusion.aspx>
- Ontario Ministry of Children Community and Social Services Act, R.S.O. 1990, c. M.20. (2014, July 24). Retrieved from e-laws <https://www.ontario.ca/laws/view>

- Ontario Ministry of Community and Social Services. (1997). *Making Services Work for People: A new framework for children and for people with developmental disabilities*. Retrieved from Ministry of Community and Social Services website: <https://collections.ola.org/mon/1000/10264783.pdf>
- Ontario Ministry of Children, Community and Social Services. (n.d.). *New regulation clarifies eligibility for adult developmental services*. Retrieved from Services <https://www.mcsc.gov.on.ca/en/mcsc/programs/developmental/regulation.aspx>
- Ontario Ministry of Children, Community and Social Services. (n.d.). *Ontario Disability Support Program: Returning to ODSP*. [Pamphlet]. Retrieved from Ministry of Children, Community and Social Services website. [https://www.mcsc.gov.on.ca/documents/en/mcsc/social/info\\_sheets/ODSP\\_return.pdf](https://www.mcsc.gov.on.ca/documents/en/mcsc/social/info_sheets/ODSP_return.pdf)
- Ontario Ministry of Children, Community and Social Services. (2006, May). *Opportunities and Action: Transforming Supports in Ontario for People who have a Developmental Disability*. (Report: Executive Summary). Retrieved from Ministry of Community and Social Services <https://www.mcsc.gov.on.ca/en/mcsc/publications/developmentalServices/opportunitiesAndActionTransformingExecSummary/background.aspx>
- Ontario Ministry of Education. (2020). *Cooperative Education – Expanded*. Government of Ontario. Retrieved from <https://www.edu.gov.on.ca/morestudentsuccess/coop.html>
- Ontario Ministry of Education. (2010) *The Ontario Curriculum, Grades 11 and 12: The Arts, 2010*. p. 17. Retrieved from <http://www.edu.gov.on.ca/eng/curriculum/secondary/arts1112curr2010.pdf>
- Open Education Database. (2014, June 18). 9 Little-Known Treasure Troves of High-Res Images. Retrieved from OEDB.org website: <https://oedb.org/ilibrarian/guide-little-known-image-collections-millions-free-hi-res-images/>
- Osburn, J. (2006, June). An Overview of Social Role Valorization Theory. Retrieved from [https://socialrolevalorization.com/wp-content/uploads/2019/03/srv\\_theory\\_joe\\_osburn.pdf](https://socialrolevalorization.com/wp-content/uploads/2019/03/srv_theory_joe_osburn.pdf)
- Osburn, J. (1998). An Overview of Social Role Valorization Theory. *The International Social Role Valorization Journal/La revue internationale de la Valorisation des roles sociaux*, 3(1), 7-12. Retrieved from <https://socialrolevalorization.com/resources/srv-journal/>
- Ott, K. (2019). Faculty of Information at the University of Toronto: Katherine Ott: When ‘No’ Gets in the Way—Katherine Ott: When ‘No’ Gets in the Way Retrieved from <https://ischool.utoronto.ca/event/katherine-ott-when-no-gets-in-the-way/>
- Ott, K. (2014). Disability things: material culture and American disability history, 1700–2010. In Burch, S. & Rembis M. (Eds.), *Disability histories* (pp. 119-135). Chicago, IL: University of Illinois Press. Retrieved from <https://www.jstor.org/stable/10.5406/j.ctt6wr5rt.11>

- Ouellette, A., & Palmiere S. (2014, January 13) *Special Services at Special Services at Home and Passport Home and Passport Coalition*. (Report to the Select Committee on Developmental Services). Retrieved from Special Services at Special Services at Home and Passport Home and Passport Coalition: <http://oddasn.ca/wp-content/uploads/2018/01/Brief-to-the-Select-Committee-on-Developmental-Services-2014-with-cover-2.pdf>
- Peacock, G. (n.d.). *Cognitive Deficits & Intellectual Disability: Meaning & Treatment*. EMedicineHealth. Retrieved from [https://www.emedicinehealth.com/cognitive\\_deficits/article\\_em.htm](https://www.emedicinehealth.com/cognitive_deficits/article_em.htm)
- Peers, D., Brittain, M., & McRuer, R. (2012). Crip Excess, Art, and Politics: A Conversation with Robert McRuer. *Review of Education, Pedagogy, and Cultural Studies*, 34(3–4), 148–155. Retrieved from <https://doi.org/10.1080/10714413.2012.687284>
- Peiry, L. (2001). *Art brut: The origins of outsider art*. Paris, France: Flammarion.
- Perrin, B. (2017). The original “Scandinavian” normalization principle and its continuing relevance for the 1990s. In R. J. Flynn & R. Lemay (Eds.), *A quarter-century of normalization and social role valorization: Evolution and impact*. (pp. 181–196). Ottawa, ON: University of Ottawa Press.
- Petricone, I. and Montigny, E. (2011, August). *Comments on A Discussion Paper: Issues and Ideas – June 2011 prepared by the Commission for the Review of Social Assistance in Ontario*. (pp. 1–42). (Report to the Commission for the Review of Social Assistance in Ontario). Retrieved from ARCH Disability Law Centre: <https://www.mcass.gov.on.ca/documents/en/mcass/social/commission/A-E/ARCH%20Disability%20Law%20Centre.pdf>
- Pettinicchio, D. and Maroto, M. (2020, March 13). Canadians with disabilities face an uncertain financial future: University of Toronto expert. *University of Toronto News*. [Toronto]. Retrieved from <https://www.utoronto.ca/news/canadians-disabilities-face-uncertain-financial-future-u-t-expert>
- Phaidon. (n.d.). *A Movement in a Moment: Art Brut*. Retrieved from <https://www.phaidon.com/agenda/art/articles/2015/april/29/a-movement-in-a-moment-art-brut/>
- Pikuét, K. (2020). *Elements and Principles of Art* [PowerPoint slides]. Retrieved from <https://www.slideshare.net/kpikuét/elements-and-principles-of-art-presentation>
- Polkinghorne, D. E. (2007). Validity issues in narrative research. *Qualitative Inquiry* 13(4), 471–486. Retrieved from <https://doi.org/10.1177/1077800406297670>
- Polkinghorne, D. E. (1998). *Narrative knowing and the human sciences*. Albany, NY: State

University of New York Press.

Portnoy, G & Hart-Angelo, J. (1982) – Where everybody knows your name (Cheers Theme). [Recorded by G. Portnoy]. On [Digital 45]. Essential Media Corp. Hallandale , FL. Retrieved from <https://genius.com/Gary-portnoy-where-everybody-knows-your-name-cheers-theme-lyrics>

Power, A., Lord, J. E., & DeFranco, A. S. (2013). *Active citizenship and disability: implementing the personalisation of support*. New York, NY: Cambridge University Press.

Prince, J. A. (1985). The metropolitan Toronto association for the mentally retarded and its policy formation, successes and failures. *Human Organization*, vol. 44(3), pp. 264–268. Retrieved from <https://search.proquest.com/openview/6393d297326756a57d0260966759e680/1?pq-origsite=gscholar&cbl=1821032>

Prince, M. J. (2004). Canadian disability policy: Still a hit-and-miss affair. *Canadian Journal of Sociology*, 29(1), 59. Retrieved from [https://go.galegroup.com.ezproxy.library.yorku.ca/ps/i.do?p=EAIM&sw=w&u=yorku\\_main&v=2.1&it=r&id=GALE%7CA115566622&asid=97c957889c1a02a12ac64ee77f9e43e7](https://go.galegroup.com.ezproxy.library.yorku.ca/ps/i.do?p=EAIM&sw=w&u=yorku_main&v=2.1&it=r&id=GALE%7CA115566622&asid=97c957889c1a02a12ac64ee77f9e43e7)

Prinzhorn, H. (2013). *Artistry of the mentally ill: A contribution to the psychology and psychopathology of configuration*. Berlin, Germany: Springer-Verlag Berlin Heidelberg

Quist, M., (2018, August 21). *Cognitive Disability vs. Intellectual Disability Chapter 6. Lesson 39. Video & Lesson Transcript*. [Audio podcast]. Retrieved from <https://study.com/academy/lesson/cognitive-disability-vs-intellectual-disability.html>

Raphael, D., Steinmetz, B., Renwick, R. et al. (1999). The community quality of life project: A health promotion approach to understanding communities. *Health Promotion International*, 14, 197-207. Retrieved from [https://www.researchgate.net/publication/255656485\\_The\\_Community\\_Quality\\_of\\_Life\\_Project\\_A\\_health\\_promotion\\_approach\\_to\\_understanding\\_communities](https://www.researchgate.net/publication/255656485_The_Community_Quality_of_Life_Project_A_health_promotion_approach_to_understanding_communities)

Ravenscroft, J. (2019). *The routledge handbook of visual impairment: Social and cultural research*. New York, NY: Routledge.

Rawvision. (n.d.). What is Outsider Art? *Raw Vision Magazine*. <https://rawvision.com/about/what-is-outsider-art>

Redvers, B, and Hart, M. (2019). *Understanding the Passport program and learning how it can help you live a more meaningful life in your community options*. Retrieved from <https://www.dsontario.ca/assets/documents/Webcast-QA.pdf>

Reid, J. (2016, May 5). Crippling the Arts: It's About Time. *Canadian Art*. Retrieved from <https://canadianart.ca/features/cripping-arts-time/>

- Rich, N. (2015, December 16). A Training Ground for Untrained Artists. *The New York Times*. Retrieved from <http://www.nytimes.com/2015/12/20/magazine/a-training-ground-for-untrained-artists.html>
- Rinder, L. (2011). *Create: Introductory essay in exhibition catalogue*. Berkeley, CA: University of California Press.
- Rioux, M. and Fraser, V. (2006). Does theory matter? exploring the nexus between disability, human rights and public policy. In W. W. Pue (Ed.), *Critical disability theory essays in philosophy, politics, policy, and law*, (pp. 48–68). Vancouver, BC: UBC Press.
- Rioux, M. H., and Prince, M. (2002). The Canadian political landscape of disability: Policy perspectives, social status, interest groups and the rights movement. In A. Puttee (Eds.). *Federalism, democracy and disability policy in Canada*. Montreal, QU and Kingston, ON: McGill and Queen's University Press.
- Roehrer Institute. (1993). *Direct dollars: a study of individualized funding in Canada*. Toronto, ON: Roehrer Institute-Institut Roehrer.
- Royal Ontario Museum. (2010 October 2- 2011 January 2). *El Anatsui: When I Last Wrote to You about Africa*. (n.d.). Toronto. Retrieved from <https://www.rom.on.ca/en/about-us/newsroom/press-releases/el-anatsui-when-i-last-wrote-to-you-about-africa>
- Rush, F. L. (2004). *The Cambridge companion to critical theory*. Cambridge, UK: Cambridge
- Said, E. (1979). *Orientalism*. New York City, NY: Pantheon Books.
- Seraj, A. (2011, September). *Create: The artists are present*. Retrieved from <http://www.azinseraj.com/1302/artwork/collaboration/create-the-artists-are-present/>
- Sherwood, K. (Producer), & Sherwood, K. (Director). (2012). *Create*. [Video file]. United States: A Yelling Clinic Production. Retrieved from <https://vimeo.com/54344468>
- Sherwood, K and Rinder, L. (2011, June 11). Katherine Sherwood & Lawrence Rinder debate create at BAMPFA, Berkeley CA: Berkeley Art Museum and Pacific Film Archive. Retrieved from <https://bampfa.org/news/katherine-sherwood-and-lawrence-rinder-debate-create>
- Shildrick, M. (2015). “Why should our bodies end at the skin?”: Embodiment, boundaries, and somatechnics. *Hypatia*, 30(1), 13–29. Retrieved from <https://doi.org/10.1111/hypa.12114>
- Siebers, T. (2008). *Disability Theory*. Ann Arbor, MI: University of Michigan Press.
- Smith, B. & Sparkes, A. (2008). Narrative and its potential contribution to disability studies. *Disability & Society*, 23(1), 17-28. Retrieved from

[https://www.researchgate.net/publication/248912857\\_Narrative\\_and\\_its\\_potential\\_contribution\\_to\\_disability\\_studies](https://www.researchgate.net/publication/248912857_Narrative_and_its_potential_contribution_to_disability_studies)

- Spector-Mersel, G. (2011). Mechanisms of selection in claiming narrative identities: A model for interpreting narratives. *Qualitative Inquiry*, 17(2), 172-185. Retrieved from <https://doi:10.1177/1077800410393885>
- Spector-Mersel, G. (2010). Narrative research: Time for a paradigm. *Narrative Inquiry*, 20(1), iii, 204-224. Retrieved from [https://doi: 10.1075/ni.20.1.10spe](https://doi:10.1075/ni.20.1.10spe)
- Spindel, P. & Associates. (2013). *Abuse by Ministry: Power dynamics, lack of resources, and the troubled relationship between the Ministry of Community & Social Services and Families of People with Developmental Disabilities* (Report to the Minister of Community & Social Services and the Premier of Ontario, p. 17). Retrieved from Special Services at Home and Passport Coalition: <https://ssahcoalition.ca/wp-content/uploads/2013/11/MCSS-Brief-Abuse-By-Ministry-1.pdf>
- Springgay, S., Irwin, R. L., & Wilson Kind, S. (2005). A/r/tography as living inquiry through art and text. *Qualitative Inquiry*, 11(6), 897–912. Retrieved from: <https://doi.org/10.1177/1077800405280696>
- SSAH & Passport Coalition. (2016). MSSC Response Stats 2015: Information Pulled from Database for year end 2015/2016 for Items 1-6. Retrieved August 3, 2017, from <https://ssahcoalition.ca/wp-content/uploads/2017/03/Response-from-MCSS-Stats2015-16.pdf>
- SSAH & Passport Coalition. (2012). SSAH & Passport Facts. Retrieved October 2, 2017 from <https://ssahcoalition.ca/ssah-passport-facts/>
- Staff Artists' Network. (2017, February 1). Sketchbooks Then and Now (Part 1). Retrieved from <https://www.artistsnetwork.com/art-mediums/drawing/sketchbooks-then-now-part-1-art-supplies-giveaway/>
- Stapleton, J. & Procyk, S, Kochen, L. The Dream Team, Houselink & CAMH (2011, May). What stops us from working? New ways to make work pay, by fixing the treatment of earnings under the Ontario Disability Support Program. Retrieved from [https://www.camh.ca/en/hospital/about\\_camh/influencing\\_public\\_policy/Documents/ODSP%20Report%20final.pdf](https://www.camh.ca/en/hospital/about_camh/influencing_public_policy/Documents/ODSP%20Report%20final.pdf)
- Starin, Dawn. (2015). A place for creative growth. *The Solutions Journal*, 6(2), 33–37. Retrieved from <https://www.thesolutionsjournal.com/article/a-place-for-creative-growth/>
- Statistics Canada. (2006). Participation and Activity Limitation Survey. *Table 7: Main help providers, Canada*, 2006. Retrieved from: <https://www150.statcan.gc.ca/n1/pub/89-628-x/2010015/tbl/tbl7-eng.htm>

- Swinburne, J. (2005). Art facilitation as an inclusive practice. Retrieved from <https://www.creativespirit.on.ca/files/resources/JSwinburne.pdf>
- Tangled Art + Disability. (2014). *Report on deaf and disability arts in Ontario* (pp. 1–19). Retrieved from <https://www.neighbourhoodartsnetwork.org/getattachment/476503ba-c2c1-4ae7-934d-7003b3084271/Disability-Arts-Report.pdf.aspx>
- Tate. (n.d.). Bricolage – Art Term. Tate. Retrieved from <https://www.tate.org.uk/art/art-terms/b/bricolage>
- Tate. (n.d.). Naïve art – Art Term. Tate. Retrieved from <https://www.tate.org.uk/art/art-terms/n/naive-art>
- Taylor, S. (2004, March 1). The right not to work, power and disability. *Monthly View an Independent Socialist Review*, 55(10). Retrieved from <https://monthlyreview.org/2004/03/01/the-right-not-to-work-power-and-disability/>
- Taylor, S. (2006). Before it had a name: Exploring the historical roots of disability studies in education. In S. Danforth, S., & S. L. Gabel, (Eds.), *Vital questions facing disability studies in education* (pp. xiv-xxiii). Bern, Switzerland: Peter Lang Inc. International Academic Publishers.
- Tellis, W. M. (1997). Introduction to Case Study . *The Qualitative Report*, 3(2), 1-14. Retrieved from <https://nsuworks.nova.edu/tqr/vol3/iss2/4>
- Thoopal, R. K. (n.d.). Pitara kids’ network: Why do flies have compound eyes? –. Retrieved from <https://www.pitara.com/science-for-kids/5ws-and-h/why-do-flies-have-compound-eyes/>
- Toronto Parks, Forestry & Recreation. (2017). Canadian adventure: New strides day camp: Retrieved from <https://www.canadianadventure.com/?action=camp.viewDetail&camp=new-strides-day-camp-toronto-parks-forestry-recreation>
- Tremain, S. (2016, January 6). *Social Policy in Canada*. [Personal Notes from Lecture at York University, Toronto, ON]
- Tremain, S. (2014). *Disability policy highlights*. (Report from The Caledon Institute of Social Policy). Retrieved from <http://www.caledoninst.org/Publications/PDF/1041ENG.pdf>
- Tremain, S. & Caledon Institute of Social Policy, (2015). *Disability supports: Missing on the policy radar*. Retrieved from <https://www.library.yorku.ca/e/resolver/id/2741227>
- United Nations: Department of Economic and Social Affairs Disability. (2006). Convention on the Rights of Persons with Disabilities. Retrieved from

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with->

Universitätsbibliothek Heidelberg. (n.d.). The public domain review: Hans Prinzhorn's artistry of the mentally ill (1922). Retrieved from <https://publicdomainreview.org/collection/hans-prinzhorn-s-artistry-of-the-mentally-ill-1922/>

University of York Department of Social Policy and Social Work. (n.d.) What is Social Policy? Retrieved from <https://www.york.ac.uk/spsw/about/what-is-social-policy/>

van Manen. M. (1990). Investigating experience as we live it. *Researching lived experience: Human science for an action sensitive pedagogy*. London, ON: Althouse Press.

Volkersz, W. (1998, Spring). Roger Cardinal on Outsider Art. *Raw Vision Magazine*. Retrieved from <https://rawvision.com/articles/roger-cardinal-outsider-art>

Wasserman, K., Drucker, J., Niffenegger, A. (2007). *The book as art: Artists' books from the national museum of women in the arts*. Princeton, NJ: Princeton Architectural Press.

Watson, S. M.R., and Keith, K.D. (2002). Comparing the quality of life of school-age children with and without disabilities. *Mental Retardation*, 40, 304-312. Retrieved from <https://pubmed.ncbi.nlm.nih.gov/12123394/>

Web Accessibility in Mind (WebAIM) (2020). Cognitive: Introduction. Retrieved from: <https://webaim.org/articles/cognitive/#functional>

Weber, S. (2008). Visual images in research. In J. Knowles & A. Cole, *Handbook of the arts in qualitative research: Perspectives, methodologies, examples, and issues* (pp. 42–54). Thousand Oaks, CA: Sage Publications, Inc. Retrieved from <https://doi.org/10.4135/9781452226545.n4>

Weber, S. (2006). IIRC- reloaded: Visual methodologies [Academic]. Retrieved from <https://iirc.mcgill.ca/txp/?s=Methodology&c=Visual%20methodologies>

Wehmeyer, M. L. (2013). *The story of intellectual disability: An evolution of meaning, understanding, and public perception*. Baltimore, MD: Brookes Publishing Co.

Weingartner, R. (1967). Historical explanation. In P. Edwards (Ed.), *The encyclopedia of philosophy* (Vol. 6, pp. 7-11). New York, NY: Macmillan.

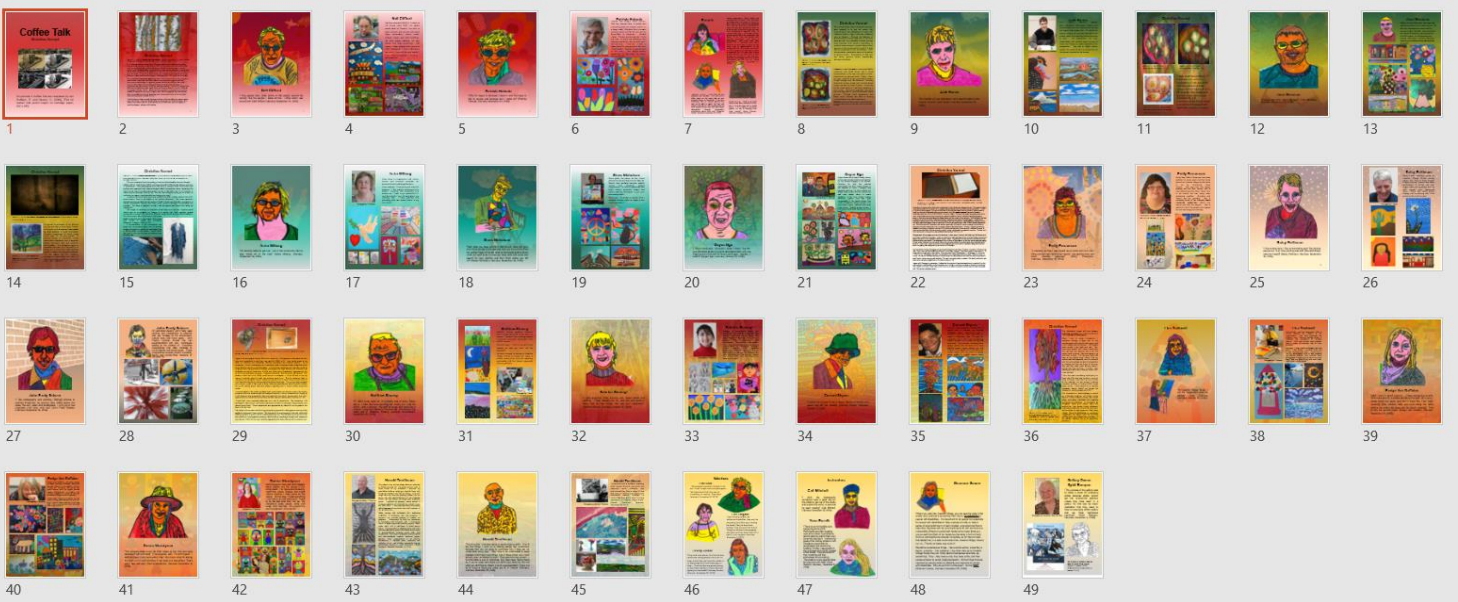
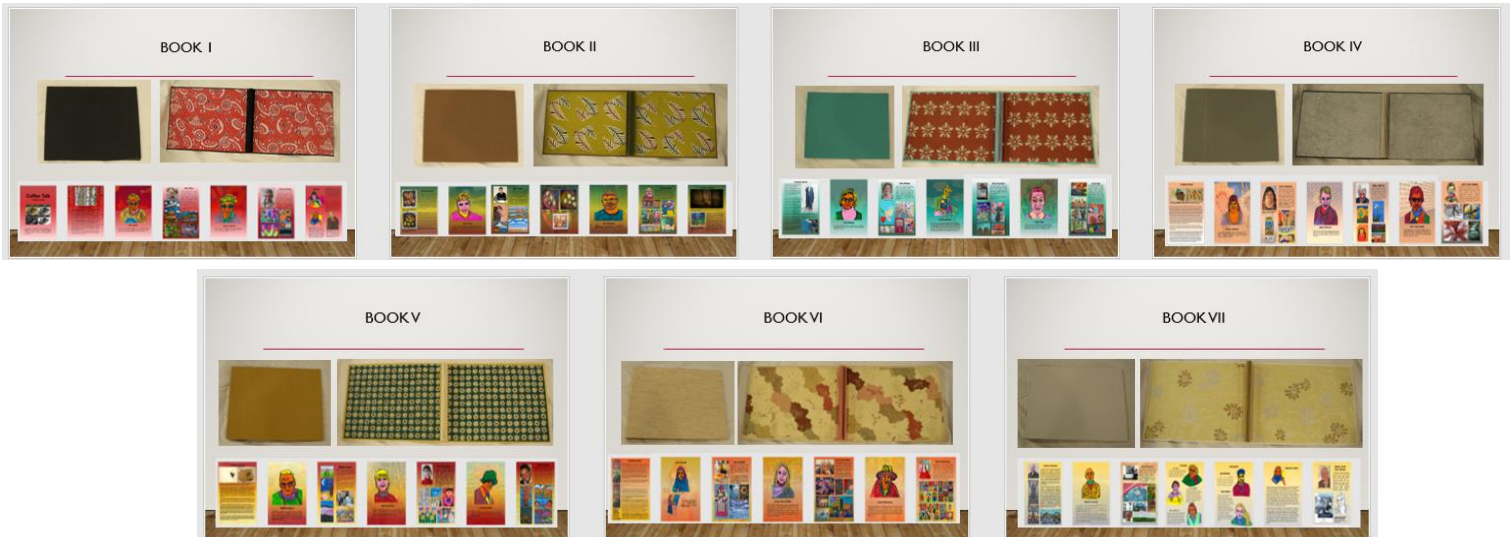
Weinstein, D. & Weinstein, M.A. (1991) Georg Simmel: Sociological flaneur bricoleur. *Theory, Culture & Society*, 8, 151-168. Retrieved from <https://journals-sagepub-com.ezproxy.library.yorku.ca/doi/10.1177/026327691008003011>

Welsh, Moira. (2015, November 29). Ontario's sheltered workshops to close forever. *The*

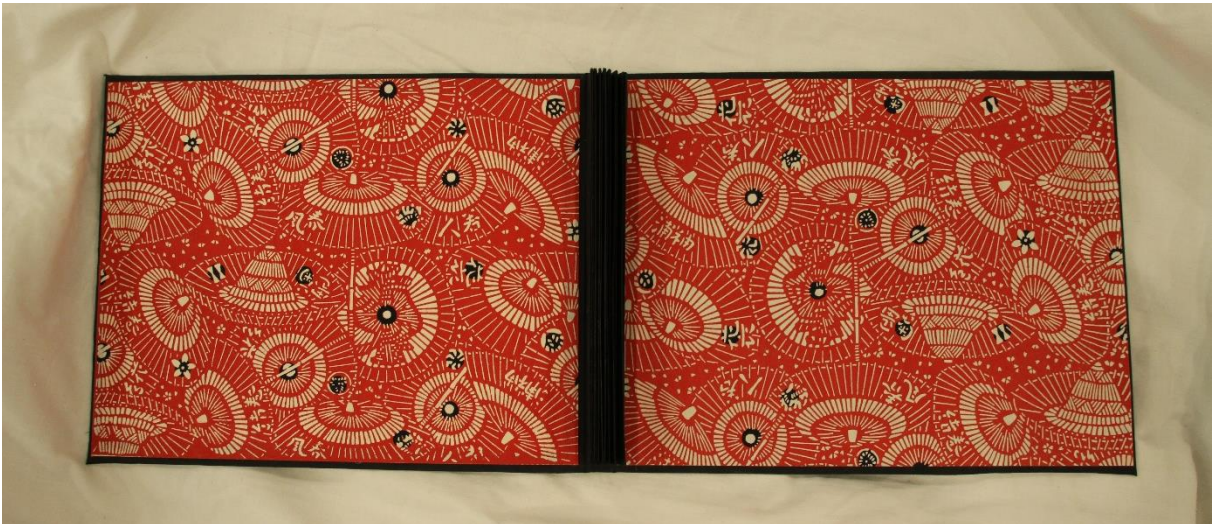
- Star*. [Toronto]. Retrieved from <https://www.thestar.com/news/canada/2015/11/29/ontarios-sheltered-workshops-to-close-forever.html>
- Wendell, S. (1996). *The rejected body: feminist philosophical reflections on disability*. New York, NY: Routledge.
- Wendell, S. (1989). Toward a feminist theory of disability. *Hypatia*, 4(2), 104–124. Retrieved from <https://doi.org/10.1111/j.1527-2001.1989.tb00576.x>
- Westgate, R.J., & Blessing, C. (2005). The power of person-centered planning. *Teaching Exceptional Children Plus*, 2(2). Retrieved from <https://escholarship.bc.edu/education/tecplus/vol2/iss2/art2/>
- Williams, P., & Shoultz, B. (1984). *We can speak for ourselves: self-advocacy by mentally handicapped people*. Bloomington, IN: Indiana University Press.
- Williams, P., & Shoultz, B. (1982). *We can speak for ourselves: Self-advocacy by mentally handicapped people*. London, UK: Souvenir Press Ltd.
- Wilson, B. (2003). Of diagrams and rhizomes: Visual culture, contemporary art, and the impossibility of mapping the content of art education. *Studies in Art Education*, 44(3), 214–299. Retrieved from <https://www-tandfonline-com.ezproxy.library.yorku.ca/doi/abs/10.1080/00393541.2003.11651740>
- Wolfensberger, W. (1985). An overview of social role valorization and some reflections on elderly mentally retarded persons. In M. P. Janicki & H. M. Wisniewski (Eds.), *Aging and developmental disabilities: Issues and approaches* (pp. 61-76). Baltimore, MD: Paul H. Brooks.
- Wolfensberger, W. (1972). *The principles of normalization in human services*, Toronto, ON: National Institute on Mental Retardation.
- World Health Organization & the World Bank. (2011). *World report on disability* (pp. 1–325). Retrieved from <file:///C:/Users/Christina/Documents/RESEARCH/COMPS/Social%20Policy/Readings/Disability/World%20Report%20on%20disability%20pdf.pdf>
- Yarmol, C. (2013). *Listening to voices of exceptional students to inform art pedagogy* (Master's Thesis, Western University, London, Canada). Retrieved from Electronic Thesis and Dissertation Repository <https://ir.lib.uwo.ca/etd/1371>
- York Support Services Network. (2011). *Passport FAQs*. Retrieved from <https://www.yssn.ca/Passport-FAQs>

# Appendices


## Appendix A: Tiled Images of Book Covers, Their Endpapers & Book's Contents



**Appendix B: Samples of Interior Endpapers of Books**



## Appendix C: Sample Book Pages with Quotes & Artists' Statements



**Quyen Ngo**

"I like to come here. It is quiet. I come. I draw. I like this one [He looks at me but points downward firmly with one finger at one of his still life flower paintings.]. I decide. I paint it" (Quyen Ngo, Interview, October 23, 2019).




Photograph by H. Tomlinson



**Quyen Ngo**

Quyen draws on his friends, family, nature, culture and everyday objects as inspiration for the diverse imagery in his artwork. Overtime his style has matured dramatically from basic organic shapes to the addition of more complex and repeating patterns. He often outlines his shapes with a solid coloured contour line and uses vibrant colors to create emphasis in his work. Quyen creates distinctive pieces that are quite recognizable to the casual viewer. The mood of happiness always prevails in his work. Quyen states, "I painted a little when I was young. Painting is easy for me. I like seeing my paintings hanging up on the walls".



**Conrod Skyers**

"It gives me a place to go, it keeps me out of trouble and keeps me off the streets" (Conrod Skyers, Interview, October 3, 2019).




Photograph by H. Tomlinson



**Conrod Skyers**

Conrod's vivid imagination enables him to explore and to cultivate his personal Caribbean island background and to combine it with his urban sensibilities to create a distinctive style. Through his exuberant use of colour and gesticulating shapes, Conrod's work exudes energy and movement. His automatic, undulating lines radiate directly from his head to his hand creating organic shapes directly onto the surface of the canvas. His lively patterned scenes openly invite the viewer to quietly pause awhile to visually explore every corner of the composition.

Appendix C continued



**Evelyn Van Duffelen**

"Well I work in pencil crayons, ...I hate sharpening pencils. [She looks down.] It drives me like up the wall! You know, I hardly touch the paper and then it looks like I am really pressing! [She motions back and forth along the table miming the action she takes with her pencil crayons.] That is why the pencils break" (Evelyn van Duffelen, Interview, September 23, 2019).




**Evelyn Van Duffelen**

Evelyn works primarily with pencil crayon on paper pressing extremely hard until the wax glistens on the paper's surface. Cutting out, arranging then gluing her pencil crayon work on acrylic painted canvas backgrounds to create new collaged imagery is a departure that has broadened Evelyn's artistic repertoire.

Evelyn says, "Making art makes me feel good. It's nice when people like your art, buy it, take it home and put it on their walls. Then my art makes them feel good when they look at it."



Photograph by H. Tomlinson



**Emily Parsonson**

"It amazes me how I see myself as an artist and now I am. [She puts her right hand to her heart.] I am getting more and more creative everyday" (Emily Parsonson, Interview, November 17, 2019).



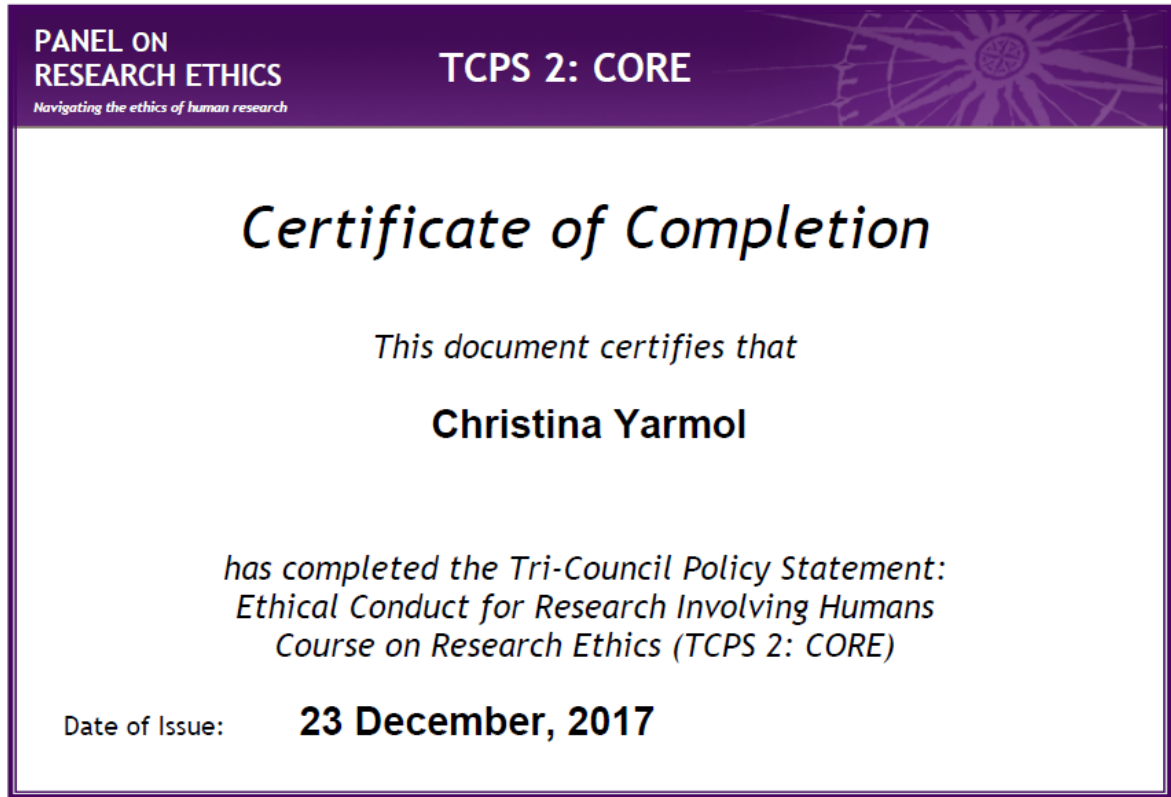
**Emily Parsonson**

Emily May Collins Parsonson has been painting for many years and has taken lessons at Creative Village Studio which is run by Community Living Toronto. She says that she enjoys painting with her Dad, Lauren, who is very talented and her Mum, Laura who is not artistic but has many other redeeming qualities. Sunshine and flowers are her specialty. She is extremely proud of her company *Emily Parsonson Productions* where she makes and sells her artwork. She is grateful to all of the people who support her and encourage her creativity.

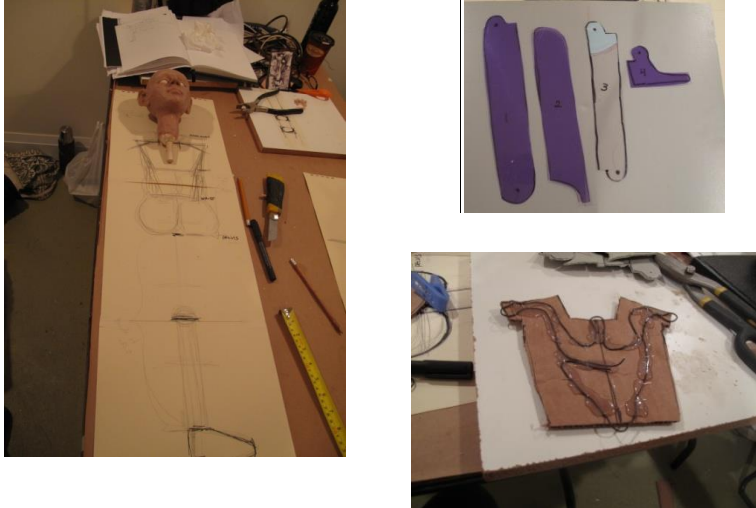




Parsonson, Lauren. *Portrait of Emily*, [Acrylic on canvas, 11" x 14"]

**Appendix D: TCP2 (REB) Ethics Process**



**Appendix E: Process Documentation of Making a Frida Kahlo Marionette**

Images	Descriptor
	<p>The proportions of the body were determined by the head and a pattern was made for the body and limbs. Various visible parts of the body were created with Sculpey, heated, sanded and attached.</p>
	<p>A body was constructed.</p>
	<p>The face was painted according to images of Kahlo. A wig from a Halloween store was added to see if the figure resembled Frida Kahlo.</p>
	<p>The marionette assembly was created, the clothing was sewn, and the marionette was strung.</p>

## Appendix F: Use of Human Participants Ethics Approval Notice



OFFICE OF  
RESEARCH  
ETHICS (ORE)  
5<sup>th</sup> Floor, Kaneff  
Tower  
  
4700 Keele St.  
Toronto ON  
Canada M3J 1P3  
Tel 416 736 5914  
Fax 416 736-5512  
[www.research.yorku.ca](http://www.research.yorku.ca)

<b>Certificate #:</b>	<b>STU 2019-012</b>
<b>Approval Period:</b>	<b>02/14/19-02/14/20</b>

### ETHICS APPROVAL

**To:** **Christina Yarmol**  
Critical Disability Studies  
Faculty of Graduate Studies

**From:** Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics  
*(on behalf of Denise Henriques, Chair, Human Participants Review Committee)*

**Date:** Thursday February 14, 2019

**Title:** **The Rights to be an Artist: Supporting Successful Studio Art Practices for People With Cognitive and Intellectual Disabilities**

**Risk Level:**  Minimal Risk  More than Minimal Risk

**Level of Review:**  Delegated Review  Full Committee Review

I am writing to inform you that this research project, "**The Rights to be an Artist: Supporting Successful Studio Art Practices for People With Cognitive and Intellectual Disabilities**" has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines.

Note that approval is granted for one year. Ongoing research – research that extends beyond one year – must be renewed prior to the expiry date.

Any changes to the approved protocol must be reviewed and approved through the amendment process by submission of an amendment application to the HPRC prior to its implementation.

Any adverse or unanticipated events in the research should be reported to the Office of Research ethics ([ore@yorku.ca](mailto:ore@yorku.ca)) as soon as possible.

For further information on researcher responsibilities as it pertains to this approved research ethics protocol, please refer to the attached document, "**RESEARCH ETHICS: PROCEDURES to ENSURE ONGOING COMPLIANCE**".

Should you have any questions, please feel free to contact me at: \_\_\_\_\_, or via email at: \_\_\_\_\_

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LLM  
Sr. Manager and Policy Advisor,  
Office of Research Ethics



**Do you want to make your voice heard?  
Do you know anyone who might have  
something to say about their studio art  
experiences?**

**Name of Study:** The Right to be an Artist:  
Supporting Successful Studio Art Practices for  
People with Cognitive and Intellectual Disabilities

Christina Yarmol from York University, is looking for participants with intellectual or cognitive disabilities for a PhD research study to share their personal stories about their studio art experiences or their lives as artists.

Participants will have the opportunity to participate in an art gallery show.

**Criteria**

- Open to people 18 years of age or older of all genders
- Have a cognitive or intellectual disability
- Have taken a visual art studio course in the past
- See himself/herself/themselves as an artist

**What is required?**

Sharing your personal thoughts about your art studio experiences  
30 to 90 minutes of your time at a mutually agreed upon location

**If you are interested or know anyone who  
might be please contact \_\_\_\_\_**

## Appendix H: Letter of Information



Dear Prospective Research Participant,

### Introduction

My name is Ms. Christina Yarmol and I am a Ph D student in critical disability studies at York University working under the supervision of Dr. Nancy Viva Davis Halifax in the School of Health Policy and Management at York University in Toronto. I am contacting you because I am seeking research participants who have been enrolled in studio Arts through the community, amateur or professional studios or programs. I would like to invite you to participate in a research study that reflects upon your experience as an artist.

**OFFICE OF  
RESEARCH  
ETHICS (ORE)  
5<sup>th</sup> Floor, Kaneff  
Tower**

4700 Keele St.  
Toronto ON  
Canada M3J 1P3  
Tel 416 736 5914  
Fax 416 736-5512  
[www.research.yorku.ca](http://www.research.yorku.ca)

### Purpose of the study

My research study examines environmental physical access, studio instruction, educational as well as financial and social policies that support your art experiences. I would like to discuss what successes and challenges you have encountered as an artist with a disability in Ontario. I will ask you to reflect on and to communicate your personal experiences about your encounters with the visual arts studio spaces, instructors and your art making (For a parent/guardian or caregiver -your observations about the success and the challenges of your charge's experiences with visual art). The research will strive to understand the importance of art practice in your life and uncover how studio experiences can facilitate your development as an artist. The research may inform and improve social, physical policy, studio visual art program delivery and practices in this province.

### If you agree to participate

If you agree to participate in this study you will be asked to discuss your experiences in visual art including any drawing, painting, printmaking, sculpture, photography, film, performance art, in an interview setting at a quiet location of your choosing (e.g. at a coffee shop, a library). You are also invited to select a sample or samples of your artwork to include in this study that will be photographed and added to the published dissertation. The interview will be video-recorded for the purpose of more accurate data analysis and interpretation. The videos will be transcribed into written form for this analysis. They will not be used for any other purpose than data analysis and interpretation. You will be provided with a copy of your transcript and will be able to make changes and or provide clarification for the researcher. This will take approximately 30 minutes to 90 minutes of your time. I anticipate that this study should not exceed 90 minutes of your time.

## **Confidentiality**

The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results unless you agree to have it published. Personal information will not be linked to interview responses and will be changed to protect the identity of a participant without changing the meaning of the story told. If you decide to submit a sample of your artwork you should be aware that it could be recognized by someone. You may choose to be identified as the artist. For those who wish to remain anonymous, every effort will be made to ensure anonymity. All information collected for the study will be kept confidential in my password protected laptop computer and in a locked home office to maintain respect for privacy and confidentiality. All video and transcribed data collected will be destroyed 2 years after the conclusion of the study.

## **Risks & Benefits**

The risks to participating in this study are that if you had an unpleasant experience with a studio program you might become anxious or upset during the interview. If you choose to remain anonymous your work has previously been displayed in a public forum, a viewer or a reader of the dissertation who is familiar with your style could recognize the work linking it back to you. You can cease to be part of the study at any time.

The benefit is that you will be contributing to knowledge about art studio practices for individuals who consider themselves already as artists or for those who would like to become artists. Artwork you share will be placed in an art show in a gallery setting and/or online for the public to view if you sign the additional consent form. The work can be posted with your name on it or as “anonymous”.

## **Study Results**

If you are interested in receiving a summary of the research findings from this dissertation you may do so by contacting me via email and I will send you a summary of the research findings.

## **Voluntary Participation**

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time.

## **Questions**

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Office of Research Ethics, York University at phone number or Ethics Review Co-ordinator, [email@yorku.ca](mailto:email@yorku.ca). If you have any questions about this study, please contact the researcher at phone number, [email@yorku.ca](mailto:email@yorku.ca) or her supervisor Dr. nancy viva davis halifax at phone number Ext.XXX, [supervisor@yorku.ca](mailto:supervisor@yorku.ca). This letter is yours to keep for future reference.

Sincerely,

**Principal Investigator:** Christina Yarmol, Ph D Student, Critical Disability Studies, York University, [researcher@yorku.ca](mailto:researcher@yorku.ca)

**Appendix I: Assent Form (Letter of Information)**



**Project Title:** The Right to be an Artist:  
Supporting Successful Studio Art Practices for  
People with Cognitive and Intellectual  
Disabilities

**Investigator:** Christina Yarmol, PhD Student, Critical Disability Studies, York University  
Toronto, Canada

**ASSENT FORM (LETTER OF INFORMATION)**

I am doing a research study about artists with disabilities experiences with art studios and art making. I would like to know how your studio experiences and classes help you to be a better artist. A research study is a way to learn more about people. If you decide that you want to be part of this study, you will be asked to share your experiences about making art.

There are some things about this study you should know. These interviews will last between half an hour to one and a half hours depending on what you share. You are also asked to bring an artwork that demonstrates the style of artwork you make.

There are risks and benefits about participating in the study. A risk is that it is sometimes difficult to talk or to remember some bad experiences or you might feel shy about sharing your artwork. If you don't want people to know that the work is created by you someone could recognize it when it is at a public art show. A benefit means that something good happens to you. A benefit might be giving you the chance to share what was good about your art experience and what was bad so that it can be made better in the future and make it easier to take more art classes. Samples of your artwork can be photographed for this study to show what you have produced. Another benefit is that this study can also give you the opportunity to celebrate your work as an artist in an art show when all the interviews are finished.

When I am finished with this study, I will write a report about what was learned. This report will not include your name or that you were in the study unless you agree to have it published.

You do not have to be in this study if you do not want to be. If you decide to stop after I begin, that's okay too. You can change your mind about participating in the study and you will not get in trouble. Your parents/guardian know about the study too. Everything will you say will be kept confidential.

If you have any questions about this study, please contact Christina Yarmol at phone number, [researcher@yorku.ca](mailto:researcher@yorku.ca) or her supervisor, Dr. nancy viva davis halifax at telephone number, [supervisor@yorku.ca](mailto:supervisor@yorku.ca). If you decide you want to be in this study, please sign your name.

I \_\_\_\_\_, want to be in this research study.

\_\_\_\_\_  
Sign your name here

\_\_\_\_\_  
Date

Christina Yarmol (Researcher explaining the study to the participant and obtaining informed consent)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**Appendix J: Consent Form for Participation in Study and Video Tape Recording of Interview**



**Project Title:** The Right to be an Artist:  
Supporting Successful Studio Art Practices for  
People with Cognitive and Intellectual Disabilities

**Principal Investigator:** Christina Yarmol, PhD Student, Critical Disability Studies, York University Toronto, Canada

**CONSENT FORM FOR PARTICIPATION IN STUDY AND VIDEO TAPE RECORDING OF INTERVIEW**

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate in the study. All questions have been answered to my satisfaction.

Please initial your choice. I agree to participate in the study:

\_\_\_\_\_ Yes, I agree to have the interview videotaped.

\_\_\_\_\_ No, I do not agree to have the interview videotaped but I prefer an audio recording of the interview.

Name of Participant (Please print.): \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Date: \_\_\_\_\_

Christina Yarmol (Researcher explaining the study to the participant and obtaining informed consent)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix K: Consent for Legal Guardian for Child/Ward's Participation in Study and Videotape**



**Project Title:** The Right to be an Artist:  
Supporting Successful Studio Art Practices for  
People with Cognitive and Intellectual Disabilities

**Principal Investigator:** Christina Yarmol, Ph D Student, Critical Disability Studies, York University Toronto, Canada

**CONSENT FORM FOR PARTICIPATION IN STUDY AND VIDEO TAPE  
RECORDING OF INTERVIEW FOR PARENT/ LEGAL GUARDIAN**

I \_\_\_\_\_parent/ guardian/ caregiver have the legal right to  
Name of parent/legal guardian

give my consent on decisions involving \_\_\_\_\_. I have  
Name of participant

read the *Letter of Information* and have had the nature of the study explained to me and I agree

that \_\_\_\_\_can participate in this study about studio visual art  
Name of participant

experiences and being an artist. All questions have been answered to my satisfaction.

Please initial your choice.

\_\_\_\_\_ Yes, I agree to have the interview videotaped.

\_\_\_\_\_ No, I do not agree to have the interview videotaped but I prefer a tape recording  
of the interview.

Name of Person Obtaining Informed Consent (please print): \_\_\_\_\_

Signature of Person Obtaining Informed Consent: \_\_\_\_\_

Date: \_\_\_\_\_

Christina Yarmol (Researcher explaining the study to the participant and obtaining informed consent)

Signature: \_\_\_\_\_Date: \_\_\_\_\_

**Appendix L: Consent Form Photography and Use of Name**



**Project Title:** The Right to be an Artist:  
Supporting Successful Studio Art Practices for  
People with Cognitive and Intellectual Disabilities

**Principal Investigator:** Christina Yarmol, Ph D Student, Critical Disability Studies, York University Toronto, Canada

**CONSENT FORM FOR PHOTOGRAPHY OF ARTWORK AND ARTIST’S NAME ON ARTWORK**

I have read the *Letter of Information*, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

\_\_\_\_\_ Yes, I agree to participate in the interview.

**Please initial your choice:**

\_\_\_\_\_ Yes, I agree to allow the photography of my artwork.

\_\_\_\_\_ No, I do not agree to allow the photography of my art. I do not want to include any of my artwork.

**Please initial your choice:**

\_\_\_\_\_ Yes, please identify my artwork with my name in the dissertation.

\_\_\_\_\_ No, my artwork may not be identified with my name in the dissertation.

\_\_\_\_\_ No, I do not want to include any of my artwork in the dissertation.

Name of Person Obtaining Informed Consent (please print): \_\_\_\_\_

Signature of Person Obtaining Informed Consent: \_\_\_\_\_

\_\_\_\_\_ Date: \_\_\_\_\_

Christina Yarmol (Researcher explaining the study to the participant and obtaining informed consent)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix M: Consent for Legal Guardian Interview, Photography of Artwork and Artist's Name**



**Project Title:** The Right to be an Artist: Supporting Successful Studio Art Practices for People with Cognitive and Intellectual Disabilities

**Principal Investigator:** Christina Yarmol, PhD Student, Critical Disability Studies, York University Toronto, Canada

**CONSENT FORM FOR INTERVIEW, PHOTOGRAPHY OF ARTWORK AND ARTIST'S NAME ON ARTWORK FOR PARENT/ LEGAL GUARDIAN**

I have read the *Letter of Information*, have had the nature of the study explained to me about my charge and I agree that my son/daughter/charge can participate in the study and answer the interview questions. All questions have been answered to my satisfaction.

\_\_\_\_\_ Yes, I agree that \_\_\_\_\_ can participate in the interview.

**Please initial your choice:**

\_\_\_\_\_ Yes, I agree to allow the photography of his/her/their artwork in the dissertation.

\_\_\_\_\_ No, I do not agree to allow the photography of his/her/their art. I do not want to include any of his/her/their artwork in the dissertation.

**Please initial your choice:**

\_\_\_\_\_ Yes, please identify his/her/their artwork with his/her/their name in the dissertation.

\_\_\_\_\_ No, his/her/their artwork may not be identified with his/her/their name in the dissertation.

Name of Person Obtaining Informed Consent (please print): \_\_\_\_\_

Signature of Person Obtaining Informed Consent: \_\_\_\_\_

\_\_\_\_\_ Date: \_\_\_\_\_

Christina Yarmol (Researcher explaining the study to the participant and obtaining informed consent)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix N: Consent Art Show Participation**



**Project Title:** The Right to be an Artist:  
Supporting Successful Studio Art Practices for  
People with Cognitive and Intellectual Disabilities

**Principal Investigator:** Christina Yarmol, PhD Student, Critical Disability Studies, York University Toronto, Canada

**CONSENT FORM FOR ART SHOW PARTICIPATION**

I have read the *Letter of Information*, have had the nature of the study explained to me and I agree to put my work in an art show in a gallery space. All questions have been answered to my satisfaction.

\_\_\_\_\_ Yes, I agree to participate in the art show.

**Please initial your choice:**

\_\_\_\_\_ Yes, please identify my artwork with my name in the art show.

\_\_\_\_\_ No, my artwork may not be identified with my name but hung as “anonymous artist”.

\_\_\_\_\_ No, I do not want to include any of my artwork in a formal art show.

Name of Participant (please print): \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Date: \_\_\_\_\_

Christina Yarmol (Researcher explaining the study to the participant and obtaining informed consent)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Appendix O: Consent Form for Legal Guardian for Participant’s Art Show Participation**



**Project Title:** The Right to be an Artist:  
Supporting Successful Studio Art Practices for  
People with Cognitive and Intellectual  
Disabilities

**Principal Investigator:** Christina Yarmol, Ph D Student, Critical Disability Studies, York University Toronto, Canada

**CONSENT FORM FOR ART SHOW PARTICIPATION  
FOR PARENT/LEGAL GUARDIAN**

I have read the *Letter of Information*, have had the nature of the study explained to me and I agree to put \_\_\_\_\_’s artwork in an art show in a gallery space.  
Name of study participant

All questions have been answered to my satisfaction.

**Please initial your choice:**

\_\_\_\_\_ Yes, please identify \_\_\_\_\_’s artwork with his/her/their name in the art show.

\_\_\_\_\_ No, \_\_\_\_\_’s artwork may not be identified with his/her/their name but hung as “anonymous artist”.

\_\_\_\_\_ No, I do not want to include \_\_\_\_\_’s artwork in a formal art show.

Name of Person Obtaining Informed Consent (please print): \_\_\_\_\_

Signature of Person Obtaining Informed Consent: \_\_\_\_\_

Date: \_\_\_\_\_

Christina Yarmol (Researcher explaining the study to the participant and obtaining informed consent)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix P: Letter of Information for Administrators and Art Instructors



**Project Title:** The Right to be an Artist:  
Supporting Successful Studio Art Practices  
for People with Cognitive and Intellectual  
Disabilities

### LETTER OF INFORMATION FOR ADMINISTRATORS AND ART INSTRUCTORS

Dear Prospective Research Participant,

#### **Introduction**

My name is Ms. Christina Yarmol and I am a Ph D student in Critical Disability Studies at York University working under the supervision of Dr. Nancy Viva Davis Halifax in the School of Health Policy and Management at York University in Toronto. I am contacting you because I am seeking research participants who have been art studio administrators and instructors who lead amateur or professional studios or programs for people with cognitive and intellectual disabilities. I would like to invite you to participate in a research study that reflects upon your experience as an expert in this capacity.

#### **Purpose of the study**

My research study examines environmental physical access, studio instruction, educational as well as financial and social policies that support your art experiences. I would like to discuss what successes and challenges you have encountered as a leader running art programs for people with disabilities in Ontario. I will ask you to reflect on and to communicate your personal experiences about your encounters with the visual arts studio spaces, and artist participants' art making. The research will strive to understand the importance of art practice in their lives and uncover how studio experiences can facilitate their development as artists. The research may inform and improve social, physical policy, studio visual art program delivery and practices in this province.

#### **If you agree to participate**

If you agree to participate in this study you will be asked to discuss your experiences in visual art including any drawing, painting, printmaking, sculpture, photography, film, performance art, in an interview setting at a quiet location of your choosing (e.g. at a coffee shop, a library). The interview will be video recorded for the purpose of more accurate data analysis and interpretation. The videos will be transcribed into written form for this analysis. They will not be used for any other purpose than data analysis and interpretation. You will be provided with a copy of your transcript and will be able to make changes and or provide clarification for the researcher. This will take approximately 30 minutes to 90 minutes of your time. I anticipate that this study should not exceed 90 minutes of your time.

## **Confidentiality**

The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results unless you agree to have it published. Personal information will not be linked to interview responses and will be changed to protect the identity of a participant without changing the meaning of the story told. All information collected for the study will be kept confidential in my password protected laptop computer and in a locked home office to maintain respect for privacy and confidentiality. All video and transcribed data collected will be destroyed 2 years after the conclusion of the study.

## **Risks & Benefits**

If you choose to remain anonymous, the researcher cannot fully guarantee your anonymity given the limited number of studio programs in Ontario that support artists with cognitive and intellectual disabilities. The potential for a knowledgeable reader of the dissertation may be able to connect them back to your working studio space.

The benefit of this study is that you will be contributing to knowledge about art studio practices for individuals with cognitive and intellectual disabilities who consider themselves already as artists or for those who would like to become artists. You may attend a public art show where artists with whom you have worked may have their artwork on display in a public forum.

## **Study Results**

If you are interested in receiving a summary of the research findings from this dissertation you may do so by contacting me via email and I will send you a summary of the research findings.

## **Voluntary Participation**

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time.

## **Questions**

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Office of Research Ethics, York University at phone number or Ethics Review Co-ordinator, [researchcoordinator@yorku.ca](mailto:researchcoordinator@yorku.ca). If you have any questions about this study, please contact Christina Yarmol at researcher's phone number, [researcher@yorku.ca](mailto:researcher@yorku.ca) or Dr. nancy viva davis Halifax at supervisor's phone number Ext. XXX, [supervisor@yorku.ca](mailto:supervisor@yorku.ca). This letter is yours to keep for future reference.

Sincerely,

**Investigator:** Christina Yarmol, Ph D Student, Critical Disability Studies, York University, Toronto, Canada, [researcher@yorku.ca](mailto:researcher@yorku.ca)

**Appendix Q: Consent Form for Administrators and Art Instructors**



**Project Title:** The Right to be an Artist:  
Supporting Successful Studio Art Practices for  
People with Cognitive and Intellectual  
Disabilities

**Principal Investigator:** Christina Yarmol, Ph D Student, Critical Disability Studies, York University Toronto, Canada

**CONSENT FORM FOR ADMINISTRATORS AND ART INSTRUCTORS**

I have read the *Letter of Information*, have had the nature of the study explained to me and I agree to participate answering the interview questions based on my observations and my experiences in the studio. All questions have been answered to my satisfaction.

\_\_\_\_\_ Yes, I agree to participate in the study.

Please initial your choice:

\_\_\_\_\_ Yes, I agree to the videotaping of the interview.

\_\_\_\_\_ No, I do not agree to the videotaping of the interview but prefer an audio recording of the interview.

Name of Participant (please print): \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Date: \_\_\_\_\_

Christina Yarmol (Researcher explaining the study to the participant)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix R: Plain Language/Pictorial Consent Form Support for Letter of Information

**Project Title:** The Right to Be an Artist: Supporting Successful Studio Art Practices for People with Cognitive and Intellectual Disabilities

### INTRODUCTION:

This interview is for a project about your experience as an artist with a disability participating in an art program.



The person who will be doing the project with you will be Christina Yarmol, from York University. You know her from Creative Village Studio. (Photograph of the researcher→)

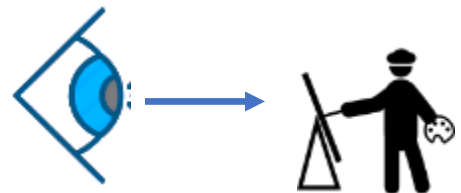


### PURPOSE:

Christina will ask you questions about your art and your Art making, what you enjoy about it, and what you think could make you more successful.



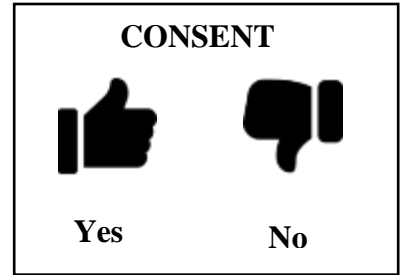
Christina will watch your art making in the studio to learn about how to create art.



Principal Investigator: Christina Yarmol, Ph D Student, Critical Disability Studies, York University, [researcher@yorku.ca](mailto:researcher@yorku.ca)

**IF YOU AGREE TO PARTICIPATE:**

You are being asked to take part in a research project and must give your consent.



Consent means that it must be your decision to participate in each part of this study and interview.

Your signature on these forms means that you want to be involved with this project.



**FOR EXAMPLE:**

I want my face to be shown.



I do not want my face to be shown.



I want my name to be shown

Name

I do not want my name to be shown.



I want to show images of my artwork in an art exhibit.



I do not want to show images of my artwork in an art exhibit.



Principal Investigator: Christina Yarmol, Ph D Student, Critical Disability Studies, York University, researcher@yorku.ca

## CONFIDENTIALITY:

Your interview will be videotaped and then written down (in a transcript).



Christina will write about you making art. She will show it (the transcript) to you later if you want. You can change it if you like.



What you say in the research will not be private. It will be read by other people.



## RISK AND BENEFITS

You might feel uncomfortable speaking about your experiences making art. People in the community might recognize your artwork.

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



Principal Investigator: Christina Yarmol, Ph D Student, Critical Disability Studies, York University, [researcher@yorku.ca](mailto:researcher@yorku.ca)

## VOLUNTARY PARTICIPATION

If you give your consent, your signature means that you understand that people will see your artwork, know your name, see your face and that you do not mind.

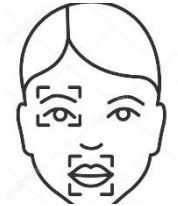


Signature

It is okay to leave the project at any time.



You can still be in Creative Village Studio and your relationship with Christina or other people at the program will not change. (Photograph of the researcher on right →)



## QUESTIONS:

If you have any questions or want more information, you can contact Christina Yarmol, [researcher@yorku.ca](mailto:researcher@yorku.ca) or Dr. supervisor either by telephone at telephone number Ext XXX or by email [supervisor@yorku.ca](mailto:supervisor@yorku.ca).



Principal Investigator: Christina Yarmol, Ph D Student, Critical Disability Studies, York University, [researcher@yorku.ca](mailto:researcher@yorku.ca)

**Appendix S: Checklist for Consent Forms**

Name of Artist/Participant	Date	Can give consent			Cannot give consent				
		Letter of Information	Video Tape Recording	Photography of Artwork & Artist's Name	Art Show Participation	Assent Form	Video Tape Recording P/G	Photography of Artwork & Artist's Name P/G	Art Show Participation P/G
<b>INTERVIEWEES</b>									
Clifford, Neil John Douglas	Sept. 23, 2019	✓	✓	✓	✓				
Habuda, Patricia	Nov. 20, 2019	✓	✓	✓	✓				
Homer, Jack	Sept. 19, 2019	✓	✓	✓	✓				
Meneses, Juan	Sept. 23, 2019	✓	Audio only	✓	✓				
Milberg, Astra	Sept. 19, 2019	✓	✓	✓	✓				
Nicholson, Steven	Sept. 19, 2019	✓	✓	✓	✓				
Ngo, Quyen	Oct. 23, 2019	✓	✓	✓	✓				
Parsonson, Emily	Nov. 17, 2019	✓	✓	✓	✓				
Pattinson, Betsy	Sept. 19, 2019	✓	✓	✓	✓				
Salazar, Johnfredy	Sept. 19, 2019	✓	Audio only	✓	✓				
Sheehy, Matthew	Sept. 19, 2019	✓	✓	✓	✓				
Simonyi, Sabrina	Oct. 12, 2019	✓	✓	✓	✓	✓	✓	✓	✓
Skyers, Conrod	Oct. 3, 2019	✓	✓	✓	✓				
Tuckwell, Lisa	Oct. 28, 2019	✓	✓	✓	✓				
Van Duffelen, Evelyn	Sept. 23, 2019	✓	✓	✓	✓				
Worotyneec, Donna	Nov. 6, 2019	✓	✓	✓	✓				
<b>VOLUNTEERS/INSTRUCTORS/ PARENTS</b>									
Barci, Pina (Volunteer)	Nov. 20, 2019	✓	✓	✓	✓				
Gordon, Beverly (Volunteer)	Nov. 20, 2019	✓	✓	✓	✓				
Groom, Shannon (Instructor/Support Worker, Parent)	Nov. 25, 2019	✓	✓	✓	✓				
Langdon, Lois (Volunteer)	Nov. 7, 2019	✓	✓	✓	✓				
Mitchell, Cait (Instructor)	Jan. 6, 2020	✓	written	✓	✓				
Parsonson, Laura (Parent)	Nov. 17, 2019	✓	✓	✓	✓				
Reznick, Yona (Instructor/Support Worker)	Dec. 6, 2019	✓	written	✓	✓				
Simonyi, Anna (Volunteer/Parent)	Oct. 12, 2019	✓	✓	✓	✓				
Tomlinson, Harold (Facilitator/Instructor)	Nov. 25, 2019	✓	✓	✓	✓				

## **Appendix T: Interview Questions**

### **Questions for Artist-Participants**

1. What classes do you participate in/go to at CVS studio?
2. Tell me what do you like best about these classes.
3. Do you consider yourself an artist? Why?
4. Tell me what do you do at your art classes?
5. Can you show me your art? Tell me a little about your art.
6. Tell me how your instructor(s) insert name(s) support(s) your work as an artist. What does/do your instructor(s) do to help support your art creation?
7. Tell me how do you pay for this program?
8. Tell me what do you think could be improved about your art classes?
9. Do you think that this program/these programs add to your life? Why or why not? (e.g. Do they make your life more exciting?) What do you think you would do if you didn't go to art programs?
10. If you could give a title to an art show where CVS work was mounted what would you call it?
11. Is there anything else you would like to tell me about your art or your art making?

### **Questions for Volunteers**

1. What classes do you volunteer in at Creative Village Studio? How did you hear about Creative Village Studio?
2. What do you like best about coming to volunteer at these classes?
3. Tell me about your training in the arts and working with people with cognitive and intellectual disabilities, social services?
4. What personality traits do you think are essential for volunteering at creative Village Studio?
5. Tell me what you do to support the artists working at Creative Village Studio.
6. What does the instructor you work with do to support participants' art creation in your view?
7. What do you think could be improved over all about the program?
8. Tell me about the greatest successes/ greatest challenges for the people in this studio program.
9. Is there something that you've learned from your experience at Creative Village Studio that you would like to share with others?
10. Is there anything else that you would like to add about your experiences working with this program?

### **Questions for Parents**

1. In which programs publicly offered or privately run (art) programs has your son/daughter \_\_\_\_\_been involved?
2. Tell me about \_\_\_\_\_'s experience with art programs.
3. How has the program enhanced \_\_\_\_\_'s conception of self as an artist?
4. How do you believe that the instructor has helped to support \_\_\_\_\_'s journey as an artist?

5. Describe \_\_\_\_'s experience with the funding process (e.g. *Passport* Application process, ODSP, other).
6. Tell me about the benefits and the drawbacks of various community/ studio art programs for people with intellectual disciplines.  
Is there anything else you would like to add about \_\_\_\_\_'s or your experiences with the program?

### **Questions for Instructors**

1. What classes do you support at Creative Village Studio?
2. Do you have artistic training or background/training in working with people with Cognitive and Intellectual disabilities? Tell me about your background.
3. Do you consider yourself an artist? Please explain.
4. Tell me about the kind of art the participants create in the studio art classes. / Can you describe your client's experience with the art program/the art studio?
5. Has the program enhanced your client's/the clients' conception(s) of self/selves as an artist(s)? How?
6. What do you believe are the central goal or goals for the artists who come to Creative Village Studio?
7. Tell me about what do you find the instructors and volunteers do to support artists or support the artistic process of artists with Cognitive and Intellectual disabilities at Creative Village Studio?
8. What do you see are the greatest successes for the people in these studio programs?

### **Questions for Facilitator**

1. Tell me how this program began.
2. Tell me about the academic and experiential background that qualifies you for this position? (e.g. social services training, art/art world?)
3. What are your objectives for the people who come to this program?
4. How many participants come on a regular basis and how do they pay for this program? Pay per service, other?
5. Tell me about what you believe are the key/essential skills, background and personality characteristics necessary to do this job? Why?
6. What are your greatest successes/challenges with this job?
7. What could be made better at this location?
8. How do you see this studio model evolving in the future?

## Appendix U: The Activism of Community Living Organizations


Date	Advocacy/ Program/Policy	Description
1948	Editorial Letter to The Toronto Star	<ul style="list-style-type: none"> <li>• Victoria Glover, grandmother of a child with an intellectual disability wrote an editorial to The Toronto Star that galvanized parents' advocacy for programs for children with IDs (Community Living Toronto: Since 1948, 2008)</li> </ul>
1951	Metro Toronto Association for Retarded Children incorporated	<ul style="list-style-type: none"> <li>• Parents' Council for Retarded Children used newspaper advertisement to form the first Canadian association of its kind.</li> <li>• Parents united to find alternatives to institutional care (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, p. 3)</li> </ul>
1953	Ontario Association for Retarded Children formed	<ul style="list-style-type: none"> <li>• Association formed soon after local groups met, united and created the first cooperative nursery schools, the first group home in Ontario for children with IDs (Prince, 1985, p. 265)</li> <li>• Forged coalitions that evolved into service agencies</li> </ul>
1958	Canadian Association for Retarded Children formed	<ul style="list-style-type: none"> <li>• Provincial associations joined to form the Canadian Association for Retarded Children (CARC) to bring a national voice to their concerns (About Us: Canadian Association for Community Living, 2017)</li> <li>• Lobbied the state to replace residential institutions with community-based services (Galer, 2014)</li> </ul>
1964  1965	Shadow Lake Centre in Whitchurch-Stouffville purchased  Shadow Lake Camp sessions ran	<ul style="list-style-type: none"> <li>• A residential camp program on Kawartha Lakes, Ontario, for people with intellectual disabilities</li> <li>• Currently has a staff of 60 members who hosts about 600 individuals annually (Community Living Toronto: Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, p. 3)</li> <li>• Offered an eight-week summer camp program with separate session held for children, youth and adults with IDs (Shadow Lake: Our History, n.d.)</li> </ul>
1967	National Institute on Mental Retardation (NIMR) and L'Institut Roehrer Institute established	<ul style="list-style-type: none"> <li>• Discussion began in 1963 about development of NIMR (Wayback Machine Internet Archive: The Spark that Unites, 2018)</li> <li>• Creation of the National Institute on Mental Retardation (NIMR) under the authority of the Canadian Association for the Mentally Retarded (CAMR) (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, p. 3).</li> <li>• Formed to translate theory into action and to research and investigate issues faced by people with IDs in society (Brown &amp; Radford, 2015, pp. 21-22).</li> </ul>

		<ul style="list-style-type: none"> <li>• Moved centre to a new building on the York University campus, 1970</li> </ul>
1969	Sheltered workshop opened	<ul style="list-style-type: none"> <li>• Opened 1<sup>st</sup> Sheltered workshop in Scarborough, Ontario (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, p. 3).</li> </ul>
1974	Government of Ontario passed Developmental Services Act	<ul style="list-style-type: none"> <li>• Act transferred responsibility for services for people with developmental disabilities from the Ministry of Health to the Ministry of Community and Social Services.</li> <li>• Focused new approach on community services, as opposed to the original medical model of care (MCSS: The Shift to Community Living the 1970, 2018) e.g. moving people into different living arrangements (Ontario Government, 8 March, 2018)</li> </ul>
1980	Apartment Program, opened	<ul style="list-style-type: none"> <li>• Opening of Apartment program altered previous conceptions of institutionalization through small social scale of group homes appropriate to the age and cultural heritage of the clients in their home communities (Prince, 1985, p. 265)</li> <li>• Enable the blossoming of community-based services and supports which enabled more and more people to live in the community (MCSS: The Shift to Community Living the 1980, 2018)</li> </ul>
1980	Ontario Government, Bill 82, the Education Amendment Act	<ul style="list-style-type: none"> <li>• Lobbied for the Bill 82</li> <li>• Signed into law ensuring publicly funded education for all students regardless of disability in the Province of Ontario (Gavan in Bennett &amp; Gallagher, 2012)</li> <li>• Made Special Education programs the law</li> </ul>
1982, 1990	Special Services at Home program (SSAH), introduced	<ul style="list-style-type: none"> <li>• Offers financial supports for families caring for a child with a developmental and/or physical disability at home</li> <li>• Enables the purchasing of services/supports in or outside the family home that are not available elsewhere in the community (designed for those not receiving supports from residential program) <ul style="list-style-type: none"> <li>• Ability to hire support staff to help their child learn new skills and abilities e.g. improve their communication skills and become more independent</li> </ul> </li> <li>• Provides respite support to the family (Special Services at Home Program Guidelines Ministry of Community and Social Services, April 2018)</li> <li>• Funded by MCSS</li> <li>• Expanded to adults in 1990 (Ontario Government, 8 March, 2018).</li> </ul>
1985	National Association's name changed	<ul style="list-style-type: none"> <li>• Canadian Association for Retarded Children changed to the Canadian Association for Community Living reflecting a shift in thinking about ID</li> </ul>

		<ul style="list-style-type: none"> <li>• Focused on core issues affecting people with an ID as basic equality, respect, dignity and human rights to create communities of equality and diversity where all people are welcomed and belong (About Us: Canadian Association for Community Living, 2017 &amp; Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, p. 3)</li> </ul>
1987	Association's name change	<ul style="list-style-type: none"> <li>• Altered name from Metro Toronto Association for Retarded Children to Metropolitan Toronto Association for Community Living (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, p. 3)</li> </ul>
1996	Individualized Support & Youth 2 Work programs created	<ul style="list-style-type: none"> <li>• Offered youth leaving the educational system chances to find success in the workplace through volunteer and supported work placements, in partnership with local high schools and other community allies,</li> <li>• Provides youth with opportunities to explore their career goals and personal interests (Skills Development: Life After School and Post 21 Planning, n.d. &amp; Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 3, 5)</li> </ul>
1999	Spinclusion, created	<ul style="list-style-type: none"> <li>• Created an interactive game in partnership with Toronto Parks, Forestry and Recreation designed for children and youth from grades two to high school</li> <li>• Promoted acceptance and respect for people with different needs and abilities.</li> <li>• Aimed to teach that disability is just one more element of diversity in today's classrooms, camps and communities (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 4, 6 &amp; Spinclusion, 1999)</li> </ul>
2001	ConnectABILITY.ca created	<ul style="list-style-type: none"> <li>• Offers accessible virtual community on the internet that provides learning and support for people with an ID, their families and their support network (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 3, 6)</li> </ul>
2002	Association's name changed	<ul style="list-style-type: none"> <li>• Altered name from Metropolitan Toronto Association for Community Living to Community Living Toronto (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, p. 3)</li> </ul>
2005	Person Directed Plans implemented for individuals in day programs	<ul style="list-style-type: none"> <li>• Builds supports that are based on an individual's goals, aptitudes, dreams and interests to give more choice and control over their lives</li> <li>• Provides the opportunity to explore resources in their community daily (Supporting Rights &amp; Choices of</li> </ul>

		People with an Intellectual Disability Brochure, 2018, pp. 3, 7)
2006	Individualized <i>Passport</i> Supports began	<ul style="list-style-type: none"> <li>• Enables Person-Directed Planning where individuals and their networks to identify areas of interest and brainstorm for possible opportunities based on the principles of choice and community participation (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, p. 3)</li> </ul>
2008	Institutes for Research and Development on Inclusion and Society (IRIS) established	<ul style="list-style-type: none"> <li>• Established by Canadian Association for Community Living</li> <li>• Provides research, knowledge generation new ways of thinking, inspiration, and education to advance the well-being of people with an intellectual disability that governments, NGOs, and other stakeholders need to advance inclusive policy and social development. (History: IRIS Institute, n.d.)</li> </ul>
2008	Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act,	<ul style="list-style-type: none"> <li>• Replaced the Developmental Services Act (Individualized Passport Supports   Community Living Toronto. n.d.).</li> </ul>
2009	Creative Village Studio opened	<ul style="list-style-type: none"> <li>• Opened a storefront studio where artists can explore their creativity through a variety of media including photography, painting, jewelry, knitting and drawing taught by community artists (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 3, 6)</li> </ul>
2009	Closure of institutions in Ontario for persons with CIDs	<ul style="list-style-type: none"> <li>• Closed down last three remaining institutions: Huronia Regional Centre (Ontario's first institution in 1876, the Orillia Asylum for Idiots), Rideau Regional Centre, and Southwestern Regional Centre</li> <li>• Ended more than 130 years of institutional functioning (Brown &amp; Radford, 2015)</li> <li>• People made the transition from institutions to community living</li> </ul>
2010	MCSS Funding for LIGHTS	<ul style="list-style-type: none"> <li>• Began the addressing significant shortage of independent and appropriate housing for citizens with IDs in Toronto</li> <li>• Started a unique synergy between individuals with IDs, families, community members and Community Living Toronto facilitating the establishment of residential solutions for people with IDs</li> <li>• Provided an interim funding to overcome financial obstacles in the establishment of a place to call home (LIGHTS: What is LIGHTS?, n.d.)</li> </ul>

		<ul style="list-style-type: none"> <li>• Provided for funding for 3 per diem children’s residences (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 3, 5)</li> </ul>
2011	Community Junction, opened	<ul style="list-style-type: none"> <li>• Provides varied, monthly roster community based, fee-for-service art, craft, music, fitness and out trip programs for people with IDs and their families in Toronto’s Junction neighborhood (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 3)</li> </ul>
2013	Partnerships with Special Needs Team & Surrey Place Centre	<ul style="list-style-type: none"> <li>• Enhances clinical capacity through partnerships with Special Needs Team &amp; Surrey Place Centre (Surrey Place, 2020).</li> </ul>
2014	STEPS to Independence, developed and launched	<ul style="list-style-type: none"> <li>• Supports individuals with ID 16 +offering a holistic tool through a guidebook that provides an opportunity to determine how prepared they are for semi-independent living</li> <li>• Helps to build skills, confidence and self-esteem; provides feedback on current life skills; identifies any areas for learning to increase readiness for semi-independent living</li> </ul> <p>(Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 3, 6).</p>
2015	Try-It-On-For-Size Toronto (TIFS), Housemates launched, STEP Up	<ul style="list-style-type: none"> <li>• TIFS-Offers a one-year commitment offering the opportunity to visit an apartment where people can practice and build skills and confidence to live more independently (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 3, 6)</li> <li>• Friendly Housemates-Offers a partnership with Centennial College and supported by their family and Community Living Toronto</li> <li>• Organizes an innovative living arrangement that matches full time post secondary students and individuals who have an ID to live together as roommates. Housemates engage in shared household responsibilities, at home leisure and recreational activities, and community experiences.</li> <li>• Participating students receive free accommodations for the duration of the project and an academic bursary of up to \$1,000 (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 3, 5)</li> <li>• STEP UP- Offers residential support to youth in transition from children’s services to adult services.</li> <li>• Operates in partnership with Cota, an accredited, not-for-profit, community-based organization that has been supporting adults with mental health and cognitive challenges to live well within their communities for over</li> </ul>

		45 years (Cota: Inspiring Change, n.d. & Supporting Rights & Choices of People with an Intellectual Disability Brochure, 2018, pp. 3, 5)
2016	Community First initiative launched	<ul style="list-style-type: none"> <li>• Provides inclusive community experiences, and support for increased independence in the community</li> <li>• Designed for individuals who: are at least 18 years old; are able to participate in the community with minimal staff support; want to work towards a personal goal of increased independence in the community; want an inclusive community experience; are able to perform daily living activities independently in the community, such as personal care; are interested in supported community-based activities; are able to manage their own transportation</li> <li>• Areas of support may include life skills training; community-based skill building; social recreation; leisure activities; job readiness training; supported employment; volunteering (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, pp. 3-4)</li> </ul>
2017	Travel Training Pilot	<ul style="list-style-type: none"> <li>• Created in partnership with Toronto Transit Commission, Geneva Centre for Autism, Holland Bloorview Kids Rehabilitation Hospital, Kerry's Place Autism Services, Salvation Army Lawson Ministries, Community Access to Transportation Hamilton and Community Living Toronto</li> <li>• Designed to teach people 18 years of age and older with an ID how to use public transit independently in Toronto</li> <li>• Participants commit to: attending one 2.5 hour class a week for 8 weeks or two 2.5 hour classes for 4 weeks, learning a new transit route with an instructor, 35 hours of route training to learn one round trip (Travel-Training-Pilot-Program-course-description.pdf, 2016)</li> </ul>
2018	Provincial Community Living logo	<ul style="list-style-type: none"> <li>• Adopted the provincial Community Living logo</li> </ul>  <p>COMMUNITY LIVING Toronto (Supporting Rights &amp; Choices of People with an Intellectual Disability Brochure, 2018, p. 3)</p>

## Appendix V: Federal Supports for People with Disabilities

The *Opportunities Fund* is an additional government program provided by the federal government. It focuses on the labour market participation of persons with disabilities to enhance their employability helping to finance skills for employment, wage subsidies, work experience, self-employment, enhanced employment assistance, employer awareness, and community coordination (Funding: Opportunities Fund for Persons with Disabilities, 2010) to assist Canadians with disabilities. It lends support for local, regional and national projects that assist persons with disabilities who have little or no labour force attachment to prepare for, obtain and keep jobs or to become self-employed (Tremain, 2014, p. 10).

Most of the other income security programs available to people with disabilities in Canada require the intensive support of knowledgeable family members who can apply for them on behalf of their family member(s). These programs are: *Employment Insurance*<sup>136</sup>, *The Canada Pension Plan*<sup>137</sup>, *Old Age Security*<sup>138</sup>, the *Canada Child Tax Benefit*<sup>139</sup>, *Canada Student Loans*,

---

<sup>136</sup> *Employment Insurance* provides financial support for unemployed, who are sick, pregnant, or caring for a newborn or adopted child, as well as those who must care for a family member who is seriously ill with a significant risk of death (Service Canada, 2017). When an individual has an accident or disability at work it is *Workers' Compensation* which acts as the immediate income support.

<sup>137</sup> *The Canada Pension Plan* (CPP) Retirement Pension provides a monthly taxable benefit to retired individuals who have made at least one valid payment to the Canada Pension Plan, and who are at least 60 years old (Service Canada, 2017). When long-term disability is the case the *Canada/Quebec Pension Plan Disability Benefit* is put into place. The CPP Disability benefit is available to people who have made enough pension credit to the CPP and have a "severe" and "prolonged" disability contributions, and whose disability prevents them from working at any job on a regular basis. "Severe" usually means that your disability prevents you from earning more than a small amount of income from work. Your disability can be physical, mental, or both. "Prolonged" means that your disability is likely to last for a long and unknown amount of time, or to eventually cause death (Service Canada, 2017).

<sup>138</sup> The monthly benefit plan of *Old Age Security* (GIS) is for those 65 or older going into retirement and who have lived in Canada for at least 40 years after reaching age 18 or who meet other criteria if they were 25 years of age or over on July 1, 1977.

<sup>139</sup> Federal and provincial child benefits, the Canada Child Tax Benefit (CCTB) is a non-taxable amount for which eligibility is geared to income. It is paid monthly to help eligible families with the cost of raising children under 18 years of age. The CCTB may include the national child benefit supplement (NCBS) and the child disability benefit (CDB). The NCBS is a non-taxable supplement for low income families that may be offset by a reduction in provincial social assistance payments. The CDB provides an amount geared to income for qualified families caring for children under 18 years of age who have a severe and prolonged impairment in physical or mental functions and who are eligible for the Disability Tax Credit (Canada Revenue Agency, [C.R.A], 2014). The universal childcare benefit (UCCB) is a taxable benefit of \$100 paid monthly for each eligible child of those who qualify for the CCTB.

and Canada Student Grants<sup>140</sup>, Working Income Tax Benefit<sup>141</sup>, Goods and Services Tax / Harmonized Sales Tax (GST/HST) credit, Disability tax credit (DTC)<sup>142</sup>, Registered Disability Savings Plan<sup>143</sup>.

---

<sup>140</sup> Under the *Canada Student Grant for Students with Permanent Disabilities*, enrolled as a full-time student with permanent disabilities may be eligible to receive \$2,000 in grant funding and \$7,140 in repayable *Canada Student Loans*. Up to \$8,000 per loan year can cover costs associated with disability (i.e. reader or brailleur, a machine similar to a typewriter, used for printing in Braille. Also called a *Braillewriter*.) through *Canada Study Grant for Services and Equipment for Students with Permanent Disabilities* through Employment and Social Development Canada. Many of the expenses also qualify for tax assistance under the Medical Expense Tax Credit (METC).

<sup>141</sup> Crawford (2013a) explains that *Working Income Tax Benefit (WITB)* (2007) was designed to support individuals (disabled and able) with low-income currently employed in the paid labour market by supplementing low earnings. “It is a refundable tax credit paid quarterly for residents of Canada who are aged 19 years of age or older People who qualify for the Disability Tax Credit may also qualify for a WITB disability supplement. Eligible individuals must have earned income of at least \$3,000 unless they meet the disability criteria, in which case minimum earned income must be \$1,500 (CRA, 2013b cited in Crawford, p. 43) however, it did not deliver what it promised as there were issues in its very design as it “excluded many of the working poor”. The benefit is geared to income and begins tapering to zero when net income falls between \$11,231 and \$17,824 (Crawford, 2013, p. 43). After taking some advice from advocacy groups, its benefits were enhanced in 2009 however “in 2014 still payed a modest maximum \$998 for a single worker per year (\$1,813 for a family) and cuts out at a low net income of \$17,985 (\$27,736 for a family)” (Tremain, 2014, p. 4).

<sup>142</sup> There are a number of tax credits available including: supplements income for children under age 18 years; the which supplements low earnings for those working in the paid labor market; the *Goods and Services Tax / Harmonized Sales Tax (GST/HST) credit* a tax-free quarterly payment that helps individuals and families with low or modest incomes offset part of the GST or HST that they pay (CRA, 2017) and the *Disability tax credit (DTC)* a non-refundable tax credit that helps persons with disabilities or their supporting persons reduce the amount of income tax they may have to pay (CRA: Disability Tax Credit, 2017). A medical practitioner must fill out and certify that you have a severe and prolonged impairment and must describe its effects. This amount includes a supplement for persons under 18 years of age at the end of the year. You are eligible for the DTC only if we approve Form T2201. Retrieved from <http://www.cra-arc.gc.ca/tx/ndvdl/sgmnts/dsblts/dtc/menu-eng.html>

<sup>143</sup> Savings plans are available for people with disabilities including the *Registered Disability Savings Plan (RDSP)* to help people who are Canadian residents, are under age 60, have a social insurance number and their families save for the future. Registered Disability Savings Plans (RDSPs) are a non-tax-deductible program in which the government provides matching savings contributions for individuals qualifying for the Disability Tax Credit (Pettinicchio and Maroto, 2020). A family who wanted to contribute to a *Registered Disability Savings Plan RDSP*, would have to earn significantly higher income to be able to put aside extra savings accounts.

## Appendix W: What Galleries Want

Arts and culture journalist Nicole Martinez (9, November 2017) puts forward 10 timely interview questions a contemporary artist should “be able to answer” for arts journalists, potential collectors, gallerists, art advisors, art consultancies and curators all part of neoliberal art exhibition system. Martinez’s summary informs visual creators about the expectations the 21<sup>st</sup> century art world asks of practicing artists. Critical disabilities curator Amanda Cachia asserts that the gallery circuit is part of a, “Deeply elitist art world, where categories like “normal” conveniently persist (Cachia, 2014, p. 121)”. These questions are typical of normative interaction galleries would expect.

Martinez urges the preparation of interview answers encouraging the transcript of potential answers and oral practice aloud. Practice enables the artist to speak fluidly during, “showtime”. She suggests a series of potential questions (indicated in italics) proposing what potential responses might include:

1. *What is your background?* The artist should mention their educational background and any experiences that may contributed to their evolution as an artist including cultural background and life experiences that make an artist’s work unique (e.g. upbringing prompting specific references to work; concepts or themes from childhood, background, socio-economic status), impact how an artist sees the world and creates art in response to this vantage point.
2. *What does your work aim to say?* A well articulated answer probes into why an artist creates a particular kind of artwork. A cohesive narrative about the work and an awareness of what audiences might see in the work is anticipated.
3. *How does your work comment on current social or political issues?* Consider how materials or aspects of the work make a comment on current events or societal issues remembering that throughout history artists’ artwork have led to the transformation of societies. Today, artwork often relates to how artists address current sociopolitical landscape.
4. *Who are your biggest influences?* Listing artistic inspirations, artistic movements, genres that influence the artist, providing a rationale for their admiration and explaining how it has led them to pursue art allow, patrons, collectors, and writers to better frame and categorize the work and connect it to the history of art fitting into a larger dialogue in the art world.
5. *How have you developed your career?* An artist shows how they have planned their art trajectory sharing information about educational/training background, work experience, creative process, studio practice, past exhibitions, and awards won leading a potential collector, curator or gallerist to appreciate what efforts the artist has made to generate opportunities for themselves based on a vision and well-thought out goals.
6. *How do you seek out opportunities?* In this question, the art establishment expects that an artist sources out new opportunities to display and showcase work through researching galleries, belonging to collectives/associations, sending portfolios, inviting visitors to the studio, attending artist panels or networking events to find marketing efforts.

7. *How do you cultivate a collector base?* Potential galleries or art collectors want to know how the artist attempts to sell work actively earning a living from their artwork. The expectations are that the artist participates in art fairs, enters juried competitions, reaches out to collectors, sells work online through art websites or online marketplaces, and seeks out commissioned public art projects.
8. *How do you navigate the art world?* Martinez cites Nikki Grattan, a founder of *In the Make* (2011), a blog showcasing the studios of contemporary West Coast, U.S. artists, who states: “To be honest, most everyone approaches the question about how they navigate the art world with too much delicacy and ambiguity. They often seem reluctant to speak of just how frustrating and baffling the whole experience can be...Artists sometimes don’t like to reveal just how hard they try— as if being ambitious about getting one’s artwork seen and sold is somehow shameful. I think it’s a disservice to perpetuate the myth of ‘opportunities just happening’ if that’s not really the case.” Martinez recommends speaking succinctly about challenges artists face bringing their work to a new audience, for example, finding and placing art in local community spaces.
9. *How do you price your work?* Martinez suggests having a good idea of what to charge by calculating costs of material, size of artwork and number of hours taken to create a piece determining price negotiation levels including an estimated market value for their artwork prior to an interview.<sup>144</sup> Canadian Artists’ Representation (CARFAC) an artist-run organization founded in 1968, is certified as the national representative organization of professional visual and media artists in Canada. It has established standards and fee scales for artists working in this sector.
10. *Which current art world trends are you following?* Artists should familiarize themselves with trends in the art world on local, national, and international levels and how their work responds to these trends or how it isn’t ‘on trend’ at all is the final suggestion Nicole Martinez makes.

Martinez’s suggestion assert that the contemporary art world still relies on an artist’s pedigree including pedagogical formation, a list of galleries in which they have exhibited, artist’s statements outlining their process, prophetic vision and an ability to communicate all that through linguistic proficiency.

---

<sup>144</sup> Canadian Artists’ Representation (CARFAC) an artist-run organization founded in 1968 is certified as the national representative organization of professional visual and media artists in Canada. It has established standards and fee scales for artists working in this sector. Their founding principle and continued concern is that artists, like professionals in other fields, must be paid fairly for their creative output and services. CARFAC also deals with issues such as copyright for artworks (Introduction—CARFAC-RAAV, 2019). Four areas that CARFAC provides a description of the kinds of work artists do and a fee schedule for the work described including: presentation; consultation; and installation; and preparation (C.1—C.3 Artists’ Professional Fees, 2019).

## Appendix X: Passport Program Assessor's Rubric

This table helps to determine a family's priority score for gaining *Passport Initiative*

Support Needs	Considerations in Determining Priority
<p><b>Behavioural</b> Support to prevent certain behaviours, including those that pose harm to the individual or others</p>	<ul style="list-style-type: none"> <li>• Does this person require support to prevent:               <ul style="list-style-type: none"> <li>• aggressive behaviour</li> <li>• property destruction</li> <li>• sexual aggression</li> <li>• self-injury</li> <li>• substance abuse?</li> </ul> </li> </ul>
<p><b>Medical</b> Assistance managing medical conditions.</p>	<ul style="list-style-type: none"> <li>• Does this person require respiratory care supports?</li> <li>• Does this person need help with:               <ul style="list-style-type: none"> <li>• feeding</li> <li>• turning or positioning</li> <li>• dialysis</li> <li>• ostomy care</li> <li>• lifts or transfers</li> <li>• bowel care</li> <li>• a catheter</li> <li>• glucometer testing?</li> </ul> </li> </ul> <p>Is the person susceptible to infectious disease or seizures?</p>
<p><b>Personal</b> Support at home and in the community</p>	<ul style="list-style-type: none"> <li>• Does this person require protection from exploitation, abuse, sexual abuse and neglect?</li> <li>• Do they require support with their overall health and safety?</li> <li>• Do they need help managing money and their personal finances?</li> </ul>
<p><b>Caregiving (unpaid, primary, caregiver)</b>  Support for a caregiver, based on their health and personal circumstances</p>	<ul style="list-style-type: none"> <li>• Does the unpaid primary caregiver have a medical, physical or mental health condition that impacts their ability to provide care to the person with the developmental disability?</li> <li>• Does the unpaid primary caregiver also provide care for another person in the family?</li> </ul>

Retrieved from: The *Passport Program* Questions and Answers (2016)

## Appendix Y: Passport Funding: What Can I Use It For?



# Passport Funding: What Can I Use It For?

These tips suggest how Passport funding can help adults with a developmental disability participate more fully in the community. For a complete list of supports and expenses covered under Passport, please see the [Passport Guidelines](http://ontario.ca/bxj7) at [ontario.ca/bxj7](http://ontario.ca/bxj7).



### COMMUNITY PARTICIPATION AND ACTIVITIES OF DAILY LIVING

- Programs, classes and supports that help develop independence, social and life skills (e.g., literacy, cooking, managing money, computer skills, assistance with personal care needs). This includes fees and supplies.
- Participation in community activities and events (e.g., recreation, club memberships, admission to festivals and museums, sports).
- Pre-employment and employment supports (e.g., skills training, resume development and job coaching).
- Transportation for activities (e.g., transit, mileage, taxis).
- Paying a support worker to help with community participation and daily living activities. This includes a support worker's expenses while providing support (e.g., meals, transportation and activity fees, expenses for accompanying the individual during trips).



### CAREGIVER RESPITE

Caregiver respite is temporary help to provide a break to primary caregivers. This can be during the day, evening or weekend, and can be in-home or out-of-home.

Respite includes supervising or providing supports for individuals with daily living activities such as personal care, while caregivers get a temporary break.



### PERSON-DIRECTED PLANNING

Passport funding (up to \$2,500) can be used to develop a person-directed plan that builds on the individual's strengths and interests and identifies supports to help them achieve their goals. These supports can be purchased from independent planners, facilitators or developmental services agencies.



### ADMINISTRATION

Passport funding can cover some employer costs (e.g., Canada Pension Plan contributions, Employment Insurance and Workplace Safety and Insurance Board premiums, vacation pay).

Passport recipients can also use up to ten per cent of Passport funding for administrative supports such as bookkeeping, bank fees, payroll and scheduling support workers.



Retrieved from Developmental Services Office. (2014). *Tips Sheet: Passport Funding: What Can I Use It For?* Ministry of Child, Community and Social Services.

[https://www.mcsc.gov.on.ca/documents/en/mcsc/publications/developmental/passport/Passport\\_Tip\\_Sheet-en.pdf](https://www.mcsc.gov.on.ca/documents/en/mcsc/publications/developmental/passport/Passport_Tip_Sheet-en.pdf)

## Appendix Z: Exemplars Submitting Expenses Passport Forms

### A. Submitting Expenses

#### Purchase of Service (POS) Form – TO BE COMPLETED BY YOU

This form must be submitted with all expenses. All receipts and invoices must be attached to this form. It is like a cover sheet for all of your expenses.

Only **four** items need to be completed on this form **as circled in red** below.

They are: the number of receipts/invoices attached, the total amount of expenses being claimed, your signature, and the date.

*Example of POS form:*

**FAMILY SERVICE TORONTO**  
For People. For Change. 1

**Passport Purchase of Service Form**

Family Service Toronto  
498 – 700 Lawrence Ave. West, Toronto, ON, M6A 3B4  
416-780-1108  
www.familyserVICEToronto.org/programs/passport  
**FAX: 416-977-6110**

**Client information:**

Name:	
Family code:	

**Payable to:**

Payee name:	
Payee address:	
Payee phone number:	

**REMINDERS**

- Only **one** Purchase of Service (POS) form may be submitted each month.
- Incomplete POS forms cannot be processed and will delay payment.
- Attach official receipts / invoices for proof of payment.
- Allow 30 business days for payment from the date received in our office.

Number of receipts / invoices attached:	
Total amount of receipts / invoices:	\$

Payee Signature \_\_\_\_\_ Date \_\_\_\_\_

By signing this form, I acknowledge I have not previously submitted the attached expenses.

OFFICE USE ONLY			
Expense account:	Total \$:	POS Admin Initials:	
		Coordinator Initials:	
		Manager Initials:	

Date Received:

Retrieved from: Family Service Toronto. (2017). *Passport Program Information Package New Clients*. <https://familyservicetoronto.org/wp-content/uploads/2016/03/Passport-InformationPackageNewClients2017.pdf>

